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Guidelines for  
pre-test discussion on  
HIV testing

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Department of Health, March 1996

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## **SUMMARY**

The United Kingdom Health Departments recommend that named testing for evidence of HIV infection should only be undertaken with informed consent, individuals having received information about how HIV is transmitted, the significance of both positive and negative results and a discussion of the particular needs and interests relevant to the individual.

The discussion about HIV and HIV testing should now be part of mainstream clinical care. Specialist counsellors may be required if the circumstances of the individual attending for HIV testing are complex and time consuming and further discussion is required.

This document is suitable for use by health care workers who may be involved in pre-test discussion. The text reflects consultation with the Expert Advisory Group on AIDS. Annex A details the result of a process audit of the content of current pre-test discussion which was conducted by the United Kingdom Health Departments in October 1994.

## **ACTION**

Health care workers and provider unit managers should:

- ensure that confidential pre-test discussion is offered to all those who have decided they wish to have an HIV test (either by self referral or referral by a practitioner). The discussion should be focused in each case to address the specific needs of the client requiring a test and the different clinical situations in which HIV testing is provided;
- monitor and evaluate the service;
- discuss the provision of the service with purchasers;
- ensure that staff receive appropriate training;
- monitor patient satisfaction with the service, and
- also ensure post-test counselling, and adequate support and services for positive patients are available.

## **AIMS OF GUIDELINES**

This guidance seeks to ensure that:

- ❑ individuals requesting an HIV test receive appropriate discussion prior to testing (whether it be in hospital, primary care or community settings) so that they can decide whether to have an HIV test in a properly informed way, and
- ❑ the extent of provision of pre-test discussion reflects the varying needs of different clinical situations.

This guidance was produced in response to concern that there is a lack of consistency in the content of pre-test discussion. The guidelines are not prescriptive but form the framework for an appropriate and adequate discussion for health care workers.

Although post-test counselling is not covered in detail in this particular document the main features are outlined in Annex B.

## **GENERAL IMPORTANCE OF THE HIV TEST**

The early detection of HIV infection by antibody testing may:

- allow the individual to obtain immediate optimum medical and supportive health care;
- allow the individual to receive counselling and advice and take action to prevent transmission;
- allow women who may have been infected to seek advice and make decisions about conception, the management of pregnancy and breast feeding;
- allow the individual to protect their sexual partners from the risk of infection;
- allow the collection of information on the spread of the epidemic which assists prevention and service planning, and
- allow partner notification.

### **Reasons for pre-test discussion**

The main reasons for pre-test discussion are that there is an opportunity to:

- understand the indications for a test and know how they apply to individuals;
- ensure the individual understands what information the test result will give him/her and the possible consequences (both the advantages and difficulties) of a positive result for their future, thereby obtaining full informed consent, and
- allow a discussion of preventive measures and/or reduction of risky behaviour where appropriate.

### **Approaches to pre-test discussion**

The approach of the health care worker involved in pre-test discussion depends on whether:

- The individual is actively seeking the HIV test because of their perception of their risk.
- HIV is a part of a differential diagnosis and if so whether the individual is aware that the symptoms may be due to HIV.
- An HIV test is being done for purposes of screening eg for ante-natal care, blood donation, insurance.

Any health care workers with appropriate skills and knowledge who conduct pre-test discussion should ensure they are aware of current developments in the management of HIV and AIDS. Health care workers who do not feel able to conduct pre-test discussion should refer the individual seeking an HIV test to another appropriately trained health care worker.

Training in pre-test discussion may be facilitated by publications such as “HIV and AIDS: The Issues - A teaching pack for doctors” (DH 1992), “Guidelines for offering voluntary named HIV antibody testing to women receiving ante-natal care” (DH 1994), “HIV and AIDS: Issues in Primary Care – Educational Pack for GPs” (DH 1994) and those from DH-funded projects such as “Caring for people with sexually transmitted diseases including HIV disease” (ENB 1994). The pack for hospital doctors is available in the libraries of postgraduate medical centres, medical schools and main hospitals. The pack for General Practitioners has been distributed to Regional Advisers in general practice, GP tutors, trainee course organisers and undergraduate departments of general practice in England and Wales.

