Dear Colleague

OFFERING HIV TESTING TO WOMEN RECEIVING ANTENATAL CARE

Summary

1. Ministers have accepted the HIV Health Promotion Strategy Review Group’s recommendation, based on advice from the National Screening Committee Antenatal Subgroup and Expert Advisory Group on AIDS, that antenatal screening for HIV should be routinely offered to all pregnant women in Scotland. Local programmes should offer and recommend screening for HIV to all pregnant women in all pregnancies as part of an integrated programme of antenatal screening. All NHS Boards and Trusts should therefore ensure that this service is put in place (where it is not already routinely offered) and is supported by the provision of appropriate advice and counselling.

2. The NHSScotland Screening Programmes, which is part of the National Services Division (NSD) of the Common Services Agency, will be responsible, in conjunction with NHS Boards and Trusts, for taking forward appropriate development, as well as the co-ordination and monitoring of the integrated screening programme, using quality standards derived from recommendations from the UK National Screening Committee (NSC) and developed and introduced by the Clinical Standards Board for Scotland (CSBS).

Aim of Policy

3. The aim of this policy is to reduce the number of babies born with HIV. By offering universal screening, it is anticipated that the percentage of HIV infected pregnant women diagnosed at a sufficiently early stage will increase, so that women can be offered advice, treatment and interventions during antenatal care to reduce the likelihood of mother to baby transmission. It is the intention that the implementation of this policy will be made as simple as possible with women receiving the offer of this service as a routine and not being hindered by complicated pre-test counselling procedures which are not considered necessary in this context.
Action

4. **NHS Boards and Trusts should ensure that the following arrangements are in place by 1 April 2003 at the latest:**

   - along with other antenatal screening tests all pregnant women to be offered HIV testing and recommended an HIV test
   - testing to be offered on the basis that it is done routinely unless a woman chooses to decline to be tested
   - clear information to be provided about the HIV test so that informed consent can be given
   - appropriate counselling to be available
   - information systems to be in place to record the offering and uptake of antenatal HIV testing together with any additional data that may be required by the monitoring arrangements being developed by the NHSScotland Screening Programmes, NSD.

5. NHS Boards and Trusts should work with the NHSScotland Screening Programmes, NSD to ensure that the appropriate screening arrangements are gradually introduced throughout 2002 with a target for full implementation by 1 April 2003 at the latest.

6. The quality of these programmes should be audited regularly against standards derived from the recommendations of the NSC that are currently being developed by the CSBS. The draft standards for antenatal screening for infectious diseases developed by the NSC have been placed on their website for consultation.

7. **NHS Board Chief Executives and Trust Chief Executives** are asked to ensure that the contents of this letter and annex are copied and drawn to the attention of all appropriate managers and staff, including GPs and LHCCs.

8. **Medical Directors of NHS Trusts** are asked to copy and distribute the attached letter to Consultants in Obstetrics and Gynaecology, Consultant Paediatricians, Consultant Medical Microbiologists, Consultant Virologists, Consultants in Genito-urinary Medicine and General Practitioners.

9. **Executive Directors of Nursing NHS Trusts** are asked to copy and distribute the attached letter to Heads of Midwifery Services/Senior Midwives NHS Trusts.

Yours sincerely

TREVOR JONES  
Chief Executive, NHSScotland

DR ANDREW FRASER  
Deputy Chief Medical Officer
Background and Other Information

1. This HDL supersedes MEL (1995)75, which encouraged Health Boards and NHS Trusts, particularly those in high prevalence areas, to offer relevant information and voluntary HIV testing to women receiving antenatal care.

2. Since this time, some NHS Boards in Scotland have introduced HIV testing as a routine for all pregnant women as part of their antenatal care. This means that currently routine testing is available in parts of Scotland where the prevalence of HIV among pregnant women is highest but not in other areas where the prevalence is lower but still appreciable. If routine testing had been in place throughout Scotland between 1995 and 2000, and had been taken up in every case, the Scottish Centre for Infection and Environmental Health estimates that between one and two mother-to-child transmissions could have been prevented each year.

3. Data for 2000 are of particular concern. The prevalence of HIV among pregnant women in Scotland increased from 0.02% in 1999 to 0.05% in 2000. Of 53,300 mothers giving birth in that year, 25 were found to be HIV positive on unlinked anonymous testing. This figure compares with an annual average of 14 during the previous 4 years and a previous annual high of 21 in 1992. Of the 25 HIV positive mothers, 8 did not know their HIV status during their pregnancy. It is estimated that 2 of the 8 mothers’ babies will have become infected with HIV. In Tayside, Lothian and Fife, the only NHS Boards in Scotland where universal antenatal HIV testing was in operation during 2000, only one of 12 HIV positive mothers was unaware of her HIV status during her pregnancy.

