

DRAFT PROTOCOL

A rapid assessment of health seeking behaviour in relation to sexually transmitted disease

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Introduction

The control of sexually transmitted disease (STD) is now recognized as a global priority.¹ HIV is clearly a major cause of premature death, and most cases are the result of sexual transmission. Other STDs cause considerable morbidity, particularly in relation to reproductive health of women, and are also associated with increased transmission of HIV.^{2 3} ^{4 5} AIDS control programmes are now being integrated with broader STD programmes in an attempt to address these significant public health problems.⁶ One major problem with an integrated STD control programme is the lack of accessible health facilities; the second, related, problem is that only a minority of people with STD present to public health facilities. An understanding of what people do when they have symptoms of an STD can assist programme planners through directing health education initiatives, approaching alternative health providers (traditional healers, pharmacists, injectors etc) with a view to involving them in the programme, and through removing or reducing barriers to presentation to health clinics. Many sexually transmitted diseases, such as syphilis, gonorrhea and urethritis, are easy to diagnose and treat, and yet millions of cases in the world are left untreated leading to continued transmission and serious sequelae. Improving the availability and accessibility of health services, training health care workers in primary health care in the diagnosis and management of STD, screening for STD in pregnant women, targeting STD prevention and care programmes at vulnerable groups - all of these efforts can reduce the burden of disease. Programmes will be most effective if they are based on local assessments of: (a) the epidemiology of STD in the population; (b) current management of STD in health care settings; (c) health seeking behaviour in the population, i.e., what people do and where they go when they suspect that they have a sexually transmitted disease.

This proposal addresses the third of those assessments. It includes a discussion of health seeking behaviour in general and specific aspects relating to STD, a brief review of the literature on health seeking behaviour for STD, followed by a protocol for assessing STD health seeking behaviour in a population

Part 1: Background and literature review

1.0 Objectives of STD control Programmes

STD/HIV control programmes have two main aims: to interrupt the transmission of infection and to prevent the development of complications and sequelae.⁷ The provision of care to those with chronic or terminal disease forms the third part of most programmes. These

three aims broadly correspond to primary, secondary and tertiary prevention. The interruption of transmission is addressed largely through campaigns to change sexual behaviour and to promote condom use, an approach which is appropriate for both HIV and STD control. The second aim, the prevention of complications and sequelae, is tackled through the provision of health care services in order to detect and treat STD as early as possible. For some STDs (e.g. gonorrhea, chlamydia, chancroid) effective treatment can prevent further transmission and sequelae. For some of the viral STDs such as herpes, treatment is palliative but the recognition of disease can help to reduce further transmission (through avoiding sexual contact when the disease is active and through measures to avoid vertical transmission).s In relation to HIV infection, early diagnosis can lead to better management, for instance, earlier and more aggressive treatment of opportunistic infections.

1.1 The standard epidemiological model for STD ^{9 10}

The basic reproductive rate (R_0) of a STD in a population is a function of the efficiency of transmission **B** (the average probability of transmitting infection from an infected individual to a susceptible person), the average rate of acquisition of new sexual partners in the population **c**, and the average duration of infectiousness **D**. The standard model suggests that these act in a simple multiplicative way: $R_0 = BcD$. Control programmes can also be looked at in relation to this model, as shown in Table I. Interventions directed to reducing any parameters should be of use in reducing the incidence of STD. The major interventions currently used target rate of partner change through prevention campaigns, and of transmission (through the use of condoms and other barriers). Theoretically therefore, reducing the duration of infectiousness should also be important in STD control

Table I: The effect of different interventions

Intervention	Prevention level	Effect on model
Reduce number of sexual partners	1 ^o	c*
penetrative sex)	1 ^o	B
Early treatment	1 ^o	D + B
Partner notifications	1 ^o and 2 ^o	D (in contact)
Palliative care	3 ^o	?? B(anti-viral treatment) ?? D(prolong life) ¹¹

* See text for symbols

1.2 Health seeking behaviour

The centrality of health seeking behaviour can be seen in this context. The early recognition of symptoms, presentation to health facilities and compliance with effective treatment should reduce the spread of treatable STDs. Early treatment is clearly most important in the context of a high rate of partner change. For example, if men with gonorrhea are infectious for an average of twenty days, and they have one new female partner per day, and the probability of infecting each partner is 50%, then each infected man would theoretically infect ten women. If the mean period of infectivity was reduced by half, the average number of men infected would also fall by half, from ten to five. In the context of lower rates of partner change the impact would be proportionately less. Thus reducing the time between onset of infection and cure, through improved accessibility of services and/or education about symptom recognition, could play an important role in STD control.

Health behaviour (in contrast to simply health seeking behaviour) will affect people's actions when they suspect an infection. If people continue to have sexual contact once they have recognized symptoms then they could infect more people and thereby increase the epidemic. Self treatment with antibiotics or other methods is another aspect of health behaviour which will have an impact on control of disease. Self treatment using inadequate methods (including antibiotics and other treatments) may prolong the period of infectiousness prior to presentation for effective treatment, and can also lead to the development of resistant strains.

In summary, knowledge about health, and health seeking, behaviour in relation to STDs can help programme planners to identify obstacles to early diagnosis and effective treatment of STD and implement appropriate interventions. For example, in some populations it may be usual for a man with a urethral discharge to go to a pharmacist and ask for help; having identified this it may be possible to train pharmacists to refer such men to a PHC clinic, or, if antibiotics are sold over the counter, to ensure that pharmacists are encouraged to treat according to effective protocols and to encourage the man to tell his partners to seek treatment. In other populations it may be felt inappropriate for a woman to discuss a genital problem with a man, in which case female doctors or nurse practitioners can be made available to diagnose and treat STD. An assessment may find that women and men have little knowledge of symptoms that may occur with an STD, and this may then be introduced into health education programmes.

