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National Health Service in Scotland
Management Executive

St. Andrew's House
Edinburgh EH1 3DG
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Dear Colleague

OFFERING VOLUNTARY NAMED HIV ANTIBODY TESTING TO WOMEN RECEIVING ANTENATAL CARE

Summary

1. The Appendix to this letter sets out guidelines for Health Boards and NHS Trusts about the provision of advice, counselling and HIV testing of women attending antenatal clinics.

Action

2. Managers should consider adopting local policies, within existing resources and taking into account such factors as cost effectiveness:

- to further encourage the offer of voluntary HIV testing for women attending antenatal clinics in higher prevalence areas; and

- to assist the decision making process in any other circumstances.

Other Information

3. 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. In view of the advantages for a pregnant woman in knowing her HIV status, Health Boards and NHS Trusts, especially those in high prevalence areas, are further encouraged to offer relevant information and voluntary named HIV testing to women receiving antenatal care.

Yours sincerely

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This guidance replaces NHS MEL(1993)154 - Appendix A.

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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. Ninewells Hospital in Dundee has taken this policy further and offered voluntary named tests to all pregnant women and has 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 from 1990 to 1994, gave a period prevalence in post partum women in Scotland of 0.3 per 1000 births in Scotland as a whole in each of the years, with an area breakdown as follows:

	1990	1991	1992	1993	1994
Edinburgh	2.5	1.6	1.2	1.6	0.8
Dundee	1.4	0.0	2.8	1.0	2.0
Glasgow	0.0	0.3	0.1	0.1	0.0
Aberdeen	0.1	0.1	1.1	0.0	0.0
Others	0.0	0.1	0.1	0.2	0.2

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. However, all women who request a test should be counselled and offered one as should those women with a history of recognised risk factors which are evident from the clinical history.

5. 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

6. Consent to testing

As with other tests performed on pregnant women, there must be no assumption of consent to a named test for HIV antibodies. Explicit consent should be obtained after appropriate pre-test information and discussion. This discussion should ensure that the woman 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. 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.

7. The rights of any woman to decline a test must be respected. The care of women who decline testing should in no way differ from that of others attending the clinic. The woman's decision should not be taken as an indication that she is infected nor that she has been at risk of infection.

8. Information should also be made available about alternative local HIV testing sites including genito-urinary medicine clinics, additional test sites, GPs and drug dependency clinics.

9. Confidentiality

9.1 All health professionals owe a common law duty of confidentiality. Results of the tests should only be available to those professionals who have relevant clinical responsibility, on a need to know basis; this should be discussed with the women who should be aware of which personnel know of their sero status.

9.2 The United Kingdom Central Council for Nursing, Midwifery and Health Visiting states in its Code of Professional Conduct that its registered practitioners should -

> "Protect all confidential information concerning patients and clients obtained in the course of professional practice and makes disclosures only with consent where required by the order of a court or where you can justify disclosure in the wider public interest."

9.3 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 case know the nature of their condition and the particular needs which they will have."

Training

10. All staff should be adequately trained about the issues concerning HIV infection. In clinics offering antenatal testing midwives, doctors and others may need more specific training particularly concerning the issues likely to be raised during pre and post test discussions. All clinic staff should also understand the reasons for confidentiality and adhere to locally agreed protocols. Such training should be in place before local policies are implemented.

11. Infection control guidelines should be followed at all times. There should be further evaluation and training as required.

The Benefits of Voluntary Named Antenatal Testing

12. For the Woman

12.1 If a positive test result is 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 12.6). If the woman raises the question of termination, then this should be dealt with under the terms of the Abortion Act 1967.

12.2 If the woman wants or is considering whether to have her child fostered or adopted, advice and counselling should be available. (See "Children and HIV: Guidance for Local Authorities and Voluntary Organisations" published by The Scottish Office in September 1993).

12.3 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. The woman can also be informed of possible interventions to reduce the risk of transmission to the child.

12.4 Irrespective of her HIV status, the woman can be given information about protecting herself from sexually transmitted infections during her pregnancy. If she has HIV, she can also be counselled on how to avoid transmitting the infection to her partner.

For the baby

12.5 Reduction of the incidence of perinatal transmission from mother to child may be aided by knowledge of HIV status. There is evidence for example that giving AZT

to HIV positive pregnant women can reduce the risk of HIV transmission from mother to child. Scientific understanding of the mechanisms of transmission from mother to baby is developing rapidly and this may inform obstetric practice in the future. Knowledge of HIV status may therefore be a relevant fact in avoidance of invasive procedures before and during labour (eg rupture of membranes, the application of foetal scalp electrodes and blood sampling). There should, however, be a balancing of risks and such procedures should be used where clinically indicated if the clinical benefits outweigh the risks.

12.6 HIV infection can be 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.

12.7 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 Scotland 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. Knowledge of the HIV positive status of a child will also help raise the index of suspicion amongst paediatricians that apparently minor infections are more likely to be of the opportunistic type such as pneumocystis carinic pneumonia (PCP). PCP is diagnosed in the majority of children who develop AIDS in the first year of life and is the major cause of mortality in HIV-infectd infants. Appropriate advice regarding immunisation may also be given if the HIV status is known. Increased awareness of the condition is required to initiate early and appropriate treatment. 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

13. The potential disadvantages of having a test will also need to be discussed with the woman before she consents to testing. They include:

13.1 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.

