(38)

Miss Bateman

AIDS: ALTERNATIVE SITE TESTING FOR HTLV III ANTIBODY

This submission seeks MS(D) agreement on the strategy for publicity on testing facilities outside the national Blood Transfusion Service.

A. Number of HTLB III antibody seropositives in the community

The number of individuals with AIDS (currently 206 in the UK up to 31 August 1985) represents a small minority of the total number of individuals infected with HTLV III which is the virus believed to be the cause of AIDS. Many seropositive individuals are asymptomatic, whilst a smaller number have AIDS related conditions which consist of "minor" symptoms and signs, and only a small minority ofseropositive individuals go on to develop the full clinical form of AIDS. Dr A R Moss (San Francisco) has estimated that the number of infected individuals is 26-28 times the number of clinical cases of AIDS and Dr J Curran (CDC Atlanta) believes that the ratio is 100 times the number of clinical cases. This would give between 5,000 and 20,000 seropositives at present in the UK.

To date, 75% of AIDS cases have been reported in London and this would give a lower estimate of 3,750 and an upper estimate of 15,000 in London itself. For the purposes of planning an approximation between these two estimates might be made of, say, 12,000 cases in the UK with 9,000 of these being in London.

B. Availability of the HTLV III Antibody Test

From mid-October 1985, the test will be generally available throughout the UK in the following sites:-

(i) The Blood Transfusion Service (BTS) will perform the serotesting on all blood donations. If the test is positive the confirmatory test will be carried out by the Public Health Laboratory Service (PHLS).

(ii) The test will be available to doctors generally, but it is expected that the majority of tests will be taken at Genito-urinary Medicine (GUM) clinics because a large number of homosexual men already attend these clinics. Outside the BTS blood samples will be sent to the PHLS for testing.

C. Sites for Testing

(i) The BTS will test all blood donations and recall blood donors with a confirmed positive test who will be seen by senior BTS medical personnel who will have had training in counselling individuals who are seropositive. The positive donor will then be referred either to a GUM clinic or to a physician with an interest in AIDS or to his general practitioner. The donor will be encouraged in any case to allow the result to be sent to his/her general practitioner.

(ii) GUM Clinics. These have, in some instances, already been carrying out the test and providing counselling services. Most clinicians agree that it is necessart to provide some counselling prior to the test. This varies from reading a leaflet explaining the pros and cons, to an interview where the situation is fully explained. If a policy option was taken recommending that all those at risk should have the test soon after its introduction, it is likely that the GUM clinics would be overwhelmed. Facilities in GUM clinics may be performing the test without informing the patients beforehand. If the test is positive, the result will come as a considerable shock to the patient. The Department has advised doctors about counselling the patient before the test is taken, but cannot ensure that this advise is adhered to.

(iii). Some people, eg married bisexuals or wives of seropositive men, may prefer to attend a counselling/testing clinic in general out-patients. Health authorities have been asked to consider if this is necessary and what arrangements might be made. In general an appointment would have to be made in out-patients and a letter of referral from a general practitioner or another doctor obtained. DHAs will need to decide locally whether these additional facilities are necessary.

(iv) Haemophilia Centres. Haempophiliac patients have usually received some counselling already and most have been tested. They will continue to attend their normal haemophilia centre and be followed-up as before.

(v) Drug abusers can be referred for testing to their local GUM clinic by the Drug Addiction Centres. Blood samples could also be sent direct from the DA Centres. The Centres are currently considering their plans regarding this.

(vi) Routine Use of the Test. It is likely that some doctors will test in-patients and out-patients who are under their care because the clinical management of the patient may be altered by a positive result. It is impractical to test every patient in a high risk group but it is likely that some will have a "sero test" without necessarily being informed beforehand.

(vii) Obstetrics and Gynaecology patients. It is likely that women in high risk groups will be tested, particularly if they are liable to become pregnant or are pregnant. This is because the virus can express itself during pregnancy and is likely to affect the foetus.

(viii) Paediatrics. Infants of seropositive mothers will need to be tested as well as haemophiliac children. The numbers of haemophiliacs affected are likely to be considered but heat treatment of Factor 8 should prevent further cases.

D. Counselling

This should be available whenever serotesting is carried out. The counselling courses at St Mary's Hospital, W2 should provide some health care works capable of counselling in all regions by the time of the introduction of the test. Counsellors will become more readily available as more personnel continue to be trained at St Mary's. Most GUM clinics in London have personnel who already have some experience in counselling.

E. Policy Options following the introduction of the test.

All options assume that a national health education programme regarding AIDS (including safer sex practices) will be underway late 1985/early 1986.

In general the four options are:

(i) to actively encourage all people in high risk groups to have the test immediately.

(ii) Not to actively encourage people to have the test but to leave it as a personal decision.

(iii) Not to actively encourage people to be serotested initially but to see how existing facilities in the NHS can cope - for instance in GUM clinics and elsewhere where counselling services are available. Allow a "run-in" period of, say, 3 months during which time health authorities will be able to judge initial demand for the test and the need for additional personnel required for counselling etc.

(iv) Not to actively encourage people to be serotested except within FUM clinics and allow the "demand and supply" equation to be balanced over a longer period.

Recommendations

- Option (i) would almost certainly overwhelm the ability of the NHS to cope, particularly in FUM clinics. There are currently not enough staff to counsel the large numbers of homosexual men (possibly 1-2 million) and the PHLS would have great difficulty in testing very large numbers of blood samples within a short period of time. This option cannot be recommended.

- Option (ii). The situation is complicated and requires discussion. There is debate within the medical profession as to whether all people in high risk groups should be tested. There is a strong public health argument for this group to be tested, as it would

help monitor the epidemic and people who may wish to have children could be counselled regarding the risks. The test may be used as a disgnostic tool to investigate a person with an unexplained illness.

However, this test has already been shown to have far reaching social implications if an individual is found to be positive, despite the fact that the test has only been available to a limited number of people. Individuals with a positive test are unlikely to be able to obtain life insurance (and so endowment morgages) and some have been sacked from their jobs. There are profound social implications regarding their family, spouses, friends and workmates as well as serious implications regarding their sex life. The most profound effect can be on an individual who fees perfectly well - as the majority of sero-positives appear to be. Many doctors and some members of the gay community are encouraging those at high risk to have the test because either a positive or a negative result can lead to behaviour modification. Other members of the gay community and some doctors feel that a positive result in a well person can only have a devasting social effect without any offer of a cure, and there is no vaccine if a person is found to be negative. The confidence and, if possible, backing of the gay community is needed to avoid widespread refusal to have the test. This option (ii) should be considered but will probably not be recommended by the majority of doctors and would not achieve the greatest public health benefit.

- Option (iii). This option has the advantage of seeing how the system can cope with initial demand and allows time for appropriately adjusting numbers of personnel to provide counselling prior to the "second phase" consisting of a publicity campaign linked in with a health education campagin which would encourage people to be tested for the medical and public health reasons outlined in the discussion on opion (ii). This option will also allow the wider issues to be discussed within Whitehall. This is the recommended option at the present time.

- Option (iv). This option would, in some ways, be similar to option (ii). The public health interest would not be served outside the relatively small group who attend GUM clinics. This option is only recommended as a "stop-gap" if FUM clinics become overwhelmed after the introduction of the test, and until appropriate provision can be made to rectify the situation before proceeding to the "second phase" of option (iii).

Recommendation:

That Option (iii) be followed and reviewed in three months time.

GRO-C

E L HARRIS

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cc
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