

## THE SCOTTISH OFFICE

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# National Health Service in Scotland Management Executive

St. Andrew's House Edinburgh EH1 3DG

Dear Colleague

A. OFFERING VOLUNTARY NAMED HIV ANTIBODY TESTING TO WOMEN RECEIVING ANTENATAL CARE;

B. PARTNER NOTIFICATION FOR HIV INFECTION

## Summary

1. It is the Government's policy that advice, counselling and HIV testing should be available for any person who might have been at risk of HIV infection or wishes to have a test. Enclosed are two sets of guidance encouraging Health Boards and Trusts to offer voluntary named HIV testing to women receiving antenatal care and to establish partner notification programmes.

#### Action

- 2. The guidelines for Health Boards and Trusts are set out in appendices A and B of this letter.
- 3. Managers should consider adopting policies, within existing resources:
  - to encourage the offer of voluntary testing for women attending antenatal clinics in higher prevalence areas and in any other circumstances where such an approach is considered; and
  - to encourage partner notification programmes for people found to be HIV positive.
- 4. A background note giving further details is also attached.

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R STEEL

Yours sincerely

Director of Administration

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Addressees

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## Background Note

- 1. Since 1985 it has been the Government's policy that advice, counselling and HIV testing should be available for any person who might have been at risk of HIV infection or wishes to have a test. Tests are most frequently carried out at genito-urinary medicine clinics, through general practitioners, and at hospital out-patient departments. In addition, of course, clinicians can request a test as part of their investigations of any patient, after obtaining consent.
- A person who is unaware that he or she is HIV-infected may drug using injecting infect sexual  $\mathbf{or}$ unintentionally Conversely people who know that they are infected have the opportunity to adopt behaviours that minimise the risk of transmitting the virus to The AIDS Task Force concluded that the increased availability and accessibility of testing, which is both voluntary and attributable, accompanied by high quality pre-test and post-test counselling, should be encouraged; and in consequence pilot initiatives designed to enhance testing facilities and accelerate the results were launched in Edinburgh and Glasgow. Further guidance on the setting up of additional testing sites will be considered in the light of the results of these pilot projects.
- 3. Meanwhile, there are two aspects of testing, to which it is considered that increasing attention should be given, viz antenatal testing, especially in higher prevalence areas; and the establishment of partner notification programmes in the HIV/AIDS context. The attached guidelines for Health Boards and Trusts have therefore been produced so that managers may consider adopting policies in these areas.

## GUIDELINES FOR OFFERING VOLUNTARY NAMED HIV ANTIBODY TESTING TO WOMEN RECEIVING ANTENATAL CARE

#### Introduction

- 1. For the past few years, some hospitals have offered voluntary named HIV antibody tests to selected women attending for antenatal care, either because the women were perceived to be at higher risk or because they themselves requested a test. A few hospitals have taken this policy further and offered voluntary named tests to all pregnant women and have consequently identified infected women of perceived low risk who otherwise would have been missed.
- 2. Between November 1988 and July 1990, antenatal clinic attenders in Edinburgh and Dundee were invited to participate voluntarily in a study aimed at determining the prevalence of HIV infection among pregnant women in these two areas. The results showed that 1 in 360 pregnant women attending antenatal clinics in Edinburgh, and 1 in 780 in Dundee were HIV positive. The anonymised HIV surveys undertaken by the Scottish Inborn Errors Screening Laboratory, Stobhill, using neonatal Guthrie cards in 1990 and 1991, gave a period prevalence in post partum women in Scotland of 0.3 per 1000 births in Scotland as a whole in both years. Prevalences per 1000 births of 2.5 and 1.6 were registered for Edinburgh, 1.4 and 0.0 for Dundee, and 0.3 (1991) for Glasgow.
- 3. Anecdotal evidence suggests that a significant number of HIV seropositive women are aware of their infection but choose to conceal it for fear of discrimination, and of pressure to have a termination or to have the child fostered or adopted.
- 4. This guidance has been prepared to assist professionals and health service managers in deciding when it is appropriate to offer named voluntary HIV testing to all women attending an antenatal clinic and to assist the development of such a service. It is, however, for each individual health board and trust to determine its own policy taking into account the sero prevalence of HIV in the board's area and the resources available.

## Issues to Consider

## 5. Consent to testing

As with other tests performed on pregnant women there must be no assumption of consent to a test for HIV antibodies. A woman should be given appropriate pre-test information and there should be discussion to ensure that she understands the purpose of the test, what it determines, the benefits and possible problems for herself her partner and her unborn child of having a test, when the results will be available, and that these results are confidential. Some women will wish to involve their partner in a decision about the test and provision will need to be made for this. A test for HIV antibodies should be undertaken only with the woman's explicit consent. Pre-test and, where appropriate, post-test counselling is very important and midwives, health visitors and medical staff will require to be prepared adequately, including access to appropriate training, for such counselling work. It is particularly important for women from black and ethnic minorities that the discussion and counselling take account of their language and culture and should be one-to-one rather than through an interpreter. There will be a need in some areas for more ethnic language speakers as counsellors.

