ACQUIRED IMMUNE DEFICIENCY SYNDROME

Note of a meeting held on 14 January 1985

Present		
	Dr Abrams (Chair)	MED SEB
	Mrs Fosh	HS1B
	Dr Graveney	OCS(P)1
	Dr Holt	MED IMCD
	Dr Hunt	MED CDPN
	Mr Lister	MED SEB
	Dr Miller	MED PCR
	Mr Murray	PMC2
	Mr Nye	FB5B
	Dr Pincherle	MED HPS
	Dr Sibellas	MED IMCD
	Dr Smithies	MED SEB
	Miss Weller	NUR
	Mr Williams	HS1A
	Mr Bailey (Minutes)	PMC2

Purpose of Meeting

1. The Chairman said that the meeting had been arranged as a result of Dr Oliver's minute of 3 December 1984 to Dr Harris. The purpose of the meeting had changed as a result of a subsequent decision to set up an Expert Advisory Group (EAG) on AIDS. Nonetheless it was important that Departmental representatives took advantage of the meeting to obtain views on a range of issues which would be looked at by the EAG at their first meeting on 29 January. These issues included disease surveillance, public health measures, health education and counselling of AIDS patients and their contacts.

Counselling

2. The practicalities of providing a counselling service to AIDS patients and their contacts, those found to be sero positive, and those seeking to be sero tested were discussed. In looking at the two latter categories it was stressed that clearance had not yet been obtained from Ministers to the proposed introduction of such a test into the Blood Transfusion Service, though it was expected that such clearance would be forthcoming shortly. The Chairman also pointed out that it was not proposed that additional funding should be provided for this activity, and it was to be expected that this could give rise to prolonged discussion at the meeting on the 29th.

3. Problems foreseen as a result of the introduction of the test included the fact that not all those who have a positive serology test will develop clinical AIDS. Also once it became known that tests were available through the NBTS, the Service was likely to be inundated with homosexuals (not necessarily existing blood donors) seeking an AIDS screening test.

4. Dr Sibellas tabled a draft position paper entitled "AIDS Counselling", and comments were invited. Dr Holt explained that at present some counselling on AIDS is carried out at STD clinics and notably at the Middlesex and St Mary's Hospitals, where screening tests are available. He was concerned that if tests were to be introduced into the NBTS - and no alternative counselling facility provided - STD clinics would be inundated with referrals. In addition many

people found to be sero-positive would not want to be referred to an STD clinic.

5. Dr Holt thought that gps had a role to play in AIDS counselling although referral to gps presented some difficulties because those individuals found to be sero-positive at a NBTS donor-session would not, in fact, be "patients" and might not wish their general practitioner to be informed. In this sense, a parallel could be drawn with the situation regarding Hepatitis B counselling. Also, some referrals would be made from drug abuse clinics and there were likely to be other sources besides the NBTS centres; this would create more difficulties for gps who could be expected to have very little knowledge about AIDS.

6. Dr Pincherle questioned whether, in setting up an elaborate follow-up/ counselling procedure there was a danger of creating excessive anxiety amongst carriers, when in fact it was not really possible to do anything for them. There was general recognition, however, that having established an individual was sero positive there was a need to provide some form of counselling.

7. Mrs Fosh thought it was important to distinguish between the need for a. counselling and b. monitoring. She suggested that to some extent the counselling could be carried out by voluntary groups representing the Gay community (eg the Terrence Higgins Trust), whilst monitoring must clearly be the responsibility of some statutory body.

8. Summarising the views expressed, Dr Abrams said that wherever a positive test occurs, the gp should be informed, but counselling should be undertaken by some other designated person or agency. This counsellor should have access to facilities for the surveillance and follow-up of "patients". The vital question, then, was who should undertake the counselling?

9. Moving on to who would undertake counselling, Dr Smithies said that a very high proportion of patients at Haemophilia Reference Centres (HRCs) would be sero-positive, and it was reasonable to assume that HRC Directors would be prepared to take on responsibility for counselling this particular group.

10. So far as other categories of individuals were concerned, there would be advantages in nominating the consultant in - say - the special clinic to be responsible for counselling. He would be able to rely on back-up from the existing network of professionals(contact-tracers, specialist nurses etc). There was however a problem in that STD clinics operate on a basis of strict confidentiality, and this would present difficulties with regard to informing gps.