1.3 What are influences on health seeking behaviour?

Health seeking behaviour is part of a wider concept, health behaviour. While little has

been written specifically on health behaviour in relation to STD, there is an extensive literature on health behaviour in general. This brief review will focus on models of health behaviour in order to suggest a simple model for approaching STD health behaviour and it will also examine the strengths and weaknesses of commonly used approaches to investigating health behavior. In its widest sense, health behaviour includes all those behaviours associated with establishing and retaining a healthy state, plus aspects of dealing with any departure from that state. Mechanic refers to "illness behaviour", a term which includes attention to pain and symptomatology, the processes by which symptoms are defined, accorded significance and socially labelled, to extent of seeking help, and the change in life regimen as a result.¹² Thus health seeking behaviour is only a small part of a wider concept.

For the purposes of planning health programmes it is generally health seeking behaviour which is of interest, more specifically the use of modern health care facilities. In addressing this aspect it is important to recognise that this behaviour does not exist in a vacuum, but is part of wider health behaviour. Successful interventions will depend on their acceptability and accessibility, both of which relate to broader social factors than simply decisions about "going to the doctor".

There have been two broad frameworks for looking at health seeking behaviour.¹³ The first is the pathway model, which describes the steps of the process from recognition of symptoms to the use of particular health facilities. This method attempts to identify a logical sequence of steps, and looks at social and cultural factors which affect this sequence. This has been primarily an anthropological approach, with qualitative methods of investigation. The second is the determinants model, based on a more bio-medical and quantitative approach, where the focus is on outlining a set of determinants which are associated with the choice of different kinds of health service.

Differing models of health seeking behaviour are still debated, but the growth of operational research into health service delivery has sponsored a more pragmatic approach to the area. In recent years the dichotomy of the "qualitative" versus the "quantitative" approach has been in part superseded at the level of measuring health seeking behaviour by a combined approach associated with "rapid assessment" methods.¹⁴ The different models of health seeking behaviour can be studied to produce a broad framework to inform investigation and intervention, particularly in the context of looking at use and non-use of "modern" medical services in developing countries. The framework includes the following categories of factors: characteristics of the subject, characteristics of the disease, characteristics of the health service. Axel Kroeger suggests a summary of these

Table 2: The choice of healer in relation to various possible explanatory variables (after Kuoeger, 1983).

	Subject characteristics	Disorder characteristics	Service characteristics	
Explanatory variables	Age Sex Marital status & position in household Ethnicity Formal education Occupation Resources (land, cash, etc) Interaction with family, community, etc.	Chronic or acute Severe or trivial Etiological model Expected benefits from treatment Psychosomatic vs somatic	Accessibility Appeal (opinions and attitudes towards traditional and modern healers) Acceptability Quality Communication Cost	
CHOICE OF HEALTH CARE RESOURCE				
Dependent variables	Traditional healer	Modern healer	Drug seller	Self treatment Or no treatment

All the factors included in the model above as "explanatory variables" can interact, leading to differences in individual behaviour for different conditions and on different occasions. The important questions for any investigation to cover include the recognition of particular symptoms; the perception of those symptoms and the threat of disease; the extent to which symptoms disrupt family, work and other social activities; availability of treatment resources, physical proximity, psychological and monetary costs of taking action (including costs, time, money, effort, stigma, social distance, feeling of humiliation and the like); beliefs in the efficiency of recommended health care (itself related to beliefs about

the cause of the disease). Most empirical work in this field has identified the importance of lay networks for determining health seeking behaviour.

Cultural factors are repeatedly included in health behaviour models. While these may seem difficult targets for intervention, it is important to include some study of this in any investigation. Cultural factors may relate to beliefs about disease causation and to the potential efficacy of different forms of care, and have been said to affect the toleration or not of different symptoms. But "between culture" variation is only one factor, with considerable, often greater, "within culture" variation in response to particular symptoms or states. These are related to many variables in the model above, including age, gender and class. These points are an important background because in the context of sexually transmitted diseases many of the aspects of the wider health behaviour model will be altered. The general stigma associated with STD, the frequent repression of discussion about sexuality and reproduction are likely to have a major impact, particularly in relation to sources of advice about what symptoms mean and where to go for help.

In developing a protocol for describing STD health seeking behaviour it is important to focus down from the broad study of health behaviour towards those aspects which are of interest to the STD programme planner. In developing countries most studies on illness and health seeking behaviour tend to concentrate narrowly on the non-use of modern health-care facilities.¹⁵ Although such a focus is very "practical" and in line with much operations research, if it is seen purely in this context by investigators and participants it will weaken the study and potentially bias results. Kanona and colleagues looked at social survey methods in relation to biomedical and ethnomedical health service use in a rural area in Zambia.¹⁶ Over 80% of 218 respondents reported seeking treatment at either the clinic or the hospital in the last 8 months, results they considered "highly questionable [as there was] a low level of accessibility/availability of clinics and hospitals". The nearest hospital was 90km away

The authors conclude:

"In most cases, traditional healing methods are often associated with disease ignorance and primitivity. It is likely that the Kabinga adults could have remained suspicious of the interviewing team, which was asking questions on some aspects of the people's healing system. The interviewers were often associated with the World Health Organisation and Ndola Central Hospital. In addition they were young Zambians with school certificates of education who always moved with the senior chiefs messengers. It is not surprising therefore that respondents could not disclose vital information which related to the use of traditional medicine".

This contains important lessons for the carrying out of surveys into health seeking behaviour.

1.4 Alternative approach

An alternative approach to the standard health survey is presented by Merrill Singer and colleagues in relation to reproductive illness behaviour in Haiti.¹⁷ They used a door-to-door survey in a selected neighborhood to identify common reproductive complaints: in-depth interviews were carried out with women who lived in the surveyed neighborhood or were encountered as outpatients at the local hospital in order to gather information on reproductive history, help-seeking strategies, and beliefs about aetiology and treatment; and the full range of biomedical and folk health-care providers (doctors, nurses, health department officials, spiritual healers, herbal healers, and midwives) were questioned about their treatment of reproductive illness. They suggest that through gaining "therapeutic narratives", i.e. participant's commentaries on illness progression, help-seeking resort and related events, they were able to gain insight into the complex relationship of "traditional" and "modern" medical systems. Their interviews with medical professionals revealed a tendency to discount the ideas and understandings of their patients as irrational, backward and irrelevant, based on the assumption that "traditional" medicine was static. In contrast the authors found that "traditional" healers frequently developed and adapted their practice. Where patients believe that honest and open discussion of their health complaints with a physician is "more likely

to elicit scorn than sympathy" they learn to say what they think the physician wants to believe. This too has important implications for the study of health seeking behaviour.