## **PRE-TEST DISCUSSION**

There are five main components of pre-test discussion. These are:

1. Ensuring the individual understands the nature of HIV infection; provision of information about HIV transmission and risk reduction.
2. A discussion of risk activities the individual may have been involved in with respect to HIV infection including the date of the last risk activity and the perception of the need for a test.
3. Discussion of the benefits and difficulties to the individual, his or her family and associates of having a test and knowing the result whether positive or negative.
4. Providing details of the test and how the result will be provided.
5. Obtaining an informed decision about whether or not to proceed with the test.

In **Section A** (page 7) these are described in greater detail.

In **Section B** (page 10) the application of the 5 components in a variety of clinical situations is described.



## **SECTION A**

In order to set a framework for the consultation, the health care worker will wish to ask the individual why they are seeking the test. If, however, the individual does not wish to discuss his/her risk activities but simply states a wish to have the test, the health care worker should proceed directly to stage 3 of the discussion. Where sexual activity or drug taking is not thought to be relevant to the reason for having a test (for example, where patients are attending after having been notified in a look back exercise), the patient should be asked if they are willing to answer such questions.

### **1. DISCUSSION ABOUT THE NATURE OF HIV INFECTION, TRANSMISSION AND RISK REDUCTION**

Depending on the reason for the tests and the individual's own knowledge of HIV infection the health care worker may need to discuss:

- modes of transmission;
- the difference between HIV and AIDS, and
- methods which reduce transmission that the individual currently uses or should be encouraged to use.

Written material should be available on general risk reduction strategies to supplement the discussion.

### **2. RISK ACTIVITIES AND THE NEED FOR A TEST**

In order to make an informed decision, the individual may wish to discuss with the health care worker:

- The individual's and the health care worker's perception of risk activities including any differences and the last date of involvement in risk activity such as;
- unsafe sexual practice;
- history of drug use and especially injecting exposure;
- history of exposure to blood/blood product transfusion particularly prior to screening of donations and heat treatment of factor VIII;
- tattooing;
- occupational risk, and
- overseas travel with exposure to high risk activity.

The level of risk and the need for a test for each individual will vary over time and therefore further discussion may be required on any future encounter with the individual. No assumption should be made about whether an individual belongs to a “high risk group”, as it is the level of the risk activity that has occurred that is important in the context of deciding whether an HIV test is indicated.

### **3. DISCUSSION OF THE ADVANTAGES AND DISADVANTAGES OF TESTING AND THE IMPLICATIONS OF THE POSITIVE OR NEGATIVE RESULT FOR THE INDIVIDUAL**

A brief discussion regarding the advantages and disadvantages should be offered by asking what the individual perceives as the main advantages if they perceive any disadvantages. Too much information at this stage may make decision making more difficult.

Advantages which may be raised are:-

- Allowing the individual to form strategies to protect subsequent sexual partners.
- Allow interventions to reduce vertical transmission (See section on pregnant women).
- Allow for appropriate medical care.
- Allow effective prophylactic care.
- Allowing decisions about their future to be made.
- Reduction of needless anxiety about HIV infection.

Disadvantages that may be raised are:-

- Psychological complications.
- Possible adverse impact on relationship including family, partners and work.
- Possible restrictions for those who are positive on testing eg travel.

It is at this point that the health care worker may encourage the individual to consider how they may cope with a positive result. They may also be encouraged to consider the social and psychological support available and who they might decide to tell of their diagnosis to allow them to plan future action.

#### **4. THE TEST PROCEDURE AND RESULT GIVING**

The test procedure and details of when and how the result will be given should be explained. A brief discussion regarding positive, negative and indeterminate results will be needed with information about follow up (See Annex C).

#### **5. OBTAINING INFORMED CONSENT**

Consent for test should be obtained prior to testing and is required on each occasion that the test is requested (See Annex C). The health care worker obtaining consent should make a written note that consent has been given.

## **SECTION B**

While not intended to be prescriptive, these guidelines set out the main components of pre-test discussion. The time allotted and the emphasis placed in discussion of these components will reflect the individual needs of the person who attends for HIV testing.

As described in this section those who have attended on several occasions for a test will require more emphasis to be placed on risk reduction strategies than repeated explanation of the test procedure. Those who are attending for their first test may require greater attention to be paid to the nature of disease and how it is transmitted.