4. This HDL requires that the new policy of universal antenatal screening for HIV be implemented across Scotland as part of an integrated programme of antenatal screening for a number of communicable diseases (hepatitis B, syphilis, rubella and HIV) and other conditions in early pregnancy. Antenatal screening would normally be offered at antenatal booking clinics. Detection of HIV infection as early as possible allows time for referral to HIV specialists, planning and implementation of the appropriate interventions. This HDL should be read in conjunction with HDL(2001)34.

HIV Health Promotion Strategy Review Group’s Consideration

5. Ministers have accepted the recommendation contained within the HIV Health Promotion Strategy Review Group Report, published in January 2001, that antenatal screening for HIV should be routinely offered to all pregnant women in Scotland. A letter was sent to Boards on 11 January 2001 drawing this point to their attention.

6. In reaching this conclusion the Group took careful account of cost implications as well as recognising the benefits which could be attained in applying effective interventions for every positive result found.

7. Universal screening in both high and low prevalence areas is recommended by the Expert Advisory Group on AIDS and the National Screening Committee for the following reason:

- the alternative to universal screening in low prevalence areas is selective screening and this has been shown to be ineffective in identifying HIV infected pregnant women. There is now clear evidence that interventions can significantly reduce the risk of HIV being passed from mother to baby. All interventions require the knowledge of HIV
status in pregnant women. Continuation of selective screening for HIV is therefore considered ethically unacceptable and it could also give rise to legal action.

8. The HIV Health Promotion Strategy Review Group accordingly recommended:

- that antenatal screening for HIV be offered routinely to all pregnant women. The offer should take the form of indicating to pregnant women that HIV testing is being done routinely, but that they can decline to be tested, if they wish. This has proved a more effective approach than simply offering a test. **It is essential that every woman is given clear information about the HIV test - and the other antenatal tests that will be done - so that she can give her informed consent to allowing the tests to be done.** She also needs to be given the opportunity to discuss any related issues with a suitably trained member of staff.

**Consent to Testing**

9. All pregnant women should be offered and recommended antenatal screening for HIV. The HIV test should be identified explicitly in written information being developed by HEBS and in consultation between pregnant women and health professionals, as one of a number of blood tests routinely offered in early pregnancy. Screening should be offered during each pregnancy. The purpose, potential benefits and implications of such screening should be explained to women. Those providing antenatal care should be sufficiently informed about HIV to be able to discuss the tests and its implications with women and their partners. Where necessary, appropriate training should be arranged for staff. The effectiveness of this programme will be dependent on the extent to which women consent to such tests.

**The Benefits of Antenatal Testing**

**HIV disease in babies and children**

10. Without any treatment, HIV infection in children results in chronic disease and about 20% of HIV infected children develop AIDS or die in the first year of life. By the age of 6 years, about 25% of the children will have died and most of the surviving children will have had some illness because of their infection. The long term picture is unknown, but all children with HIV will benefit from early life-prolonging treatment.

**Interventions to reduce mother to baby transmission**

11. Once women are aware of their HIV infection, all the evidence points to them choosing to accept interventions which will reduce the risk of mother to baby (vertical) transmission and protect their babies. For instance, if the appropriate interventions are accepted, the risk of vertical transmission can be reduced from 25% to around 2%. The Interventions are set out in the British HIV Association Guidelines for the Management of HIV Infection in Pregnant Women and the Prevention of Mother to Child Transmission. (HIV Medicine (2002); 2: 314-334). These interventions include:

- use of antiretroviral drugs
- delivery by caesarean section
- careful obstetric management
- bottle feeding
12. In the United States the numbers of children with AIDS has declined by 66%. France, Italy and Spain have shown improvements in the annual number of infant AIDS cases. In France, a combination of elective caesarean section and the use of antiretroviral drugs has significantly reduced vertical transmission. A number of European countries are now reporting that transmission rates have been reduced to 6%. There have now been reductions in the number of infant AIDS cases in the UK since the peak in 1997, although the UK is still lagging behind some European countries where screening was introduced earlier.

Data Protection and Confidentiality

13. The processing of any sample or test result which contains patient identifying information such as a name, address or date of birth must comply with the Data Protection Act 1998. This means that each person being tested must be provided with the following information:

- **the identity of the data controller**: data controllers are specified in the 1998 Act as the legal entities responsible for processing any individual items of data. In this case, the data controller will be the Trust carrying out the test;

- **the purposes for which the data are intended to be processed**: in other words, why the test is being undertaken and what the samples and results will be used for. This would include making sure that women are informed of systems for quality assuring tests and results and any likely research uses, *even if the data are provided to researchers in an anonymised form*; and

- **any further information which is necessary, taking into account the specific purposes in which the data are to be processed**: the Act offers no guidance on what further information might be necessary. SEHD recommends that the procedures for keeping samples and data secure are explained in general terms.