The relationship of traditional to modern medicine is crucial in STD control, and attitudes towards traditional medicine will have an impact on control programmes. Pillsbury wrote in 1978, "In many cases prejudice on the part of health planners against traditional... aspects of their own cultures has precluded understanding of traditional therapies.. [However] health care for the rural and urban poor cannot be satisfactorily provided without a basic understanding of the traditional and other local practices of the intended beneficiaries and the value and belief systems that underpin health-related behaviour."¹⁸

1.5 A model of health-seeking behaviour in relation to STD

The brief review presented above suggests a need to combine determinants and explanatory models in the design of any assessment of STD health behaviour. It is clear that general determinants - social class, gender, resources, availability and organisation of health

services, etc - will affect health seeking behaviour within the population, but for the purposes of designing effective interventions this needs to be linked to an understanding of how people make decisions about their health. The investigation must therefore include in depth interviews with those with and without STDs in an attempt to describe a pattern of decisions and actions, in addition to looking for general determinants, such as geographical and financial accessibility of services and level of care provided.

The combination of "determinants" and "pathway" models is particularly important for STD. The social meanings attached to sex and to diseases related to sex, while varying in different populations, generally make these difficult issues to discuss and to study. Education on "sexual health" and disease is frequently lacking, people are embarrassed about discussing symptoms of STD, those with STD are frequently stigmatized and blamed. Feelings of fear and guilt may affect all aspects of the process from the way people acquire and handle knowledge about STD, to the intentions they have and the actions they take. This has many possible effects: STDs are thought of as things that affect other people, making it more difficult to make educational messages relevant to wider populations; having an STD suggests infidelity - people will be reluctant to recognise symptoms and deny the problem; going to a doctor about an STD will involve intimate questions and examinations that many men and women will fear and therefore avoid. These and many other reactions will interact with factors such as the availability of health care locally, how affordable it is etc, to determine who uses which services and when.

1.6 What is already known about health seeking behaviour in relation to STD?

The short answer to the title of this section is "not very much". However, the literature which exists provides a framework for approaching an investigation of STD health seeking behaviour in an operational fashion. Amaro and Gornemann provide a useful approach to the factor affecting utilisation of STD prevention and treatment services.¹⁹ This is a development of the approach outlined above and incorporates elements of the health belief model, the Anderson and Newman model of social and individual determinants of medical care utilisation and the theory of reasoned action.

Their model is therefore based on a combination of patient characteristics and provider characteristics, looked at specifically in relation to STD. Patient characteristics include sociodemographic, knowledge and skills, beliefs attitudes and values, psychological and psychosocial factors, sociocultural and socioenvironmental factors (cultural norms, nature of informal networks, situational factors like childcare responsibilities, transport and

time), and treatment and provider characteristics. Provider characteristics include sociodemographic factors, knowledge and skills, beliefs attitudes and values, psychological and psychosocial factors, sociocultural and socioenvironmental factors and treatment service structure characteristics.

Very few studies have addressed STD health seeking behaviour with any such model, and therefore relevant information has to be cautiously sought in reports whose main focus is generally not health seeking behaviour. These reports relate to cultural beliefs about STD, the recognition of symptoms, behaviours once symptoms are recognised, and when, where and why people chose particular forms of health care.

1.7 Beliefs about STD

Edward Green reports a study from Swaziland in which herbalists and diviners were interviewed and observed over a four year period.²⁰ He suggests that many Swazis regard diseases thought to be transmitted by sexual intercourse to be most effectively treated by traditional healers. This relates to a belief that sorcery is the root cause of most such conditions and Western medicine is considered ineffective in treating sorcery. How widespread such beliefs are is not clear, since the study was only of providers of traditional care. He reports another study in which a random sample of urban Swazis were interviewed along with clinic, personnel, which concluded that a significant proportion of Swazi STD patients consult traditional healers for treatment, and that others use antibiotics to protect or prevent the transmission of disease. 31% of respondents in this sample cited traditional healers as the therapists of choice for most people with an STD. Studies in Nigeria and Mozambique also indicate that STDs are commonly held to be better treated by traditional healers (cited in Piot and Teuo, 1990).⁶ Such findings relate to the decisions about where to seek care. However, a more detailed study of reproductive infections among women by O'Toole Erwin in Nigeria showed that beliefs about STD related to the specific symptoms, with some seen as the result of sexual activity, usually of their husband, others were considered the result of "natural" imbalance." These beliefs related to choices about care, although many of the women interviewed used more than one type of care, i.e., self treatment, traditional healers and western medicine.

1.8 Symptom recognition

The starting point for most health seeking behaviour is recognition of symptoms. Depending on the nature and stage of infection, STDs may be asymptomatic, mildly symptomatic or highly symptomatic. Even when symptoms are present in the genital area, they may not be associated with STDs. Hence, it would be useful to develop a taxonomy of not-normal genital conditions to begin with. Following this, the links between symptoms, signs and perceptions of causes of these conditions could be explored. Another important issue to explore is what the not-normal, non-genital conditions are attributed to STDs by the people. There are a number of symptoms that are relatively specific to STDs. such as genital ulceration and urethral discharge. Other symptoms, such as vaginal discharge, pelvic pain in women, and inguinal lymphadenopathy, are not so specific and may occur with other infectious and non-infectious conditions. This lack of specificity hinders the recognition of symptoms. In addition there may be an uncertainty about normality, particularly for women in relation to vaginal discharge, but also regarding such things as genital ulceration which can be regarded as a result of trauma and therefore to be expected after vigorous sex.