### **1a) Individuals actively seeking an HIV test for the first occasion**

Here a pre-test discussion session involving all 5 stages is desirable, supplemented by written information.

Referral or follow up for further counselling may be necessary where an individual does not understand the discussion through, for example, difficulties in language comprehension, or if the individual appears to need further help for other reasons.

### **1b) Individuals actively seeking an HIV test who have had previous tests**

The individual should be encouraged to discuss recent exposure to risk activity. However, if an individual returns repeatedly, with no evidence of involvement in risk activities, there may be a need to ascertain whether there is inappropriate anxiety which may need to be addressed.

If the individual is felt to have been at risk, the discussion may simply proceed to obtaining consent for the test.

### **2a) When HIV is part of a differential diagnosis and the individual is unaware that symptoms may be due to HIV**

Here the need for a test has been ascertained by the health care worker from the individual's clinical state. Stage 2 of pre-test discussion may therefore need to be explained, possibly briefly if the individual is ill, in the context of his/her symptoms.

Stages 1-5 will need to be followed as indicated but the length of the discussion, in particular information provision, will need to be tailored to the individual's clinical state. For example, it would be inappropriate to enter into lengthy discussion of risk reduction or the pros and cons of the test when the individual is very unwell, although only in exceptional circumstances should a test ever be performed without informed consent.

### **2b) When HIV is part of a differential diagnosis and the individual is aware the symptoms may be due to HIV**

If the individual has had previous tests, discussion may be brief (see example 1b).

### **3) Individual is offered HIV test as part of wider screening procedure**

The 3 examples described below demonstrate that HIV testing which takes place in a screening situation requires a condensation of the pre-test discussion format due to practical considerations.

#### **3a) Ante-natal care**

In ante-natal clinics midwives are well placed to undertake pre-test discussion. Women in ante-natal clinics are likely to have less knowledge of HIV than those actively seeking testing and they will be receiving information about a wide range of other issues. HIV testing is often most appropriately dealt with in the context of obtaining consent for these tests although a specific consent to an HIV test must be obtained. It may be helpful to provide written information in addition as part of the general package of information provided.

For women tested in both high and low prevalence areas, the advantages and disadvantages of the test are described as in standard pre-test discussion.

However, in outlining the advantages of knowledge of serostatus for a pregnant woman, certain additional factors should be mentioned. These are that:

- knowing her HIV status permits the woman to make informed choices about the management of her pregnancy;
- advice on the avoidance of breast feeding may be given as transmission of HIV from mother to child frequently takes place via breast milk;
- plan and arrange for early monitoring of the baby's health;
- prophylactic treatment for the mother and child (if HIV positive) may be given earlier which may prevent development of severe opportunistic infections, and
- there is an opportunity for clinicians to discuss the use of AZT (Zidovudine) as treatment to significantly reduce the risk of transmission to the foetus.

As a policy of offering ante-natal HIV testing to all women in high prevalence areas is already encouraged, women can be informed that the test is voluntary, confidential and part of the general ante-natal care in their area. Where ante-natal testing is not routinely offered in ante-natal care i.e. in low prevalence areas, more time may need to be allotted to assessment of risk and the need for a test (stage 2). During discussion with a woman who seeks a test by self referral, the procedure for discussion is similar to example 1a.

In all clinical centres where unlinked anonymous HIV testing is being carried out, patients are informed by posters (in 15 different languages) and leaflets. However, it should be emphasised to women attending such centres that if they wish to be informed of the result they should seek voluntary confidential named testing.

### **3b) Blood donation**

At the time of donation, time constraints prevent all the stage of pre-test discussion being worked through, for all individuals.

Therefore, risk assessment and the need for a test (stage 2) occurs at an earlier stage when potential donors invited to attend are sent information to allow them to exclude themselves if they fall within one of several higher risk categories. On arrival for donation of blood, individuals are given information in the form of an AIDS leaflet which would substitute for stages 2 and 3 of pre-test discussion. Stages 4 and 5 of pre-test discussion occur on registration, when patients are asked if they have read and understand the AIDS leaflet. In some centres a slightly longer interview at the stage of registration may occur when a fuller discussion of the AIDS leaflet may be given. Informed consent is then obtained by the blood donor, giving written consent to say that they have understood that a battery of tests, including that for HIV, will be performed on a blood sample.