## 6. Confidentiality

- 6.1 All health professionals owe a common law duty of confidentiality. The consent of the woman will be required before the result of a test is given to anyone. Only those with direct clinical responsibility should be informed that a woman is seropositive.
- 6.2 The United Kingdom Central Council for Nursing, Midwifery and Health Visiting states in its Code of Professional Conduct that its registered practitioners should -

"Respect confidential information obtained in the course of professional practice and refrain from disclosing such information without the consent of the patient/client except where disclosure is required by order of a court or is necessary in the public interest".

6.3 Similarly the Guidance from the General Medical Council states -

"The Council believes that, where HIV infection or AIDS has been diagnosed, any difficulties concerning confidentiality which arise will usually be overcome if doctors are prepared to discuss openly and honestly with patients the implications of their condition, the need to secure the safety of others, and the importance for continuing medical care of ensuring that those who will be involved in their care know the nature of their condition and the particular needs which they will have."

## The Benefits of Voluntary Named Antenatal Testing

#### 7. For the Woman

- 7.1 If the test results are available early enough the woman and her partner will be able to make fully informed decisions about the pregnancy at an early stage eg concerning future care during and after the pregnancy, including whether to breast feed (see paragraph 7.6). If the woman raises the question of termination, then this should be dealt with in the usual manner (under the terms of the Abortion Act 1967).
- 7.2 If the woman wants or is considering whether to have her child fostered or adopted, advice and counselling states (See "Children and HIV: Guidance for Local thorities and Voluntary Organisations" published by The September 1993).
- 7.3 The woman can be referred to a specialist for further follow-up, management and treatment of her infection. This can include the option of prophylaxis against opportunistic infections or the use of antiretroviral drugs (which may delay the progression of the disease) at an appropriate time according to her clinical state.
- 7.4 The woman can be given information about protecting herself from sexually transmitted infections during her pregnancy, irrespective of her HIV status. If she has HIV, she can also be counselled on how to avoid transmitting the infection to her partner.

## For the baby

- 7.5 Avoidance of invasive procedures before and during labour (eg rupture of membranes, the application of fetal scalp electrodes and blood sampling) may reduce the incidence of transmission from mother to child. There should however be a balancing of risks and such procedures should be used where clinically indicated if the clinical benefits outweigh the risks.
- 7.6 HIV infection is transmitted through breast feeding. Current estimates are that breast feeding about doubles the risk of transmission from mother to child. The World Health Organisation advises that in developed countries breast feeding by HIV infected mothers should be discouraged. The Government supports this and recommends that women at risk should be counselled about the dangers of transmission by breast feeding. The woman can then make an informed choice, balancing the various risks.
- 7.7 All babies born to HIV positive women carry the maternal antibody for 6-10 months (and sometimes up to 18 months) and thus will test positive at birth. Although current estimates are that in Western countries only approximately 15-20 per cent of these babies are infected they should all be referred to a paediatrician for follow-up. New diagnostic procedures are being developed that enable infected babies to be identified soon after birth. This means it will be possible to introduce prophylactic therapies which may delay or prevent the onset of life threatening opportunistic infections, with more confidence at an earlier stage. A few vertically infected children are living into their teens and it is possible that these prophylactic therapies may allow more to do so.

## Potential Disadvantages of Being Tested

- 8. The potential disadvantages of having a test will also need to be discussed with the woman before she consents to testing. They include:
  - 8.1 If found to be infected:
  - the need to cope with the medical, psychological and social implications of knowing she has a potentially lethal infection and the significance of this for herself, her child and other family members
  - the impact this diagnosis might have on her personal and family relationships (including discrimination) and the possible need for further individual and group support.
  - 8.2 If found to be negative:
  - there has been concern over the possible difficulties in obtaining life insurance after a negative test result. However, the Association of British Insurers has issued a statement of reassurance for women being tested as part of their antenatal care. (Annex A.)