The most common symptoms related by Nigerian women to impaired reproductive health (in O'Toole Erwin's study) were lower abdominal pain, and a complex of severe lower abdominal pain with vaginal discharge, itching and irregular dark or smelling menses. The latter, i.e. the extreme of symptoms, was considered to be due to promiscuity. The treatment reported for this was herbs in the first instance and then, if they are ineffective, western drugs such as an antibiotics. The severity and frequency of symptoms are likely to be important in determining health seeking behaviour, a problem because so much STD presents with mild symptoms.

There are many anecdotal reports of responses to symptoms of STD - some report patients who increase their sexual activity as this is said to provide symptomatic relief, but there is a dearth of published information on this. One study of sexual behaviour in Zulu men and women with genital ulcer disease (GUD) found that 36% continued to have sex despite having genital ulcers.²² This was particularly associated with donovanosis and secondary syphilis.

1.9 What people do, where they go for help and when they go there

As indicated in the previous section, symptoms which are clearly STD related in the view of health workers may not be associated with STDs at all, in the minds of the people and vice versa. Once a working list of terms, used by the people has been developed, the next question is to ask what people do when they have the conditions. The answers to these questions are likely to vary between locations and even within locations depending on subject

characteristics or disorder characteristics as described in section 2.

When people wish to seek help, they may choose to do so from a wide range of available service providers. In most countries, there is often a mixed economy of care patients choose between private and public, or more often in developing countries between private and public allopathic care, traditional healers and pharmacists. The proportion of people consulting each of these, and the factors influencing the choices people make, are key factors in the development of an STD control programme.

The tendency of patients to shop around for care is another issue that is only poorly understood. There is some anecdotal information about this but very little has been published on the subject. In many developing countries only a minority of patients with an STD present to 'allopathic' health facilities, and those that do have frequently consulted other practitioners previously. A large number of patients are thought to consult pharmacists when they have symptoms of STD obtaining over-the-counter antibiotics. In Kinshasa, Zaire, 57% of 1200 prostitutes participating in a survey had signs and symptoms suggestive of an STD in the previous year, but only 32% had visited an official health care facility.²³ In contrast, in the UK 92% of 104 prostitutes reported that they would visit an STD clinic if they thought they had an STD, and only 1 of 193 women reported using non-prescribed antibiotics (Ward H, unpublished data). A population study in Zimbabwe of knowledge of and attitudes to antimicrobial agents suggested considerable self-medication with antibiotics when STD was suspected.²⁴ Respondents reported sharing antibiotics provided for STD with friends for prophylaxis. The authors suggest that this may underlie the growth in drug resistant microorganisms and in part due to the stigma attached to the treatment and management of STD at health centers.

Factors associated with the time taken to present for care are poorly understood. A recent study of university students in Canada looked at factors associated with an expressed intention to seek medical care promptly of symptoms of sexually transmitted disease were suspected.²⁵ Factors associated with greater intention to seek prompt care were perceived advantages of medical care, ease of access to care, social norm among friends, age (older) and gender (female). Perceptions of risk in delaying care and personal risk of getting an STD were not significant factors. A study of 171 Zulu patients with donovanosis at an STD clinic found that ulcers had been present for over 28 days in 55.4% of the men and 46.3% of the women..²⁶

Part 2: Protocol for assessing STD health seeking behaviour

2.0 Rationale

Health seeking behaviour in relation to STD will depend on a large range of interacting factors. For the purposes of designing effective control programmes it is most useful to look at those factors which are open to intervention by health professionals, while recognizing that it is not possible to make a rigid separation between this and other aspects of health behaviour. A general population survey is of limited use in this context: random samples based on households or census methods are likely to underrepresent mobile people who may be at greatest risk of STD; if contact is made through addresses/households men will be underrepresented; structured questionnaires are of limited value when attempting to elicit information about understanding of and attitudes to STD and experiences of dealing with an episode of STD; the proportion of people interviewed who will recently have had an STD and sought care may be small, therefore this is not an efficient way of rapidly obtaining the information required.

2.1 Objectives

The overall aim is to describe the health seeking behaviour relevant to the implementation of a control programme for sexually transmitted disease. The survey should provide practical information for those planning STD control programmes, and must be feasible in a short period of time with limited resources. The proposal will attempt to obtain information on STD health seeking behaviours from a range of key informants (including health care providers), individuals from groups identified by key informants and from persons presenting to health care facilities (including traditional~ healers) concentrating on answering the following key questions:

Group 1: Taxonomy (what are STDs)

- a) What normal genital conditions are believed to be STDs?
- b) What normal, non-genital conditions are believed to be STDs?
- c) What abnormal genital conditions are believed to be STDs?
- d) What abnormal genital conditions are not considered STDs?
- d) What abnormal, non-genital conditions are believed to be STDs

Group 2: What people do and why

- a) When one has any of the conditions as named above, that are believed to be STDs, what do they do?
- b) When one has a condition as mentioned above, which is believed not to be an STD,

what do they do?

- c) Why do they take any of the actions mentioned in (a) and (b)?

2.2 Expected outcomes

The purpose of answering the above key questions is to be able to then outline points for intervention. Such points may include:

- a) The need for improved education about STD, what they are and their causes.
- b) The need for effective treatments for STD
- c) The need to improve the dissemination of information about health care facilities for STD
- d) The need to tackle problems in the organisation of such facilities - location, cost (including costs relative to other forms of health care), opening times, waiting times, staff attitudes etc)
- e) The involvement of pharmacists and traditional healers in the control of STD.

2.3 Methods

2.3.1 Overview of study design

The assessment involves a number of steps which enable the investigator to build up a picture of STD health seeking behaviour in a relatively short period of time. The results will relate specifically to the population and area covered, and will not necessarily be broadly generalisable. A stepwise descriptive survey using existing sources of information, key informant interviews, in depth interviews and focus group discussions will be used. The steps are:

Sub-study 1: A review of current knowledge through studying published material and documents related to health seeking behaviours and sexually transmitted diseases in the community

Sub-study 2: Semi-structured interviews with relevant informants as suggested by Sub-study 1 (e.g. bar owners, army/police personnel, garage owners, mothers group leaders, youth group leaders, prostitute leaders, midwives/TBAs, doctors/nurses in private and public health clinics, pharmacists, traditional healers).