Individuals are informed that should the test be abnormal they will be notified in a confidential manner. If the result on the first test is confirmed as positive, individuals are given a further appointment with a trained HIV counsellor, frequently a physician with counselling training, who would take a second sample for further confirmatory testing and if necessary give further counselling if this result is also positive. Referral for further follow up occurs with the patient's consent.

### **3c) Insurance**

In certain circumstances an insurer may request an individual to have an HIV test before agreeing to provide life insurance.

In this instance, individuals are notified in writing of the need for an HIV test, the test procedure, asked to provide their written consent to the test and to nominate a doctor (usually their general practitioner) to take the blood sample and to receive the result (stages 4 and 5 of pre-test discussion). Pre-test discussion in stages 1, 2 and 3 will then be performed by the patient's nominated doctor.

## **HIV PRE-TEST DISCUSSION QUESTIONNAIRE**

### **Summary of Results**

**(Survey carried out in October 1994)**

#### **Overall Analysis**

Of the total 80 questionnaires sent out, 46 were completed and returned. Respondents fall into five categories: ante-natal clinics, drug dependency clinics, general practice, GUM clinics and HIV specific clinics. Also included are 12 clinics which did not offer any form of counselling, it is not known which category these clinics fall in. The responses have been divided into high and low prevalence areas. Overall, 34 clinics in high and low prevalence areas offered pre-test counselling.

#### **Staff Group & Place of Work**

Pre-test counselling is mostly undertaken by Health Advisors at the clinics, except at General Practices where all counselling is carried out by GPs. At ante-natal clinics a combination of counsellors, Health Advisors and midwives carry out the counselling sessions.

#### **Training for Pre-test Counselling**

The types of training most common amongst staff groups in the survey were general counselling training and specific pre-test counselling training. 4 of the 7 GPs had some form of counselling training. Of the 14 Health Advisors, 10 had general counselling training, the remaining 4 had specific counselling training only. 3 Health Advisors had more than one form of training.

## Number of Patients Counselling in a One Week Period

Overall high prevalence areas saw approximately two thirds more patients than low prevalence areas. GUM clinics in the survey saw an average of 15 patients per week in high prevalence areas and 9 patients a week in low prevalence areas.

**Table 1 Number of Patients Counselling in a One Week Period**

Clinic	Clinic Area		
	High Prevalence	Low Prevalence	Total
Ante-natal	21	0	21
Drug Dependency	0	0	0
General Practice	3	0	3
GUM	134	76	210
HIV Specific	0	15	15
<b>Total</b>	<b>158</b>	<b>91</b>	<b>249</b>

## Appointments

Of the 34 clinics in both high and low prevalence areas, 38% see patients by appointment only, 15% see patients without requiring an appointment and 47% see patients both with or without appointment.

## Patient's Reason for HIV Test

The survey shows that for patients who attended for their first pre-test appointment, the main reason for ordering an HIV test was patient self referral; in both high and low prevalence areas. However, at ante-natal clinics the major reason for an HIV test was for screening purposes.

**Table 2 Patient's Reason for HIV Test**

Clinical Type	Self Referral	Differential Diagnosis	Screening	Total
Ante-natal	2	1	18	21
Drug Dependency	0	0	0	0
General Practice	2	0	1	3
GUM	164	41	5	210
HIV	15	0	0	15
<b>Total</b>	<b>183 73%</b>	<b>42 17%</b>	<b>24 10%</b>	<b>249 100%</b>



### **Average Length of Counselling Session by Patient Risk Group**

Overall, the average length of time spent on counselling sessions with most patient groups was not less than 21 minutes. On average, heterosexual males and females received the shortest counselling sessions, between 11-20 minutes.

### **Average Length of Counselling Session by Clinic Type**

Drug Dependency clinics in the survey spent the longest average length of time on counselling sessions (between 31-60 minutes), whilst GPs spent the shortest (between 0-10 minutes).

**Table 3 Average Length of Time Spent with Patient by Clinic Type**

Clinic Type	Average Time Spent
Ante-natal	11-20 mins
Drug Dependency	31-60 mins
General Practice	0-10 mins
GUM	21-30 mins
HIV	11-20 mins

### **GUM Clinics Response**

Half the GUM clinics spend on average between 11-20 minutes on a counselling session, whilst the other half spend between 21-30 minutes.