## Implementing Antenatal Clinic Testing

## 9. WHO should be offered a test?

- 9.1 Studies have demonstrated that offering the test selectively to women considered to be at higher risk or who request the test will miss those who are infected but believe themselves to be at little or no risk. Therefore there is a need to consider offering the test to all women.
- 9.2 Women should be given information about the HIV antibody test. This could be included in information given them about their pregnancy, about the tests that are usually offered to all women and the tests that are sometimes offered (or which are available on request).
- 9.3 Offering an HIV test to all women receiving antenatal care has resource implications, as illustrated in Annex C. It is therefore for each individual health board and trust to assess what antenatal clinic testing can be provided in their area, giving due regard to the sero prevalence of HIV in the population they serve and to the resources available.
- 9.4 The decision to offer HIV antibody testing to all women attending an antenatal clinic will be based on knowledge of the local prevalence of HIV infection, the local demography and on any other information that suggests that there could be a significant incidence of HIV infection in the area, for example the prevalence of injecting decided The local policy should be drug misuse. consultation with the consultant obstetrician(s), the head midwifery, local Director of Public Health Medicine, the pathology services and the local director of anonymised antenatal studies if these are being carried out in the locality. Alternatively, the CDEH(S)U could be consulted about anonymised serosurvey results in demographically similar districts.

#### 10. WHEN to offer testing?

Ideally testing should be offered as early as possible in pregnancy. This may miss a very small proportion of women who are in the window period of seroconversion or who become infected during their pregnancy. Women who believe that they have been at recent risk of infection but test negative should be offered a further test later in pregnancy. They should be counselled to ensure that they understand that, in spite of the negative test, they may be infected and infectious. Women who book late in pregnancy should also be offered the test in the same way as those who book early.

## 11. HOW to offer such testing?

- 11.1 The test must only be performed with the woman's explicit consent (see paragraph 5), obtained after appropriate pre-test counselling in private. Consent may be obtained by midwives or doctors who have received training about the issues or by specialist counsellors.
- 11.2 Some clinics have found that it is helpful to provide women with written information about the test before they attend the clinic. As

with discussion and counselling, leaflets should pay regard to the languages, cultures and education of those attending the clinic.

- 11.3 Where it is local practice for the initial blood tests in pregnancy to be taken by primary care staff then general practitioners, their staff and community midwives will need education and training about HIV and about obtaining consent as testing for HIV antibodies is most appropriately done at this time.
- 11.4 Some women, both in hospital and in primary care clinics, may need referral to a specialist counsellor before deciding whether to have a test if they have particular anxieties or difficulties. Such a specialist counsellor may or may not be attached to the antenatal clinic but ideally they should be available to see the woman during that clinic attendance.
- 11.5 The management of the pregnancy of a woman who decides not to be tested should be the same as that of others attending the clinic. The woman's decision should not be taken as an indication that she is infected or that she has been at risk of infection.
- 11.6 It should be remembered that the test is carried out for the benefit of the woman and her baby, not for the protection of those involved in her care. Infection control considerations should be met by strict adherence to a basic standard of personal hygiene and safe working practices. Published recommendations should be applied to all women before, during and after delivery.

## 12. HOW to inform the woman of the test result

- 12.1 Policy will be needed on how and where all women will be informed of their results (this should be in person, whether they are positive or negative) so that this information can be given in privacy and immediate anxieties addressed. Particular care needs to be taken over the post-test counselling of HIV positive women and which member of staff should inform them. It could be the GP, clinic doctor or midwife as long as they have been appropriately trained or they may wish to use the support of a specialised counsellor. There should be strong links, too, with clinicians with expertise in HIV disease so that those found to be infected can receive any necessary immediate and long-term care and support.
- 12.2 Waiting for the result of an HIV antibody test is stressful for many people, especially those who believe that they have been at risk and the delay between a person being tested and receiving the result should be as short as possible. This is particularly important in antenatal testing so that women can make informed decisions about their pregnancy. The local pathology services should be involved in drawing up a protocol for antenatal clinic testing as they will need to make arrangements for performing the tests and providing results in a timely way.

## 13. WHAT services will be required for the infected women and their children?

13.1 Mechanisms need to be in place to care appropriately and sensitively for those found to be HIV antibody positive. In practice this will mean that before the introduction of such a programme the following services need to be identified and in place:

## For the pregnant woman

- 13.2 Appropriately trained midwives, health visitors, and members of the primary care team with the knowledge to support the woman and co-ordinate her care throughout the pregnancy.
- 13.3 In addition to the obstetrician, a physician with an interest in HIV infection to provide specialised care during and after the pregnancy.

## For the baby

- 13.4 A paediatrician with appropriate expertise involved with the care of the woman before as well as after the birth of the child.
- 13.5 The paediatrician and microbiologist need to make arrangements to obtain the more specialised investigations that may be required to establish as early as possible whether the child is infected or not.
- 13.6 General practitioners and health visitors with knowledge and expertise about HIV infection and AIDS.