Sub-study 3:

- a) Focus group discussions with groups as suggested by results of Sub-study 2

(e.g. soldiers, factory workers, women's groups, prostitutes)

- b) Individual in-depth interviews with 10 people from each group identified.

Sub-study 4: Interviews with individuals presenting with STD in different settings

2.3.2 Study sites

The following should be considered when selecting a study site:

- a) A geographical area needs to be selected for the assessment. This should be done in relation to the overall assessment programme
- b) If the assessment is done alongside the assessment of the epidemiology and of existing health care services for people with STD then a number of points will overlap and resources can be minimised by careful planning of data collection.
- c) If the programme relates to the development of a national programme, the assessment may need to be repeated in different geographical areas as the patterns of health seeking behaviour and existing health care services may vary.
- d) In addition, rural and urban populations may need to be surveyed separately. In the design suggested below, it is assumed that the programme relates to a single city or region

Part 3: Implementation plan

3.0 Overview of implementation plan

After each sub-study, a review of results will be needed to decide how to adapt the next study to local conditions. A structure for this decision-making should be established at the outset, and include a discussion between those who have commissioned the work and those who have been commissioned to do it. Sub-study 3 and sub-study 4 can be implemented at the same time

SUB-STUDY 1

3.1 Sub-study 1: Review of current knowledge

Objective: To review of current knowledge through studying published material and documents related to health seeking behaviours and sexually transmitted diseases in the community.

Rationale: There are many sources of information about sexually transmitted diseases which will be drawn together as part of the first step of this, the epidemiological (see section 3.11 of that protocol) and health care provision assessments. To avoid overlap if the three protocols are being carried out simultaneously, the investigators should agree a division of labour in relation to who investigates which data sources, but agree that all information obtained should be available to each assessor.

Sources of information

- a) Library search including medical and social science citations to identify any published material relevant to HSB in general in the population (or similar populations in the country/Region) and STD in particular. University libraries should be asked if they have any theses/dissertations on related topics (HSB for reproductive health for example).
- b) The national AIDS/STD Control Programme should be asked for publications and reports on health care, and results of any population surveys. They will also know if there have been any surveys funded by other agencies (WHO, research councils etc) which may include information on HSB.
- c) Any social scientists with an interest in HIV/STD should be approached directly and asked if they are aware of any published or unpublished material on HSB for STD or reproductive health
- d) Family planning agencies may have information on surveys relating to reproductive health in general.
- e) Non governmental organisations may also have information on surveys.
- f) Identification of routine data if available leg. numbers of different health care providers for STD, distribution of antibiotics to PHC and pharmacists)

Outcomes

At the end of this sub-study the principal investigator should have an idea of:

- a) the common STDs in the area
- b) the local names for these STDs
- c) prevailing beliefs about STDs
- d) the population groups known to be (or believed to be) most affected
- e) the actions these people are known to take (or believed to take) when they have these STDs
- f) the range of care providers.

This step should be limited in time in order that the whole process is not delayed. It may take much less time if little information is found. At the end of this time the researcher should produce a brief report on what is listed above, the studies have already been done, a list of sources identified and a list of useful informants. It should end with recommendations for the next step in the assessment and should include the following information which is required for Sub-study 2:

- a) Who are the key informants for Sub-study 2; this will be based on providers of care (who do people go to for help)
- b) How the interview schedule should be amended for local use (including names of STDs, which health care providers to include discussion of, need for different schedules for men and women)
- c) Who will carry out the next phases of interviews (do they have to be male, female, what background should they have and what training they will require.)

Example

*Discussions with the National AIDS Control Programme in Ethiopia revealed a special edition of the **Ethiopian Journal of Health Development on AIDS**. This included reports on a number of studies of STD patients, truck drivers and prostitutes which provide useful background to an assessment of HSB. One study² reported that over 80% of patients seeking STD treatment having had symptoms for over a week, with 40% already on some form of treatment. The sources of treatment prior to contact with the health centre are shown, by sex, in*

Table 3.

Table 3 Sources of treatment prior to presentation at an STD clinic, Ethiopia.

<i>Source of treatment</i>	<i>Male STD patients %</i>	<i>Female STD patients %</i>
<i>Private clinic</i>	<i>30.9</i>	<i>33.9</i>
<i>Pharmacy</i>	<i>23.9</i>	<i>17.9</i>
<i>Hospital</i>	<i>8.2</i>	<i>25.0</i>
<i>Local injector</i>	<i>20.6</i>	<i>14.3</i>
<i>Traditional healer</i>	<i>16.6</i>	<i>8.9</i>

(From ref 28)

A random non-clinic sample of 282 sex workers in Addis Ababa in 1990 were asked about past history of STD. ²⁸ The majority of the women (97.7% had sought medical care as shown in table 4. The examination of these women revealed a high prevalence of STD (gonorrhea 30.1%, trichomoniasis 23.9%), and almost half of the women reported having symptoms, most of them for one week or more.

Table 4 Source of treatment for STD reported by female sex workers, Ethiopia.

Source of treatment	Female sex workers %
Health centre or hospital	53.9
Private clinic	37.5
Self treatment	6.3
Pharmacy	2.3

(From ref 29)

A further, unpublished document was available from the National AIDS Control Programme which provided an estimate of the numbers of people with STD and the proportion that presented to public health facilities. A brief discussion with a sociology researcher from the University identified another publication (in press at the time) on broader aspects of health seeking behaviour. Discussions with workers in the Maternal and Child Health programme provided information on the numbers of women presenting for antenatal care as a proportion of total numbers of pregnancies, and on the role of traditional birth attendants in reproductive health.