### **Average Number of Pre-test Counselling Sessions**

Overall, 28 out of 34 (82%) respondents reported the average number of pre-test counselling sessions as one per patient and 6 out of 34 (18%) reported an average of two sessions. All 17 GUM clinics in both high and low prevalence areas responded with an average of one session of pre-test counselling per patient. An average of 2 sessions per patient was reported in 3 out of 5 Drug Dependency clinics and 2 out of 6 GPs.

### **Topics Covered at First Pre-test Appointment**

Overall the topics of history and issues regarding the test itself (excluding written consent and travel abroad), were covered by 80% or more of respondents. Under the subject of education, safer sex issues are also discussed by most (91%) clinics (Table 4).

**Table 4 Topics Covered at First Pre-Test Appointment**

Content		Area		
		High	Low	<b>Total</b>
History	Sexual history	21	12	<b>33</b>
	Drug use history	20	12	<b>32</b>
	Patients risk perception	21	12	<b>33</b>
	Condom use	19	11	<b>30</b>
	Travel abroad	12	10	<b>22</b>
Education	Safer sex	19	12	<b>31</b>
	Info about STD/Hepatitis	14	10	<b>24</b>
	Safe drug use	13	11	<b>24</b>
	Written info test procedure	11	2	<b>13</b>
	Medical aspects HIV	15	6	<b>21</b>
Test	Test procedure	18	13	<b>31</b>
	“Window period”	20	12	<b>33</b>
	Significance negative result	21	12	<b>33</b>
	Confidentiality	20	13	<b>33</b>
	Positive result	21	12	<b>33</b>
	Who to share result with	18	11	<b>29</b>
	Partner notification	10	9	<b>19</b>
	Verbal consent to test	16	11	<b>27</b>
	Written consent to test	7	2	<b>9</b>
Issues about HIV testing	Employment issues	14	9	<b>23</b>
	Discrimination negative test	12	10	<b>22</b>
	Discrimination positive test	15	12	<b>27</b>
	Early medical treatment	13	6	<b>19</b>
	Reducing onward transmission	13	8	<b>21</b>
	Reassurance if negative	13	7	<b>20</b>
Special Q's pregnant women	Termination of pregnancy	15	5	<b>20</b>
	Prophylactic treatments mother	11	4	<b>15</b>
	Breast feeding	14	5	<b>19</b>
	Drug treatment	11	4	<b>15</b>
	Mode of delivery	10	5	<b>15</b>
		Maximum possible total = 34		

Topics covered by between 60-80% of clinics include; travel abroad, medical aspects of HIV, partner notification, employment issues, discrimination against those testing negative and reducing onward transmission.

Topics which feature lowest in the first pre-test appointment are written information on test procedure and written consent to the test.

A breakdown of topics covered by clinic type and area shows that clinics in low prevalence areas are less likely to cover written information on test procedure and written consent to the test, than high prevalence areas.

All ante-natal clinics cover topics relevant to pregnant women.

### **Average Length of Time between Counselling Session and Test Procedure**

62% of clinics carry out the pre-test counselling session on the same day as the test procedure, where as 21% take between 7 to 10 days.

Of the 17 GUM clinics, 66% in high prevalence areas carry out the counselling session on the same day as the test procedure, whilst the figure for low prevalence areas is 87%. 3 out of 5 drug dependency clinics all in high prevalence areas take between 7 to 10 days, whilst the other 2 clinics, which take between 1 to 3 days, are in low prevalence areas.

### **Location of Blood Sampling**

85% of clinics replied that sampling was carried out on the same site as the pre-test counselling, whereas only 15% carried out sampling elsewhere.

### **Average Length of Time between Counselling Session and Test Procedure by Location of Blood Sampling**

All ante-natal clinics taking part in the survey carry out blood sampling on the same location as pre-test counselling. All but one of the clinics taking more than 5 days between counselling and test procedure did so despite carrying out sampling on site (Table 5).