14. Trusts responsible for HIV testing must also ensure that procedures are in place to protect the confidentiality of people being tested. They must ensure that results of the tests are only available to staff who are responsible for the care of an individual. Trusts must therefore put in place protocols for managing access to samples and test results. These should include the establishment of audit trails which should be checked, with results being reported to the relevant Caldicott Guardian.

15. All health professionals will be aware of the their legal binding obligation of confidentiality towards those in their care and the codes of conduct on confidentiality set by their professional body. In view of the particularly sensitive nature of HIV tests, they must take care to comply with these standards at all times. Failure to do so is a serious disciplinary offence. Staff should make sure that the women being tested are aware of the lengths to which the Service will go to protect confidentiality and that they are aware of which personnel know of their sero status. Women being tested should have the opportunity to discuss any concerns they have on this matter.

16. When discussing confidentiality issues with women being tested it is also necessary to stress the importance of giving the professionals who will be providing care, information which they need to know about the patient's disease or condition. In particular health professionals in specialist care must make sure the patient understands that general practitioners cannot provide adequate clinical management and care without knowledge of their patients’ conditions.
Implications for Insurance

17. The Association of British Insurers, which represents the vast majority of the insurance industry, has recommended since July 1994 that insurance companies should only seek information from applicants for life insurance about positive HIV tests. In February 1996, the ABI extended this recommendation to classes of insurance other than life insurance, where health/lifestyle questions are asked.

18. In June 2000, the ABI introduced a new industry standard general practitioner's report form and guidance for situations in which a GP is asked to complete a medical report about an applicant for insurance, with the applicant's consent. The guidance makes it clear that GPs should not provide information about negative HIV tests.

19. If a woman is asked about negative HIV tests in an insurance application, it should be made clear that the test has been carried out as part of general antenatal screening and not because of a perceived risk. This should ensure that the application is not adversely affected. However, a positive HIV test would be subject to normal underwriting considerations as with other serious medical conditions. In view of this, insurance concerns are only a potential disadvantage if a woman is found to be HIV positive, not if found to be negative.

Training

20. All staff should be adequately trained about the issues concerning HIV infection. In clinics offering antenatal testing all midwives, doctors and others may need more specific training so that they can provide accurate, consistent and quality information to women and their partners about the purpose, potential benefits and implications of HIV screening.

Counselling and Follow Up of HIV Positive Women

21. Policy will be needed on how, by whom and where HIV positive women will be informed of their results so that information can be given in person, in privacy and immediate anxieties addressed. Care needs to be taken over the counselling of women found to be HIV positive 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. To avoid any confusion this should be the responsibility of the professional who organised the test. They may wish to use the additional support of a specialised counsellor where available. The counselling of women found to be HIV positive, their partners and families will need to be ongoing and they will need referral to specialists in management of HIV, other agencies, social services and voluntary organisations as necessary. There should be strong links with clinicians with expertise in HIV so that those found to be HIV positive can receive the necessary treatment and support and continuity of care can be maintained. NHS Boards and Trusts will need to work with appropriate groups of healthcare workers to ensure the clinical care and follow up of mothers and babies identified as being HIV positive who have been detected through the screening programme.

Funding Implications

22. Earmarked funding for prevention – which currently stands at £8.1 million per annum – can be used towards the funding of the additional antenatal HIV tests and associated costs, such as the provision of information leaflets and training of staff for both the simple pre-test discussion and on some staff to specialise in dealing with the handling of positive results.
Laboratory Implications

23. All NHS Boards and Trusts should use laboratories accredited by CPA to provide HIV antibody screening tests for their programme. The test is readily combined with the existing antenatal screening for rubella and hepatitis B (and syphilis if done in the same laboratory) and does not require an extra blood sample. The primary screening laboratory must be achieving satisfactory performance in the UKNEQAS scheme for HIV antibody testing. Reactive samples should be referred to the relevant Regional Virus Laboratory for the recommended HIV confirmatory tests before positive results are released to the requesting clinician. (Antenatal sera are prone to produce a proportion of low reactive results on screening that do not confirm as genuine positives.)

Monitoring and Audit

24. The introduction of the antenatal HIV testing policy outlined above should be subject to local performance management and audit. The Information and Statistics Division (ISD), the Scottish Centre for Infection and Environmental Health (SCIEH) and NHSScotland Screening Programmes, NSD will collaborate to develop a national information return based on an agreed minimum dataset and establish a suitable information system for this purpose.

25. The quality of these programmes should be audited regularly against Scottish standards that are currently being developed by the CSBS. They will be derived from the recommendations of the NSC, will be subject to consultation and will be available at a later date.

26. A report on progress towards implementation of a universal antenatal HIV testing policy up to 31 March 2003 should be included in the AIDS (Control) Act reports for 2001/2002 and 2002/2003. A reference to progress should thereafter form an integral element of these reports.