### For the Family

- 13.7 The various care and support needs of the infected and affected family members will need to be assessed and co-ordinated. The services offered should pay regard to the wishes of the woman. A number of agencies are likely to be involved in providing medical, psycho-social and respite care when required. Policies will need to be drawn up with the assistance of local general practitioners, Directors of Midwifery, the social work departments of local authorities and of voluntary organisations.
- 13.8 Arrangements need to be made for the medical follow up of the woman, the seropositive baby and other infected family members.

  Ideally facilities should be available to enable all the infected family members to be seen together if that is their wish. In some areas there may be sufficient numbers of infected families to justify setting up specialised "family clinics".
- 14. A checklist of the aspects to which consideration should be given is at Annex B.

#### 15. Conclusion

15.1 Boards and Trusts are encouraged to introduce, where appropriate and as resources permit, a policy of offering named voluntary testing to all women attending antenatal clinics.

- 15.2 Testing for HIV antibodies should only be performed with the woman's explicit consent obtained after appropriate pre-test information and counselling (in private) with a midwife or doctor who has received education and training about HIV or with a specialised counsellor. Information, pre-test discussion and counselling should have regard to the languages and cultures of women from ethnic minorities attending the clinic.
- 15.3 A programme of education and training for doctors and midwives in the hospital services and in the community and for health visitors should be in place before such a policy is adopted.
- 15.4 Professionals and managers should ensure that services are available for any women and their seropositive children and for infected and affected family members, who are identified by the testing programme.

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## GUIDANCE ON PARTNER NOTIFICATION FOR HIV INFECTION

#### Introduction

1. The purpose of this guidance is to assist health care professionals, Health Boards and Trusts in the development of local policies and guidelines aimed at identifying partners of people infected with HIV who might have been put at risk of the infection and who may wish to consider whether to seek an HIV antibody test. Partner notification should be part of comprehensive, co-ordinated HIV and STD prevention, care and support programmes, not an isolated activity.

## Development of Partner Notification

- 2. Partner notification (contact tracing) for sexually transmitted disease (STD) has been a central activity in the control of STDs in the UK for more than 40 years. In the early years of the HIV epidemic, when many of those infected had multiple partners over many years, it was the view of some experts that it was impractical and unproductive as a method of limiting the spread of the infection. Nevertheless, the majority of physicians have always counselled those infected with HIV about the need to inform their partners.
- 3. Because of the advent of therapies which may delay the progression of HIV disease and also because of changes in the nature of the epidemic (ie spread to heterosexuals in low prevalence areas where those infected might not perceive themselves at risk) there has been increasing discussion about, and research into, the importance of partner notification, including notification by clinic staff ("provider referral" see definitions below).

Definitions: (from WHO consultation document WHO/GPA/ESR/89.2)

"Partner notification: that public health activity in which sexual partners of individuals with HIV infection and those sharing injecting equipment are notified, counselled about their exposure, and offered services. Partner notification consists of two general approaches: patient (index person) referral; and provider referral.

Patient (index person) referral: the approach by which HIV-infected persons are encouraged to notify partners of their possible exposure to HIV without the direct involvement of health care providers. In this approach the health care provider counsels the HIV-infected person with regard to the information to be passed onto their partners and ways of doing it.

Provider referral: the approach by which health care providers or other health workers notify an HIV-infected person's partners having first obtained the consent of the HIV infected person. In this approach HIV-infected persons give their partners' names to health care providers or other health workers, who then confidentially notify the partners directly. This notification can be undertaken in the context of primary heath care and may involve the index person as well as the health care providers or other health workers."

[Note - for the purposes of this document partner notification is synonymous with contact tracing.]

4. Most physicians actively encourage partner notification by, or with the consent of, the infected person. Practice does, however, vary and most partner notification is in fact undertaken by the infected person with the support of the clinic.

#### The Benefits of Partner Notification

- 5. Partner notification can be of benefit to the person notified and to the public health, including:
- identification of contacts who are then given the opportunity to consider whether they wish to be tested
- those who have unknowingly been infected may wish to know that they are to enable them to take steps to prevent transmission to others
- women who may have been infected may wish to be tested to help them decide whether to take steps to prevent conception and to help them make decisions about the management of a pregnancy and about breast feeding
- access of infected contacts (including children of infected mothers) to treatment and support programmes so that they may benefit from long term monitoring of their clinical condition from appropriate therapies (ie prophylaxis against pneumocystis, pneumonia and possibly anti-retroviral therapy), which may delay the progression of the disease and from appropriate psychological support
- identification of uninfected contacts who could also, where appropriate, be counselled about avoiding risky behaviour in the future.