**Table 5 Average Length of Time by Location of Blood Sampling**

Average Length of Time						
Clinical Type	Location	Same Day	1-3 Days	3-5 Days	7-10 Day	Total
Ante-natal	On site	3	1	0	1	5
	Off site	0	0	0	0	0
DDC	On site	1	0	1	2	4
	Off site	0	0	0	1	1
GP	On site	3	0	0	2	5
	Off site	0	0	1	0	1
GUM	On site	10	3	0	1	14
	Off site	3	0	0	0	3
HIV	On site	1	0	0	0	1
	Off site	0	0	0	0	0
<b>Total</b>		<b>21</b>	<b>4</b>	<b>2</b>	<b>7</b>	<b>34</b>

## **POST-TEST COUNSELLING**

It is beyond the remit of this guidance to discuss post-test counselling in detail. Post-test counselling should be available for both those diagnosed as HIV negative and those diagnosed positive. The main features of post-test counselling are outlined below.

The topics and the timing of the discussion (which should be performed in person) will depend on the patients' reactions to their positive result.

The aims of post-test counselling are to:

- Address immediate concerns and provide support for those who are positive.
- Provide information on the prevention of HIV transmission for both those who are diagnosed as HIV positive and those HIV negative.

If the individual is diagnosed as HIV positive the counsellor should:

- Address the patient's immediate reactions.
- Refer for specialist management, including treatment where appropriate.
- Give details of support services.
- Offer follow up appointments and ongoing support which may include addressing issues concerned with legal matters and support for carers and partners.

## **THE HIV ANTIBODY TEST**

### **Test Sites**

Those who wish to have an HIV antibody test should be able to do so with the minimum of inconvenience. In the United Kingdom testing for HIV antibodies is available at GUM and other specialist clinics, open-access same-day test clinics, general practitioners and a few private clinics. Injecting drug users may be offered testing in drug dependence clinics. In higher prevalence districts, a policy is encouraged of offering named voluntary HIV antibody tests to all women attending for ante-natal care.

An HIV test may also be part of diagnostic investigations.

### **Test procedure**

The diagnosis of HIV infection is most commonly based on the detection of specific antibodies to HIV.

The test for HIV antibodies is a sensitive one and sera that are negative on testing are not usually tested further. Sera that do react are retested twice and/or with other confirmatory tests.

### **Negative results**

A negative test indicates that HIV antibodies have not been detected. This means that either the patient is not infected or, rarely, in the “window period” between HIV infection and detectable antibody production. This period is usually less than three months although exceptionally it may be longer.

If through a recent possible exposure, a patient could be in the window period they should be advised to undergo a repeat test in three to six months’ time.

### **Positive results**

A confirmed positive result may extremely rarely be a false positive. If a patient’s result is thought likely to be a false positive, the patient should be retested.

## **Indeterminate results**

When confirmatory testing fails to establish that a reactive sample is negative or positive, the result may be said to be indeterminate. The laboratory may then seek a follow up specimen or do direct tests for the virus as well as for the antibody to it.

## **Consent to testing**

Informed consent has three requirements:

- The individual must be competent to consent.
- The individual should understand the purposes, risks, harms and benefits of being tested and those of not being tested.
- The individual must consent voluntarily.

## **Confidentiality**

All medical staff have a legal duty to maintain the confidentiality of personal health information. Additional confidentiality is provided by Section 2 of the NHS Venereal Disease Regulations 1974.

“Every Regional Health Authority and every Area Health Authority shall take all necessary steps to secure that any information capable of identifying an individual obtained by officers of the Authority with respect to persons examined or treated for any sexually transmitted disease shall not be disclosed except:

- a) for the purpose of communicating that information to a medical practitioner, or to a person employed under the direction of a medical practitioner in connection with the treatment of persons suffering from such disease or the prevention of the spread, thereof, and
- b) for the purpose of such treatment or prevention”.

Where the NHS Venereal Diseases Regulations 1974 and National Health Service Trusts (Venereal Diseases) Directions 1991 do not apply, the usual duty of confidentiality applies.

## REFERENCES

1. Introduction of a test for HTLVIII Antibody. CMO(85)12 Department of Health and Social Security 1985.
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7. Caring for people with sexually transmitted diseases including HIV disease. English National Board for Nursing, Midwifery and Health Visiting 1994.  
  
Similar guidance was issued by the Health Departments of Scotland, Wales and Northern Ireland and copies of the relevant publications can be obtained from these departments.
8. The National Health Service (Venereal Diseases) Regulations 1974 HMSO.
9. National Health Service Trusts (Venereal Diseases) Directions 1991 HMSO.