13.2 If found to be negative:

- a woman who has been infected with HIV may have a negative test result if the test is carried out within the "window period" between infection and seroconversion. Women with a recent history of exposure to HIV may therefore require counselling that a repeat test will be necessary.

- 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

14. WHO should be offered a test?

14.1 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. Their right to refuse must be respected and these women should not receive any different care as a result of this decision.

14.2 Women should be given information about the HIV antibody test including potential advantages of knowing whether they are HIV infected and whether any interventions to reduce the risk of vertical transmission are possible. This could be included in information given to 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).

14.3 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. However the quality of the service including information, counselling and confidentiality should be as high in low prevalence areas as in areas more familiar with the test procedure.

14.4 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 drug misuse. The local policy should be decided following consultation with the consultant obstetrician(s), the head of 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, and where possible suitable representatives of appropriate community groups, for example Local Health Councils and voluntary organisations. Alternatively, the Scottish Centre for Infection

and Environmental Health (SCIEH) could be consulted about anonymised serosurvey results in demographically similar districts.

15. 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.

16. HOW to offer such testing?

16.1 The test must only be performed with the woman's explicit consent (see paragraph 6), 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.

16.2 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.

16.3 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. See Annex B at "Training" for information about the Scottish HIV training pack.

16.4 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 and at any time in their pregnancy.

16.5 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.

16.6 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.

17. HOW to inform the woman of the test result

17.1 Policy will be needed on how, by whom 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. The post test counselling of positive women, their partners and families will need to be ongoing and they will need referral to other agencies, social services and voluntary organisations as necessary. 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 treatment and support, and continuity of care can be maintained. Post-test counselling of HIV negative women should include behavioural advice to those at evident risk of HIV infection; advice regarding a repeat HIV test may also be necessary (see paragraph 13.2).

17.2 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.

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

18.1 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, with care taken to respect confidentiality.

For the pregnant woman

18.2 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. The team should be aware of any information on interventions which may reduce the risk of mother to child transmission and discuss with the woman how they could affect her care.

18.3 In addition to the obstetrician, a physician with an interest in HIV infection to provide specialised care during and after the pregnancy. The woman may wish also other agencies such as social services and voluntary organisations to be involved.

For the baby

18.4 A paediatrician with appropriate expertise involved with the care of the woman before as well as after the birth of the child.

18.5 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.

18.6 General practitioners, nurses, midwives and health visitors with knowledge and expertise about HIV infection and AIDS.

For the Family

18.7 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 and should be available regardless of whether the woman wishes to inform all those involved in her care of her sero-status. 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.

18.8 Arrangements need to be made for the medical follow up of the woman, the seropositive baby and other infected or affected 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".

19. A checklist of the aspects to which consideration should be given is at Annex B.

20. **Conclusion**

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

20.2 Testing for HIV antibodies should only be performed with the woman's explicit consent obtained after appropriate private pre-test information and counselling 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.

20.3 A programme of education and training for doctors, nurses, midwives and health visitors working in either a hospital or community setting should be in place before such a policy is adopted.

20.4 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.

ANNEX A

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 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 numbers 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 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. In October 1995, The Scottish Office Department of Health, in conjunction with the Health Education Board for Scotland and the Scottish Council for Postgraduate Medical and Dental Education, published a Scottish HIV training pack for members of the primary care team involved in counselling patients. Copies were distributed to those who train health care workers and others with an interest in the subject, and a study day was organised to assist trainers to use the materials effectively.

- Monitoring and evaluation

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

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

why women refuse testing and any practical solution to this eg through study of demographic characteristics of those who accept and refuse testing.

quality of practice including the views of women attending antenatal clinics.

SOME ILLUSTRATIVE COSTS FOR ANTENATAL TESTING

1. In the context of providing HIV antibody testing services for women receiving antenatal care, the Regional Virus Laboratory at Ruchill Hospital, Glasgow advise that where an HIV antibody test is carried out concurrently with the rubella and hepatitis B surface antigen screen on an antenatal specimen the additional cost would be approximately £1.70 per specimen. Operational overheads of around 15% would take the figure to around £1.95. 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 (£2.60) should also be adequate, and the necessary counselling and testing in the great majority of cases would therefore cost £4.55 per case.

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 £7,280. The cost for each woman detected as HIV positive would be about £22,750 in low prevalence areas and £455 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 around £3,800 if the prevalence of HIV infection amongst pregnant women was 1:100 to some £192,000 if the prevalence was 1:5,000.

4. There will also be costs relating to the support services involved.

Footnote

The 1993 guidance inappropriately gave the cost of a basic HIV antibody test as £13.80. This did not take into account the fact that the HIV antibody test would normally be carried out concurrently with the rubella and hepatitis B surface antigen screen on an antenatal specimen. It is the additional cost per test that matters and, at that time, this was estimated to be approximately £2 per specimen, excluding overheads.