From such initial steps a picture can be built up of what information is available, and what appears lacking. If there are people who have worked in the area of HSB and who may have useful insights, they should be approached for an interview to help in the planning of the next steps of the assessment. If there are a number of such people, a small workshop may be a useful way of pooling their knowledge

3.2 Sub-study 2: Key informant interviews

Objective: To find out what the local beliefs are about STDs, who gets STDs, who does not get STDs and what are recognized as symptoms of STDs and where people with such conditions might go for advice and treatment.

Study subjects:

- a) people in the community likely to know who gets STDs and where people go for STD care (e.g. bar owners, taxi drivers, women's organisation leaders, leaders/representatives of prostitutes, army/police personnel, traveling or migrant workers)
- b) providers of health care (e.g. doctors/nurses in private and public health clinics, pharmacists, traditional healers, midwives/TBAs).

Methods

- a) The interviews should be semi-structured with a number of topics to be covered, and open-ended questions to elicit information.
- b) They should be carried out by field workers trained in interviewing, preferably with a social science background. An outline structure for the interviews is provided in Part 6. This will need adapting to local conditions and according to the people to be interviewed.
- c) The investigator should aim for 10 to 15 such interviews; they are likely to take 1-2 hours and a further 1-2 hours to write up interview notes. Ideally these interviews should be done by the investigator or one or two interviewers with experience in ethnographic fieldwork

Data Handling and analysis

- a) The interview data - the completed interview schedules and field notes, should be typed up.
- b) Analysis should be by the investigator in collaboration with the interviewers and use standard ethnographic methods. Content of interviews will be examined for the issues listed in section 2.2
- c) Analysis of these interviews will be used alongside results of Sub-study 1 to decide which groups should be chosen for Sub-study 3, and whether these should take the form of focus group discussions (3a) or individual in depth interviews (3b)

3.3 Sub-study 3: Focus Group Discussions and/or Individual interviews

Objective: To obtain a range of perspectives on health seeking behaviour from particular social groups (as decided on from Sub-study 2).

Methodology:

- a) **Focus group discussions:** These would provide an efficient and an acceptable way of obtaining a range of perspectives on health care seeking behaviour or STD among a particular social group. (However, for a subject such as STD it may be felt inappropriate for some populations or sections of the population to discuss STD in an open forum).
- b) **Individual interviews:** These would potentially explore the respondents own experience of STD and discuss how they behaved at that time.

3.3.1 Focus groups

1. Rationale

A focus group allows for discussions of topics in a creative way that depends on the relationships and interactions between participants in addition to the interaction with the interviewer. In such groups topics can be explored to see which ideas, beliefs are widely accepted in the group, which are challenged etc. For this assessment participants should ideally belong to the same socio-economic class, age group and gender but they should not know each other. This is important because it has a bearing on what the people will disclose about themselves and the prevailing norms in their networks. An individual interview would potentially enable the interviewer to explore the respondents own experience of having an STD, and to discuss how they behaved at that time

2. Study subjects

Focus group discussions to be carried out with groups as suggested by Sub-study 2. The criteria should be:

- a) Those people who have been identified as at risk for STD (ie groups likely to have higher prevalence of STD)
- b) One group of men and one of women not identified as at particular risk (eg groups of female and male workers identified through a factory/union).
- c) Groups should be of 8 - 10 people. The participants in the group should be decided as randomly as possible. If the group is of men working in a local factory, then if possible a list of all workers should be obtained and ten randomly selected and asked to take part. For prostitutes this may be more difficult, but there should be an attempt not simply to include those who want to take part, or a group of very close friends. The researchers could approach two women in each of five bars, and ask them to come to a meeting place at a future date, for example. The exact methods will have to be determined locally.

4. Discussion topics

- a) Will be similar to those used in the key informant interviews
- b) The participants in this case will be giving a different perspective (as individuals), i.e., as prostitutes rather than leaders, as bar patrons rather than bar owners, as soldiers rather than their leaders, and as potential users rather than providers of health services.
- c) Focus groups are complex to organise, facilitate, write up and analyse. Trained social scientists will be needed as for the key informant interviews. Two will be needed for each group - one to lead the group and one to take detailed notes

5. Example

A study of reproductive health in Nigeria (ref 21) involved a focus group discussion with women, and was able to identify which diseases women thought were most likely to be due to sex, which were due to a natural imbalance, and how each should be managed. The use of antibiotics tended to be reserved for diseases with more severe symptoms, or where other treatments, based on diet or herbal remedies, had failed.

In this case a number of in-depth interviews with individuals from the same groups could be carried out.

3.3.2 Individual interviews

1. Rationale

These interviews will be able to look more directly at the participants' own experiences than in the focus groups, but where the person has never had experience of an STD this may be fairly limited, although clearly quantitative generalizations will not be appropriate.

2. Study subjects

Selection of the groups from which the individuals will come from should be based on information from key informants. The criteria for selection should also depend on locally available information. The number of groups should be limited and should not exceed five. The following should be adhered to:

- a) Participants should be selected as randomly as possible from the groups they are representing.
- b) Ten to fifteen in depth interviews with people each of group should allow for this rapid assessment

3. Methods

- a) Individual interviews will be carried out by an experienced interviewer using the semistructured schedule shown in section 7.3.
- b) Notes should be written during the interview and then written up more fully afterwards.
- c) Ten interviews with each group will take 1-2 hours each plus writing up time of 1-2 hours per interview, ie an average of 30 hours per group chosen.

4. *Example*

The sample would be similar in size to that used by Scrimshaw and Surtado's influential "rapid assessment" of health behaviour in Guatemala relation to diarrhoeal disease, which involved 75 randomly selected households in 5 communities, ie. 15 households in each community²⁹ They had 12 contact hours per household. The information from this study was used to develop intervention programmes appropriate for each community. These are currently being evaluated

3.4 Sub-study 4: Individual Interviews of people with STDs

Objective: To get some idea of how the reported actions from all the previous interviews/group discussions relate to actual behaviour when someone has an STD.

