1. Dr Scott
2. Dr McIntyre
3. Dr Moir
4. Dr Bell
5. Dr G I Forbes
6. Return to Dr Covell

EXPERT ADVISORY GROUP ON AIDS, TUESDAY 29 JANUARY, DHSS, HANNIBAL HOUSE

Please see the agenda and papers for the above meeting which I attended. Also present were Dr McClelland and Dr Cash who contributed abundantly to the proceedings. Unfortunately the agenda was much too long for a morning meeting and many of the items were highly controversial. The result was that some discussion had to be unnecessarily curtailed, especially in the last two items. Even so it was past one o'clock before the meeting closed.

Dr Abrams opened the meeting by welcoming all present and stressing the importance of the meeting. Papers had been marked "not for publication" so that an atmosphere of freedom of speech could be maintained. He introduced Dr Acheson who was attending for a short time.

Dr Acheson said that the urgency of the substance of the meeting was emphasised by the convening of a second meeting in a month's time. He rated AIDS as the most serious public health problem for 100 years. The most important advice that was needed from the meeting was on the public health measures which might control its spread. The most immediate need was advice on the speedy introduction of a serological test for AIDS and advice to Ministers on AIDS and the Blood Transfusion Services. He mentioned the Bournemouth case of an AIDS patient who wanted to discharge himself while ill with a Higson catheter in situ. He drew attention to the tables at the end of Dr Galbraith's table (EAGA 2) and the fact that over three or four years in a disease which was spread venereally, half the patients were over 40. What did that mean?

Item 1 Terms of Reference of the Group

Dr Pinching referred to the paragraph on research on page 3 of the background paper and noted that as well as funds supplied by MRC, AIDS research had been funded by other trusts, pharmaceutical firms and private funds.

Item 3 Public Health Implications of AIDS

Dr Abrams said that this item had been brought up as Ministers were considering making AIDS a notifiable disease in the light of the Bournemouth episode previously mentioned.

Dr Galbraith went over the reasons for making diseases notifiable -

(i) so that local preventive action could be taken;

(ii) so that legal means could be used to confine infectious patients; and

(iii) for local and national surveillance.

As far as national surveillance was concerned he was satisfied that the present system of reporting cases of AIDS to CDSC plus the lab reporting of HTLV III positive cases, soon to be introduced, was sufficient without notification. He suggested that local reporting systems could be set up for counselling services to be arranged if they are not already provided by venereologists and haematologists.

As far as legal powers were concerned, if clinicians needed them to confine patients, then the appropriate means lay in the 1984 Public Health Act by which AIDS could be made notifiable by a Magistrate's Order but:-

(i) notification might not be acceptable to physicians, although it could be made confidential of leprosy;

(ii) clinicians may regard HTLV III infection as much a public health issue as clinical AIDS, and a notification law probably would not cover this. You cannot detain carriers. However the diagnosis of AIDS might be extended to included PGL.

A discussion followed in which it was agreed that AIDS cases should not be subjected to long term confinement like that in leper colonies. Prof Weiss pointed out that at the moment AIDS was defined as a condition where immuno-suppression was from an unknown cause. This would have to be altered to cover the disease as we know it today. However seropositive patients without AIDS can be as dangerous or more dangerous as sources of infection than those with AIDS. There was no point in confining them only when they had the frank disease. We don't know how infectious seropositive people are. It will be even more difficult when a vaccine comes in and seroconversions are achieved by their use.

It was suggested that a syndrome would have to be defined as the law could not permit notification of something that was not a disease. However Infective Jaundice and Food Poisoning were similarly vague conditions which were notifiable. Perhaps AIDS or suspected AIDS could be made notifiable but even in hepatitis B the carrier state was not.

Dr Pinching said there was no point in trying to legislate for a very rare happening which could be dealt with by persuasion. There were no major arguments in favour of notification and many people were actively against it. AIDS itself was only the tip of the iceberg. The worry would be the variablility of criteria for notification which would exist if inexperienced physicians were made to use it. All in all there was no justification for it.

Dr Rodin fully supported this view. He said notification would only lead to alienating vulnerable groups. Bracketing AIDS with leprosy for confidentiality is the worst that could be done. The day may well come when patients will have to invoke the laws to get into hospital of the United States where some hospitals will not admit AIDS cases. There was no reason to panic for one type of case and thereby do a lot of harm. In the United States syphilis and gonorrhoea have been notifiable for years but it had not helped - many cases are still not notified.

Prof Adler supported Dr Pinching strongly. There was no evidence that AIDS constituted a risk to the public or to people looking after cases. There was great concern that ignorant people might misinterpret legal powers - eg children of AIDS cases in the United States ostracised at school. The introduction of legal notification would lead to increased alienation of AIDS patients. The Terence Higgins Trust were very concerned over this issue and the gay community might become very militant if notification were introduced.

Despite the Departmental view that this action would help to reassure the public at large, which was understood, it was known that AIDS was spread by sex or in blood and given this epidemiology it was hard to consider a broader public health threat.

The question was raised whether any other legislation might be used - for instance section 47 - but to alter this would need a change of primary law, not just new regulations.

Dr Abrams summed up by saying that the clinical view was clearly that notification was not indicated. In a remote contingency some other legislation might be necessary.

It was also noted that in the absence of notification Social Security etc would not apply to sufferers.