#### Issues to Consider and Potential Disadvantages

## Informed consent to testing and to partner notification

- 6. Seeking an HIV antibody test is voluntary. Because of the medical, psychological and social implications of being found to be infected the test should only be carried out following appropriate pre-test discussion and with the explicit consent of the individual. The General Medical Council and the United Kingdom Central Council for Nursing, Midwifery and Health Visiting guidance on HIV testing both state: "..the test should be carried out only where the patient has given explicit consent'
- 7. Infected persons who do not want to inform partners themselves should be encouraged, but not put under undue pressure, to allow provider referral. Partner notification by the provider should be undertaken only with the infected individual's explicit consent. The General Medical Council has issued guidance on the exceptional instances when partner notification without consent might be considered. ("HIV Infection and AIDS: The Ethical Considerations". General Medical Council April 1991).

8. The infected person should understand the consequences for himself or herself of notifying partners and the consequences for those partners. For example:

## for the infected person

when the index case informs partner(s) (or where information implicitly identifies the index case) there will be automatic loss of confidentiality about his or her HIV status to those partners who may then inform others

consequent risk of discrimination and of harassment.

## for the person notified

anxieties about possibly having a potentially lethal illness

the need to decide whether to seek a test

possible future difficulty obtaining insurance for those who are tested.

## Confidentiality

- 9. All health professionals owe patients a common law duty of confidentiality.
- 10. That patients have a right, albeit not an absolute right, to medical confidentiality is well recognised by health care workers.
- 11. Equally there is the need to recognise that confidentiality helps to protect the public health. Without it, patients with sexually transmitted diseases, including HIV infection, may be unwilling to come forward for diagnosis, treatment and counselling.

#### Undue pressure

12. Clinic attenders should be encouraged to notify partners or to agree to provider referral as failure to notify partners could well leave many partners, and others, at risk. Clinic attenders have a right, however, to expect to be treated sensitively and not to be put under undue pressure. There is the danger that, if there is a perception that patients are put under pressure to reveal names of partners, then people might be deterred from coming forward for an HIV antibody test.

## Partner notification in settings other than Genito-urinary medicine (GUM) clinics

- 13. HIV infection is not always a sexually acquired disease and some patients have always been cared for in settings outside GUM services. However, it is always a sexually transmissible disease.
- 14. When HIV infected people are cared for in settings other than GUM clinics the question of notifying sexual partners should be part of any counselling provided. (See paragraphs 29-32).

#### Resources

15. Partner notification by the infected person should have few implications for resources. Discussion and counselling about telling partners that they may be infected is already part of good clinical practice and should be raised during pre-test discussion and post-test counselling. Increased provider referral is also unlikely to have significant resource implications. Some illustrative costs are given in Annex A.

## Research and evaluation

16. The effectiveness and benefits of partner notification will vary depending on the setting. Research and evaluation studies will be necessary to determine, for example:

the general effectiveness of partner notification, including its cost/benefits, as a component of local HIV and STD prevention programmes

the relative effectiveness and acceptability of the various strategies adopted

the evidence for sustained behaviour changes as a result of the partner notification

the outcome of referral of notified persons for diagnosis, treatment, care and support

any effect of offering partner notification on attendance at the clinic.

## Implementing Partner Notification for HIV infection

#### WHAT is needed?

- 17. Implementation of policies on partner notification will vary according to a number of factors including the local prevalence, the populations served and the geographical setting. When a policy on partner notification for HIV infection is being developed, managers will need to draw on the professional skills and knowledge of the medical, nursing and health advisory staff in GUM services. In addition, it may be helpful to consult with general practitioners, regional advisers in general practice and other clinical disciplines that care for people with HIV infection and with voluntary organisations and others with an interest.
- 18. When formulating and implementing partner notification programmes it is essential to take into account the attitudes, beliefs, practices and language needs of black and ethnic minorities likely to attend the clinic.
- 19. Managers will need to ensure that services are quickly and easily available for people notified that they have been exposed to HIV and other STDs to minimise the period when they have no access to expert support. They will also need to ensure that facilities are available to provide long term follow up, treatment, care and support for those found to be infected with HIV. In both cases, managers will wish to ensure that adequate training to ensure knowledge of, and familiarisation with, the particular problems is available within clinics and general practices.

## WHEN should partner notification be encouraged?

- 20. Preliminary discussion about the need to tell partners should be part of every pre-test discussion about testing for HIV antibodies.
- 21. Ultimately each individual found to be infected will make his or her own decision about whether to tell a partner or partners at risk and how to tell them. Health workers responsible for informing a person that he or she is infected must be prepared to discuss whether and how that person's partners are to be told and to put to the person the benefits and disadvantages of the notification in a clear and unbiased way.