Study subjects:

1. Patients with STD who have presented for care will be interviewed. Fifteen

women and fifteen men should be interviewed when they attend the main providers of STD treatment

2. Places for recruitment should include, public facilities (clinics/hospitals), private facilities (private clinics, pharmacies), traditional healers and any others identified in Sub-study 2. The distribution of individuals interviewed from each type of facility should be equal.
3. Fifteen interviews should take place in each facility selected. This will take 2 - 3 days in each health care setting, depending on the numbers of patients with STD and the length of the interviews.

Methods

1. When the health care providers have been chosen they should be visited and asked to participate.
2. There should be two interviewers in each place; one interviewing men and one interviewing women.
3. The interviewer should approach the first patient with an STD after they have completed their consultation and are ready to leave; after each interview is completed and notes written up, the interviewer should approach the next available patient.

Content of interview

The questions will be similar to those developed for the interviews in Sub-study 3, but will include detailed enquiry about the current episode of STD. This should include knowledge about STD and different sources of care, perceived advantages and disadvantages of different types of care.

Part 4: Data Analysis, Reporting and Dissemination

4.0 Analysis during the studies

A considerable part of the analysis will be carried during the survey in order to inform the next steps. It is essential that at each step a written report of the interviews and conclusions is produced.

4.1 The final the analysis

This will be of the focus groups arld individual interviews with people with STD. Records of interviews should he studied for common patterns. The report should include the following sections:

- a) Introduction and objectives
- b) Outline of methods used and study subjects
- c) Description of findings (symptoms and signs, local terms for STDs, beliefs

about causation, actions taken (ranging from no action to seeking care).

d) Discussion on the implications of the findings of the study for public health

e) Recommendations: health education, medical education, alternations to health care delivery, role of different providers.

4.2 Dissemination of results

Where possible workshops should be held with participants (particularly key informants) to discuss the findings and help in the drawing up of recommendations

Part 5. Draft Interview Schedule

Draft interview schedule

5.0 Sub-study 2: Key informant interviews

Introduction

The order of the interview will depend on the situation and the role of the person. The interviewer should start by introducing themselves and outlining the purpose of the interview, although without identifying it too specifically; ie should mention reproductive health and illness. The interview should not be too personal as the informant is being asked about their local knowledge. The headings are intended as subject areas to be covered, not a questionnaire. The interviewer should use opportunities presented in the discussion to move onto different areas, in whatever order seems to follow the discussion.

1. Personal information

- a) Name
- b) Address
- c) Sex
- d) Age
- e) Occupation
- f) Ethnicity +/- nationality
- g) Religion

b. Information about their role

- a) Where they work and how long they have worked there
- b) How many people work there
- c) Participant's local community
- d) What they own (e.g. bars etc)
- e) How long they have owned place
- d) Who they interact with
- e) Information about place (such as, clients, how many people use the (bar), what type of people, any daily, weekly, seasonal variation.

- f) If health care provider, what training they have received, what their role is, where they work, who are their patients, how many are they.

c. Health care

- i) Local facilities
 - where do local people go when they are ill
 - what are the differences according to people and diseases

- are there any obvious obstacles to health care
- ii) Availability of treatment/advice
 - pharmacies
 - antibiotics over the counter
 - who gives advice on different diseases

d. Sexually transmitted diseases

(For each of these areas ask separately about men and women)

- i) What are STDs
 - what abnormal genital conditions are believed to be STDs
 - what abnormal non-genital conditions are believed to be STDs
 - what are the beliefs about causation of the conditions named above
 - what diseases are related to sex
 - what causes these conditions that are related to sex
- ii) Recognition
 - how do people know when they have the diseases/conditions listed above
 - what are the symptoms (what do people look for)

iii) Help seeking

- if someone thinks they have the above condition(s):
- who do they tell
- where do they go for help (in any particular order?)

v) Complications

- what happens to people with these conditions who don't go for treatment
- who else is involved with these people
- what are the long term problems such people have

vi) Who is at risk

- who gets the above conditions (which type of people)
- what do you and others think of them

vii) Prevention

- how do people prevent these conditions
- are condoms available locally

e. For a health care provider add:

- i) -Function of the health facility (general HC, specialist clinic etc)
- ii) -Who uses it (geographical population served, particular groups)
- iii) -*Organization* (who sees the people what facilities, payment, availability of drugs)
- iv) -*What are the most common conditions (STDs) and how do they present?*
 - How do patients understand these conditions?
 - How long do patients wait prior to consulting you?
 - Where do you think patients go first when they have symptoms?
 - What other sources of care are there for people with these conditions (STD)?
 - What are the main obstacles to people attending early on in the course of an infection?

f) *other health care providers:* (ask about others)

- what they think the role is of eg. pharmacies, herbalists etc.

At the end of the interview ask for suggestions for other local people to talk to.

In addition to the interview information. the following should also be recorded:

- a) where the interview takes place
- b) how long it lasted
- c) who else was present or may have been listening/watching
- d) how easily the informant talked about the issues, whether they seemed confident and well informed about their area.

Interview schedule

5.1 Sub-study 3a: Focus Group Discussions

a) Introductions

Everyone is asked to introduce themselves, starting with the facilitator and the person who will be taking notes on the discussion. The purpose of the group should then be outlined - "we are interested in finding out what people do when they are ill". The facilitator should also explain what will be written down (notes of the conversation but no names etc.) and who that will be accessible to. Participants may wish to be able to see the notes of the meeting at some point.

Topics for discussion

The structure of the group discussion will be determined by each group, but the following areas should be brought (as in section 1.d)

i) What are STDs

- what abnormal genital conditions are believed to be STDs
- what abnormal non-genital conditions are believed to be STDs
- what are the beliefs about causation of such conditions
- what diseases are related to sex
- what causes these conditions that are related to sex

ii) Recognition

- how do people know when they have the diseases listed above
- what are the symptoms (what do they look for)

iii) Help seeking

- if someone thinks they have the above condition(s):
- who do they tell
- where do they go for help (in any particular order etc)

iv) Complications

- what happens to people who don't go for treatment
- who else is involved
- what are the long term problems

v) Who is at risk

- who gets the above conditions (which type of people)

-what do you and others think of them

vi) Prevention

- how do people prevent these conditions
- are condoms available locally

For each of these broad areas, the facilitator should encourage people to give specific examples of situations that have happened to people they know, or to them if they will talk about it. The following areas should be discussed in relation to the questions:

- a) knowledge about STDs and sources of treatment;
- b) costs of treatment from different sources;
- c) access to care - including location, cost, loss of work time etc, acceptability, stigma.

