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**Screening**

## *Editorials*

# The first report of the National Screening Committee

The first report of the UK National Screening Committee (NSC) was published in April 1998 (www.open.gov.uk/doh/nsc/nsch.htm), summarising the main achievements of the committee to date, and presenting the strategy for the review of all present and future population screening programmes.

The NSC, comprising the chief medical officers of each of the health departments of England, Scotland, Wales, and Northern Ireland, was set up in July 1996 to advise the secretary of state for the National Health Service on both new and existing population screening technologies and programmes. Hitherto, there had been no means to ensure that the screening technologies being used were effective for their purpose, that the appropriate populations were being screened, or that regardless of where one lived there was a consistent and reliable approach to guaranteeing the quality of the screening service. Screening had developed in a piecemeal and uncoordinated fashion, without a framework of guidelines or coordinated monitoring.

The work of the NSC has two main themes—policy development and quality management. The full remit and terms of reference can be found in Appendix A of the report. The committee is not responsible for technology assessment, and relies principally on the Health Technology Assessments produced by the Research and Development programme of the National Health Service for its scientific input (http://www.soton.ac.uk/~hta).

In its first year the NSC aimed at reviewing screening nationally, and at identifying key issues and criteria to be used to assess screening programmes. As a first step towards this goal, the first national inventory of screening, identifying over 300 screening programmes either already in use or under research, was completed. The committee then set about the task of developing the framework for screening—the definition and classification of population screening programmes, together with a review of the ethical and social issues.

The committee's first attempt to specify key issues for defining and managing screening programmes is the first edition of the *NSC Handbook of Population Screening*, which is included in the first report. The handbook presents the criteria for appraising the viability, effectiveness, and appropriateness of a screening programme, a recommended format for the presentation of the systematic reviews, and a strategic framework for quality assurance. Work is already in progress on defining UK standards for antenatal, childhood, and adult screening programmes, and for specific disease based programmes, and these will be incorporated into the next edition, to be published in 1999.

During the past two years the NSC has considered evidence about the effect of screening on breast, cervical, colorectal, and prostate cancers, chlamydia, and hepatitis B in pregnancy. Ministers have accepted NSC recommendations that (*a*) prostate cancer screening should not be introduced until further evidence shows there to be a reliable screening test, (*b*) universal screening for hepatitis B in pregnancy should be introduced, and (c) pilot programmes should be launched to test both the acceptability and practicalities of screening for chlamydia, and for colorectal cancer. It is expected that the pilot screening programmes for chlamydia will be up and running by the end of 1998, and those for colorectal cancer will start in 1999. Both will run for up to three years.

The population screening programmes that are currently under active consideration for change are:

- Cancer: breast, prostate, and colon and rectum
- Antenatal: cystic fibrosis, Down's syndrome, fragile X, HIV, syphilis
- Children: congenital dislocation of the hip, cystic fibrosis, hearing, inborn errors of metabolism, haemoglobinopathy, speech, language, and vision
- Adult: cardiovascular disease, blood pressure, and diabetic retinopathy.

The present status of these population screening programmes will shortly be available on the web site. Additional project work, in line with the recent white paper, "A first class service", is also continuing to develop a strategic framework for quality assurance for population screening programmes; the results are expected in the spring of 1999.

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# Antenatal screening for HIV in the UK: what is to be done?

In well resourced countries like the UK the case for HIV positive pregnant women being aware of their infection status has never been stronger. With the availability of strategies for preventing opportunistic infections, and effective antiretroviral combinations, an HIV infected woman is now better able to protect and promote her health.[1] However, it is interventions that reduce the risk of mother to child transmission that have grabbed most attention. The reduction of transmission risk from non-breastfeeding mothers from 25% to 8% by the use of zidovudine in pregnancy in the ACTG076 trial was a defining event.[2] In the view of many this changed the landscape, making it obligatory to have HIV testing available to pregnant women.[3,4] Subsequent progress has been rapid, shorter zidovudine courses have been shown still to halve transmission,[5] other antiretroviral drugs are used with zidovudine, and planned caesarean section has additional benefits.[6,7] Combining these interventions, and avoiding breast feeding, can seemingly reduce transmission to around 1%.[8] For once, clinical practice, admittedly augmented, has exceeded the expectations from trial data.

The policy and practice that should follow look simple—test all pregnant women so that those infected can take advantage of these interventions. WHO has now established the requirements for routine testing undertaken for pregnant women (including less resourced countries[9]). A policy of routine testing, but with consent, is operating in much of France and the USA, and the numbers of new paediatric infections and AIDS cases have fallen dramatically.[4,10–12] In contrast, the UK does poorly. Even in London, where two thirds of HIV positive births occur, and where routine antenatal testing has been recommended since 1992, less than 30% of HIV positive mothers had their infections diagnosed before birth in 1997.[13–15] Indeed when previously diagnosed maternal infections were excluded the figure was 13%.[13]

Why is the UK failing its women, especially in London where testing would be very cost effective?[16] In the 1980s many people felt that HIV positive people would not wish to know their status, and testing should only follow lengthy specialist counselling. This established a legacy of exceptionalism and mystification around HIV testing, which persists, particularly, in antenatal care.[17,18] In contrast, many STD clinics have moved on, abandoning routine specialist pre-test counselling, following official guidance.[19] Some obstetricians, midwives, and general practitioners have found it hard to take on the issues surrounding HIV testing. The women most affected by HIV are black Africans,[13] and some professionals have been reluctant to raise HIV issues with them. Discovering HIV positive status is hard for any woman, and there can be poor acceptance of a diagnosis by African families. However, uptake of testing is no different between black and white women in London,[20] and failing to offer testing to black African women is discriminatory in denying those who are the most likely to benefit.[21]

Currently, in London, antenatal testing is rarely routine.[22] Unlike for other infections, such as rubella, syphilis, and, now, hepatitis B,[23] testing has to be explicitly sought or offered and is often contingent on discussion of the risk factors. Attitudes of mothers are important, but those of professionals are crucial in determining whether and how testing is offered. Consequently, the most important determinant of whether a woman is tested is which midwife she sees, or the attitude of her GP or obstetrician.[24] Testing is therefore a lottery, depending on where women book and who they see, scarcely an equitable situation. Given official policy,[25] it is also a situation where a woman with an infected child may succeed in litigation if she cannot be shown to have been offered a test.