## WHO should discuss informing partners with the client?

- 22. A variety of caring professionals (doctors, nurses, midwives, health advisers, health visitors etc) may be called upon to tell someone that he or she is infected with HIV. Appropriate training for these workers will be essential to enable them to discuss with the person the need to tell the partner or partners. The health care worker will need to discuss with the infected individual how notification is to be achieved and what support is needed for the notifier and notified. There will be a need in some areas to find and train more ethnic language speakers for involvement in the partner notification process.
- 23. When an infected person requests or consents to the assistance of a health care worker in notifying partners (provider referral) only those with the appropriate skills should be involved.
- 24. Employing authorities have the responsibility to ensure that the skills associated with partner notification are enhanced for all care professionals involved in the process. In particular they need to provide specific education and training.

## WHERE should partner notification be discussed?

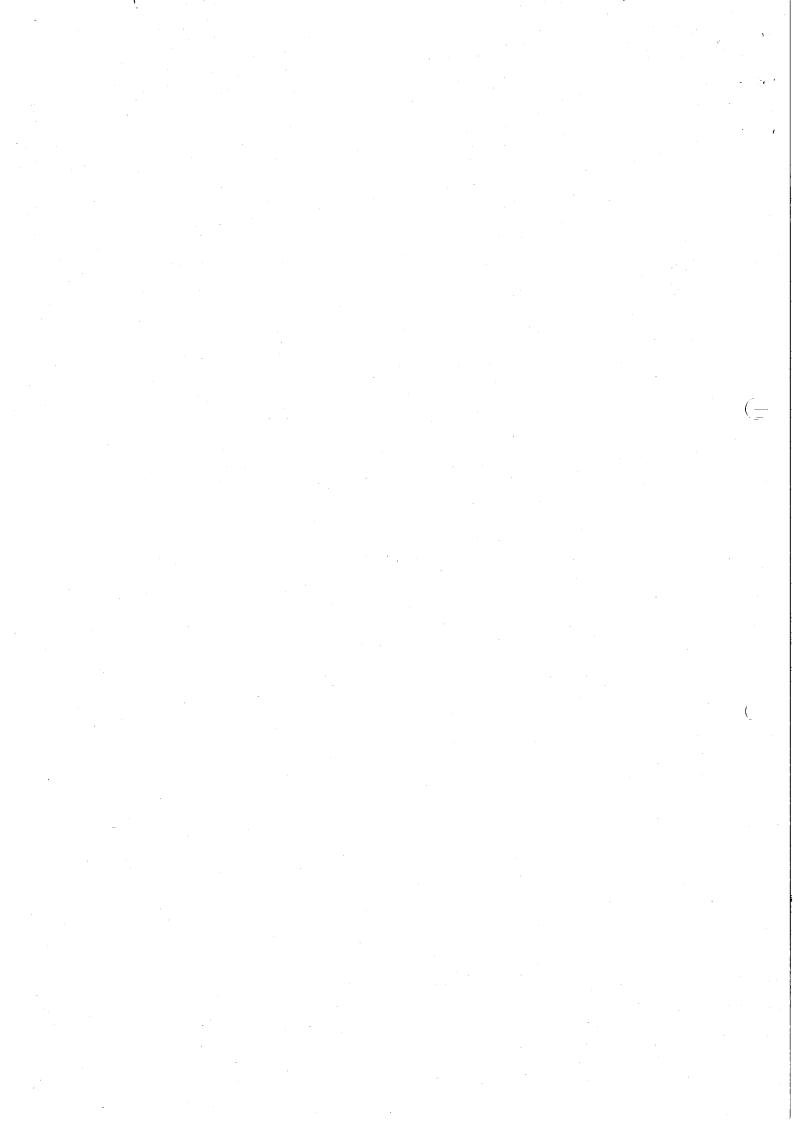
- 25. Only a proportion of tests for HIV infection are performed in GUM clinics. Managers and clinicians should ensure that those found positive in other settings are offered support and counselling about the question of informing their partners.
- 26. They should also consider whether there is a need for provider referral notification programmes in these settings. If there is a need, then managers, clinicians and GPs should consider how best to provide the expertise required in these settings.
- 27. The need to inform drug users' partners is a particularly difficult area, not least because of the illegal aspects of drug misuse, but every attempt should be made to encourage partner notification where drug misuse is a factor in the case.
- 28. Partner notification arrangements for those found positive in general practice, in maternity services, haemophilia and other specialties will also need to be provided.