11. The Consultant Physician in Immunology was identified as another possible source of counselling, who might provide a more suitable focus for AIDS information. However, not every District would have such a specialist. It was recognised that each District would have its own views on the arrangements which best suited its local situation.

It was agreed however that whatever arrangements were operated there should be a nominated consultant in each district to take responsibility for AIDS counselling. He should be able to call on the services of other health professionals as appropriate including STD specialists.

12. There was strong support for the development of "Counselling guidelines" which could be available to those health professionals dealing with AIDS counselling and it was agreed that the Expert Group should be asked to advise on the content and form of the guidelines and how best such guidelines could be disseminated. Those already working in the field (the Middlesex/St Mary's Hospitals) should be encouraged to produce a paper on this subject for publication in professional journals. Training and training material would also be required.

Availability of Screening Tests

13. Mr Williams was concerned that if some form of "walk-in" testing service were not provided, the NBTS would be flooded with requests from homosexuals and would be unable to cope. Following discussion, there was agreement in favour of a 'walk-in' service being made available, though not by the NBTS. It was felt that this would be better, and cheaper, than a system of "up the line" referrals, involving gps, hospitals, consultants etc and the inevitable problems associated with appointment systems and long delays. It was considered that the views of the Expert Advisory Group on this would be particularly valuable.

14. Regarding cost, it was not thought that the introduction of such a service would present insuperable problems for health authorities, though of course this would depend upon demand.

Prevention/Health Education

15. Dr Hunt questioned whether prevention of AIDS was simply a question of health education, or if other factors were involved. Dr Sibellas said the only real message, at present, for the at-risk groups, was "change your life-style" and she referred to the HEC leaflet "Some Facts About AIDS." This was being distributed to Health Education Officers, STD clinics, various family planning centres and organisations and Gay groups.

16. The wisdom of mounting a large-scale publicity campaign was questioned. It was pointed out that there had been only just over 100 cases of AIDS in the UK, and the recent RCN statement predicting one million cases within six years was somewhat alarmist. Recorded cases fell clearly within the defined risk groups, so education efforts could be restricted to these groups. Nevertheless, a wider campaign - if properly conducted - could in fact be reassuring to the population at large.

17. Action by voluntary groups concerned with the Gay community, if properly managed, was seen as an effective way of getting the message across to this major risk group. This might also overcome the problems associated with a leaflet which would need to be of a sufficiently explicit nature, to be of use to practising homosexuals. Mr Murray advised that an application for S64 funding had already been received from the Terrence Higgins Trust. Mr Williams reported that an application for financial support under S64 could also be expected from the Haemophilia Society.

18. It was agreed that the Expert Advisory Group would be asked, on 29 January, to consider the views of the Transplant Advisory Panel on the question of groups at-risk of AIDS carrying organ-donor cards.

Public Health Implications

19. A draft paper entitled "AIDS - Public Health Implications (The Pros and Cons of Making AIDS Statutorily Notifiable)" was tabled. It was pointed out that if AIDS was to be made notifiable it would be the first STD to be so classified, and difficulties could arise because of confidentiality. Also, the requirement to notify suspected cases could present further problems.

20. It was noted that statutory notification would not necessarily lead to improved information; it would not help the NBTS; and it might be seen by some (eg the Gay groups) as a punitive measure. However without notification, legal powers to control the movements of AIDS patients would not be available. And the notification process made confidentiality a statutory requirement. The views of the EAG would be sought.

Research

21. Dr Graveney referred to the Departmental contributions to two of the MRC funded AIDS Research projects. Of a total of £30,000 pa for three years, £15,000 pa was committed to Prof Adler's research and £7,500 pa to Dr Craske's. This meant that there was £7,500 uncommitted this year, a similar amount uncommitted for next year, and probably the same for the year after that. The Chairman said it was not his intention that research be discussed at the meeting on 29 January.

Departmental Attendance at the Expert Advisory Group Meeting

22. Departmental presence on 29th should be kept to a minimum. Apart from the Chairman, Drs Sibellas, Smithies and Holt would attend. Also Dr Hunt, Dr Miller and Dr Pincherle (for the item on the carrying of organ-donor cards). Mr Harris would probably represent HSI. Miss Weller for Nursing and Messrs Murray and Bailey for PMC.

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EAGA Secretariat.