A distressing consequence of this situation is the number of sick children presenting to paediatricians with acute AIDS defining illnesses as the first indication of HIV in a family. The official change of policy encouraging routine testing in 1992 did little to improve this situation (fig 1). In 1997–98 this caused paediatricians to convene a working party from all Royal Colleges involved in antenatal care, the Department of Health, the Public Health Laboratory Service, and other public health bodies. The working party's report, which was endorsed by all Colleges and published in April 1998, made 20 recommendations.[26] At its core was the need to make HIV testing readily available to all women within antenatal care and in higher prevalence areas, such as all of London, making it obligatory for all those giving antenatal care to offer and recommend an HIV test to all women as a routine part of antenatal care. This would make antenatal testing the standard of care in London, the approach recommended in France and the USA where it is characterised as "informed right of refusal".[3] This approach has been tried in Edinburgh where, as routine voluntary testing, it was well accepted by women and midwives and nearly trebled uptake from 30 to 88%.[27]

The report recognised that routine HIV testing is but one necessary part of a process and it recommended other initiatives (table 1).[26] Clear explicit information is needed for women and those advising them. All professionals delivering antenatal care have to be able to respond confidently to most women's questions. The new diagnosis of HIV infection in a woman requires a prompt competent response with skilled advice and management. While the

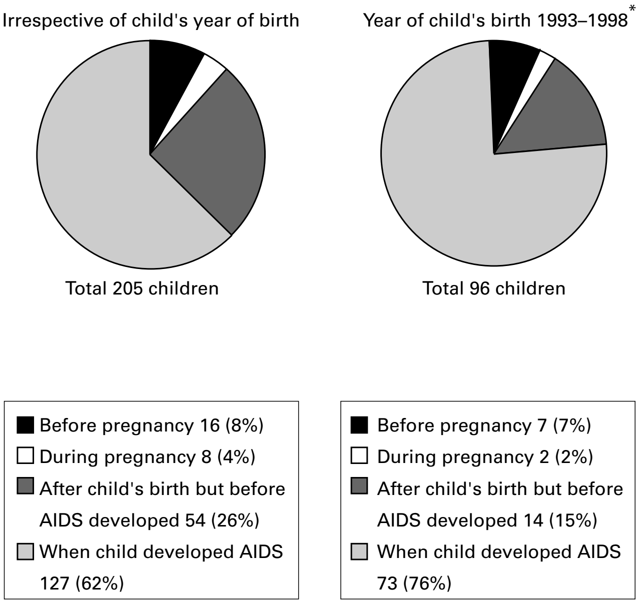

*Figure 1 Vertically infected children born in the United Kingdom and developing AIDS: data to September 1998. *Time period choice to reflect the period when routine antenatal HIV testing in higher prevalence areas was first officially recommended (1992). Source of data: AIDS reports from paediatricians through the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health to the Institute of Child Health (London), PHLS, and Scottish Centre for Infection and Environmental Health.*

*Table 1 Necessary components for routine voluntary antenatal HIV testing*

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| Education and training for the professionals concerned |
| Positive and culturally appropriate information for women |
| Consultation with and involvement of groups at higher risk (black African women) and their families |
| Resources for large scale diagnostic HIV testing |
| Preparedness for caring for the newly diagnosed infected women |
| Authoritative advice, counselling, and support for HIV infected women |
| Information systems to monitor progress |

decision to have a test is usually straightforward, once an HIV positive woman knows her status her options can be complex. Considerations such as termination of pregnancy, testing of the partner and previous children, which antiretroviral combination to choose (and appreciation that the long term side effects of these on the fetus are unknown), are all difficult, and this is the point when scarce counselling resources are needed rather than being wasted on routine pre-test counselling.[18] The black African community, especially its women, must be involved and their confidence retained.[26] If not, resources will be wasted testing women at low risk but missing those most likely to benefit. Also, women might avoid antenatal care if they believed they would be tested against their wishes. Resources have to be found, but this is a legitimate use for a district's HIV prevention budget—a point that should be emphasised in the new national HIV/AIDS strategy.[28]

If it is clear what is to be done in high prevalence areas it is harder to see what should be practised in low prevalence areas—that is, where HIV occurs in fewer than 1 in 2000 births.[29] While waiting for the results of economic studies[30] the report recommends continuing a selective approach and strongly offering and recommending testing to women at higher risk—women who come from, have links with, or travel to countries with high HIV prevalence—notably, black African women, women who have injected drugs or whose sexual partners have injected drugs, and women whose sexual partners are bisexual.[26] Experience of selective testing for HIV has not been encouraging,[31] but it may be difficult to justify routine voluntary testing where the prevalence is less than 1 in 5000 births.

The challenge is now to those providing antenatal care to implement these recommendations. A London implementation group, including African representation, has been established to stimulate and assist this challenge under the chairmanship of an international expert in the field. Antenatal care in London has until the year 2000 (when the intercollegiate group reconvenes[26]) to start doing as well as colleagues do in Paris and New York.

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