#### Conclusion

- 29. There should be discussion about informing partners whenever a person is found to be infected. The person should be encouraged to inform, or give consent to the notification of, his or her partner(s) but should be counselled in an unbiased way and not put under undue pressure.
- 30. Each Health Board or Trust, in consultation with health professionals and other interested parties, should provide adequate facilities for partner notification by clinic staff (provider referral) when this is requested or agreed by the infected person.
- 31. Partner notification both by the infected person and through provider referral is an issue for all settings in which testing for HIV infection is performed. Managers and clinicians will need to consider how best to provide the expertise required.
- 32. All staff with responsibility for informing a person that he or she is infected with HIV should have appropriate education and training about partner notification and the need to maintain confidentiality.

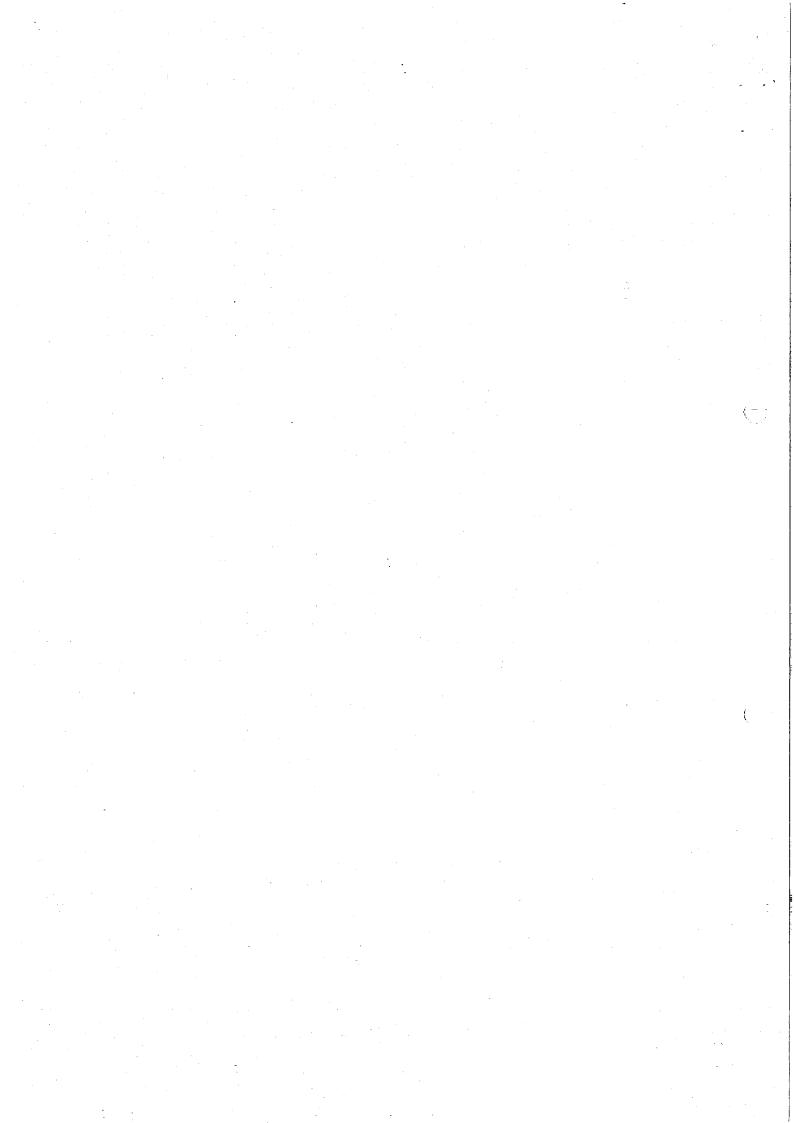
#### ILLUSTRATIVE COSTS OF PARTNER NOTIFICATION

- 1. The costs of partner notification will vary according to local prevalence, the population served and the geographical setting. These will influence factors such as the proportion of patients requesting provider referral, the amount of support required to help patients with patient referral, the average number of contacts for each index patient, the amount of time required to follow up each contact. For the purposes of cost estimation it has been assumed that the work in provider-referral cases will be carried out by a member of the clinic or unit's nursing team. Discussion of provider referral during pre- and post-test counselling may, however, be done by doctors, nurses or midwives who have received the appropriate training.
- 2. It is estimated that for each case about 4 to 5.5 hours of nurse's time would be required for partner notification. The approximate cost per index case would be £86-£106 (including estimated costs of travelling, stationery, telephoning and so on). This includes the cost of HIV testing for partners notified and nurse time discussing partner notification with the index case and contacting and providing initial counselling to the partners.
- 3. Thus, for a board seeing 20 new HIV infected people per year, about 80-110 hours of nurse's time would be taken up solely by partner notification for HIV. The full running costs of the service would be in the region of £1,720-£2,120. In addition to these costs, it would be necessary to provide ongoing training for each nurse involved in partner notification. Carrying out provider referral is demanding and stressful and a certain amount of time needs to be allocated to management and support of the nurse. Thus the overall cost to the board could be about £2,000 to £2,400.