At the end of the discussion everyone should be asked if there is anything else they would like to add. The opportunity should also be taken to answer any specific questions that have come up in the group (factual questions on STD treatment etc.) Finally, the facilitator should explain how the information will help in designing more effective health care, and discuss how the group might like proposals to be fed back to them at a later stage in the assessment exercise

Interview Schedule

5.2 Sub-study 3b: Individual in depth interviews

1. Personal information

- a) Name
- b) Address
- c) Sex
- d) Age
- e) Occupation
- f) Ethnicity +/- nationality
- g) Religion
- h) Measure of socio-economic status (income)
- i) Type of house
- j) Educational level
- k) Marital/civil status

2. Household:

- a) Number of other people in household
- b) Relationship to other people in household (diagram)
- c) Position in household
- d) Decision making
- e) Money in household - who controls?
- f) Spending on health care - who decides?

3. General use of health care facilities

a) Specific questions (dependent on local situation):

- Do you ever visit - health centre. hospital, other doctor (eg private), pharmacy, other healers.
- Are there any difficulties using any of these?
- How much do they cost?
- When were you last ill. what did you have then, and what did you do?

d. Sexually transmitted diseases

(For each of these areas ask about men and women)

ii) What are STDs

- what abnormal genital conditions participant believes are STDs
- what abnormal non-genital conditions participant believes are STDs
- what do they believe about causes of such conditions
- what diseases do they believe are related to sex
- what do they believe causes these conditions that are related to sex

iii) Recognition

- what would participant do if they have any of the conditions named above the diseases listed above
- what are the symptoms that they look for

iv) Help seeking

- if they had any of the above condition(s):
 - who do they tell
 - where do they go for help (in any particular order etc

v) Past experience

-Have they had any of the conditions named above? If YES:

- a) what was it
- b) what did they do
- c) who did they talk to
- d) who did they see and why
- e) what treatment did they receive

vi) Complications

- if they did not see anybody, what happened to the condition?
- who else is involved when they had the condition
- do they know of any long-term problem as a result of any of the conditions named?

vii) Who is at risk

- who do they think gets the above conditions (which type of people)
- what do they and others think of them

viii) Prevention

- how would the participant prevent these conditions
- are condoms available locally

In addition to the interview information, a record should be kept of how far the household is to the nearest health care providers (pharmacy, health centre and hospital), what transport is available, costs of care etc

Interview schedule

5.3 Sub-study 4: Individuals with STD

The interview is the same as the one for individual interviews (5.3), plus the following questions which should be asked instead of the general section on STD.

Sexually transmitted diseases

1. Why did you come to the clinic/pharmacist/healer today?
2. Describe your symptoms (record type, severity, duration).
3. When you first noticed the symptoms, what did you do (record what and when)

In this section want to know about self-treatment (what and when), consultations (who and when, friends, pharmacists, others), change in behaviour (sex, work, contact with others).

1. Have you told anyone about your symptoms? (who and when)
2. What have you been told by the (doctor, nurse, healer, pharmacist) is wrong with you?
3. Do you agree?
4. Why do you think you have got it? (beliefs about causes, transmission etc)
5. What treatment have you been given?
6. Will you take it?
7. What else will you do? (record telling partners, avoiding sex etc)
8. Have you considered going anywhere else?
9. What are the advantages and disadvantages of going to different places for STD treatment?

10. How far away do you live?
11. How much has it cost you to come here? (include have you had to take time off work etc)
12. Have you told anyone in your family that you are coming here?
13. How do you feel about your visit here (probe about attitudes, difficulties talking to staff about symptoms, confidentiality, privacy, embarrassment, shame)

Part 6. Timetable & Budget

6.1 Timetable

Initial planning and identification of a principal investigator (a senior social scientist /anthropologist), agreeing a timetable and a steering group to guide the work at each step. A training programme for the fieldworkers should be planned, and interviews held for these fieldworkers.

Month 1 Sub-study 1: review of current knowledge; writing up report and agreement of proposals for Sub-study 2 and 3. This will require the employment of one experienced social scientist full time and an administrative assistant full time.

Month 2 Training of interviewers for key informant interviews, focus groups and individual interviews. This training to include knowledge about STD and HIV, and basic ethnographic techniques, including conducting interviews, writing up of interview data and basic interpretation. A manual should be produced to guide the key informant interviews.

Key informant interviews. These should be carried out by the PI plus two trained interviewers.

Month 3 Report on the results of key informant interviews and decide Sub-study 3 (a) +/- (b) and 4. Amend interview structures as appropriate. Plan focus groups and sites for interviews with people with STD. Further training of interviewers for these next stages.

Month 4 Sub-study 3 and 4. All focus groups, individual interviews and interviews with STD patients. Four interviews plus the PI should be able to carry these out within the month.

Month 5 All the interviews should be reviewed and analyzed (two weeks). The final report should be completed by the end of this month.

Month 6 Workshops to report back to participants.
Implementation

6.2 Resources

Staff

One experienced social scientist full time for 6 months to plan the work, train the other interviewers, carry out some of the interviews and write the report. Four ethnographers full time for three months to carry out interviews and focus groups. One admin worker full time six months.

Equipment

Access will be needed to computers for typing up interview data.

Office costs

Photocopying of interview schedules.

Phone calls to set up interviews, organize focus groups, workshops etc.

Costs of writing and reproducing reports.

Travel

To libraries in step one, to interview sites etc.

Plus: external consultancies/GPA input for piloting the protocol.

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