On the subject of surveillance of HTLV III infection and particularly the informing of the Blood Transfusion Service of HTLV III positive patients, it was agreed that a small sub group should be formed to examine this subject in detail and report back to the main Committee at the next meeting.

Item 8 Transplantation and Artificial Insemination and AIDS

It was agreed that it was irrational in the case of transplants to risk immuno-suppression from AIDS on already immunosuppressed patients. The gay community would not consider exclusion from carrying transplant donor cards perjorative and they should be asked not to do so. When a good test is available this might be relaxed. The same applied to artificial insemination which should also be discouraged for those at risk.

Item 4 AIDS Counselling

Dr Sibellas spoke to the paper from DHSS; the issue was who should counsel patients with positive HTLV III serology. Should it be GPs, if so who should pay for the extra training needed? Should a named consultant be asked to do it? Should there be a counselling service? It was suggested that before these questions be answered it was necessary to know whether regional AIDS centres were proposed by the Department. This had not been decided.

Both those concerned with haemophiliacs and those concerned with homosexuals said that counselling took up a great deal of their time. Prof Adler said there was increasing pressure for counselling married people as well as the patients themselves, without additional resources.

Dr Gray, Consultant Adviser in General Practice, said that counselling was an every day part of general practice. Deaths and alterations of life style went with many diseases. There were however special problems of the impact of AIDS on households. He said that sharing of care with consultants according to resources available had been accepted in many other conditions and could be used in AIDS.

It was pointed out however that many AIDS patients present through genito-urinary departments and not through GPs.

The discussion went on at length as to who should do the counselling and where. The view was supported strongly that wherever the diagnosis of HTLV III positivity was made counselling should take place on the spot. Finally it was agreed that a small working party consisting of Dr Pinching, Miss Jenner, Dr Gunson, Prof Adler and Prof Zuckerman, should review the principles of counselling and report back at the next meeting.

Item 5 Availability of AIDS Screening Tests

Prof Weiss said that he was negotiating with Wellcome Diagnostics to develop a test for BTS which would be as reliable as other tests and would detect serum antibodies specific to HTLV III. Negotiations were just beginning and he could not give a date when it would be available. It may turn out that overseas tests may be produced quicker and could be more reliable.

Prof Zuckerman said that three United States firms, Travenol, Dupont and ? have tests ready which he hopes to evaluate within the next three months and to compare with Dr Tedder's test. He hoped they would not only be available for BTS, indeed even if there was a delay they should wait until others could also be supplied.

Dr Whitehead said there were technical difficulties in the scaling up of the test. He also mentioned the possibility of patent restrictions on the viral strain involved.

In the discussion that followed it was generally agreed that just to give BTS the test would have the effect of attracting at-risk groups to go to blood transfusion sessions to get tested. Dr Gunson said that the BTS were in overwhelming favour of an RIA test since it was more accurate than an Elisa test on which all the American tests are based and suited the equipment which they already had for hepatitis B. Prof Zuckerman's view was that the American test should be evaluated before an RIA test was adopted. The false positives which occur with the Elisa test were also cited as an argument against the use of this test.

Dr Tedder said that because of anxiety, a test must be made available to all who want it. Many attenders at GUM clinics, haemophiliacs and needle stick reactors want the test even though doctors cannot tell them its full significance. Appropriate resources must be provided.

Dr Pinching suggested that clinically there are very few instances in which a test is needed. Cases of PGL and frank AIDS do not need testing. If a person is a little unwell he may need a test. If he is symptom free and at-risk, advice will be the same whether he is sero negative or sero positive, ie alter his life style. If the test wasn't needed for blood transfusion purposes it would not be necessary except for public health reasons.

Dr Abrams said that the Department would be evaluating all the tests.

It was agreed that another small group - Dr Tedder, Dr Rodin, Dr Mortimer, Dr Pinching and Dr McClelland - would look into the issue and report at the next meeting. Dr Mortimer reported that he and Dr Tedder are making a control panel of sera for validation of tests.

Item 6 AIDS Guidelines for Laboratory Staff

Concern was expressed that this document was not just concerned with PGL and AIDS but also for HTLV III positive patients without overt disease. If this was so, many centres would be involved and resources just wouldn't be sufficient to implement the recommendations. Prof Bloom said that all the staff in the haemophiliac service have accepted this and there was no going back on it.

It was also pointed out that if this was so the press release differed from the guidelines. Fear was expressed that patient care must be reduced because of the excessive biosafety rules.

The Chairman invited those who were worried to write to ACDP expressing their views.

Item 7 Prevention and Health Education

Dr Abrams invited comments on the leaflets attached to the papers.

It was suggested that mention of AIDS should be included in health education for drug addicts. They did not at the moment represent a large proportion of AIDS patients but it was only a question of time as drug addiction in this country increases.

Prof Zuckerman objected to the naming of Haiti and specific African countries in the leaflets. He alleged that AIDS was more prevalent in Switzerland and Denmark (according to WHO) than in other countries. Others however doubted that these patients were without other risk factors. Dr Pinching suggested that more use should be made of the popular press for education in AIDS.

In view of the fact that it was past one o'clock Dr Abrams brought the meeting to an end and proposed that the matter be discussed at the next meeting.

Item 9 Date of Next Meeting

13 March.

DR R G COVELL
4 February 1985

Room 2
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