STATEMENT AGREED BETWEEN THE DEPARTMENT OF HEALTH AND THE ASSOCIATION OF BRITISH INSURERS ON THE IMPLICATIONS FOR WOMEN TESTED FOR HIV ANTIBODIES WHILE RECEIVING ANTENATAL CARE

"The results of an HIV test taken as part of antenatal care need to be declared on any future Proposals for life insurance (existing policies will not be affected). If the result is negative your application for life insurance will not be affected in any way provided you make it clear that the test was taken as part of routine antenatal care. However, where there is a serious medical condition or there are other risks unconnected with the test, normal underwriting considerations will apply and it may be that a very small percentage of those taking part will still be charged an additional rate of premium."



## CHECKLIST FOR THE INTRODUCTION OF VOLUNTARY NAMED ANTENATAL HIV TESTS

## 1. Information gathering

#### Sketch local picture:

- Numbers of reported AIDS cases and reports of seropositive people in the Health Board area and their breakdown by age, sex and route of transmission
- Local demography, in particular are there women especially at risk of HIV infection, eg injecting drug users or the sexual partners of drug users, ethnic minorities from countries with a high prevalence of HIV infection in the heterosexual population
- Published or unpublished information on incidence of seropositive women attending local antenatal clinics and numbers of HIV infected children attending paediatric clinics
- Information from any local anonymised serosurveys in antenatal clinics or of Guthrie tests of neonates.
- 2. When drawing up a protocol appropriate to local circumstances you will need to consider:
- People you need to involve:

Obstetric staff
Midwives and nursing staff
Physician responsible for HIV services
Paediatric staff
Pathology services
Counselling services
Local GPs providing maternity services
Health Board AIDS Co-ordinator
Health Visitors

and various support services.

- Whether to consult patient's representatives eg Local Health Councils and voluntary groups including those representing black and ethnic minorities
- Whether testing can be offered to all within resources available or whether testing should be offered on a selective basis
- How to provide information at or before first attendance about investigations usually offered (eg rubella screening etc) and those offered in particular circumstances
- How and where the pre-and post-test counselling and result giving will be organised, given the need for privacy
- Management of HIV positive woman during pregnancy and labour
- Other issues to consider:

availability of a service for early termination of pregnancy issues of confidentiality

how result will be recorded which staff need to be informed the need for consent to inform GP and/or other staff of result at what point to involve the paediatrician and family support services

- Clinical management of HIV positive baby
- Need for care and support of the family

provision of appropriate psycho-social support and counselling involvement with local GP access to social services for benefits if needed consider how, if needed, all infected members of a family could be cared for at the same clinic fostering and adoption policies for HIV positive children

- Laboratory services:

how results will be reported and how quickly

- Training

all General Practitioners and clinical staff concerned will need education and training about HIV infection and the issues it raises

Monitoring and evaluation

programmes should be monitored and evaluated to assist in their further development eg:

uptake of testing and could it be improved without undue pressure being put on women

why women refuse and is there a practical solution to this demographic breakdown of the characteristics of those who accept and refuse testing

## SOME ILLUSTRATIVE COSTS FOR ANTENATAL TESTING

- 1. The cost of a basic HIV antibody test is currently estimated, using data from Ruchill Hospital, Glasgow, at £13.80. Such testing is considered adequate for women not included in high-risk groups or in high-prevalence areas, ie the great majority of women receiving antenatal care in Scotland. In such cases, pre-test counselling of 10 minutes by a midwife (£2.50) should also be adequate, and the necessary counselling and testing in the great majority of cases would therefore cost £16.30 per case. Where additional pre-test counselling is given by GP or specialist counsellor, this will increase costs, in some cases by up to £4.50.
- 2. Adequate arrangements for post-test counselling will also be required where test results prove to be HIV positive, but this is unlikely to represent a high number of cases.
- 3. The cost to a health board of offering HIV antibody tests in any year to 2,000 women with 80% uptake of testing would be in the region of £26,000. As above, additional pre-test counselling by GP or specialist counsellor could increase costs by up to £4.50 per case. The cost for each woman detected as HIV positive would be about £81,500 in low prevalence areas and £1,630 in high prevalence areas. On the assumptions that 15% of HIV positive mothers will request a termination of pregnancy and that the likely rate of transmission of HIV infection to child from mother will be 14% the cost per truly infected child detected would range from, for example £13,697 if the prevalence of HIV infection amongst pregnant women was 1:100 to £684,874 if the prevalence were 1:5,000.
- 4. There will also be costs relating to the support services involved.

