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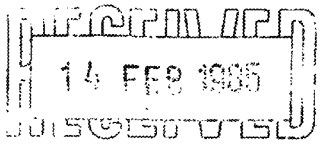

EXPERT ADVISORY GROUP ON AIDS

Note of the first meeting held on Tuesday 29 January 1985, Room 30, Hannibal House.

Present:

Dr M E Abrams, DHSS, in the Chair

Professor M Adler
Professor A L Bloom
Dr J D Cash
Dr M Contreras
Dr N S Galbraith
Professor A Geddes
Dr H Gunson
Miss E Jenner
Dr D B L McLelland
Dr P Mortimer
Dr D Pereira-Gray
Dr A J Pinching
Dr P Rodin
Dr R Tedder
Professor R Weiss
Mr R Wells
Dr M Whitehead
Professor A J Zuckerman

DHSS
Dr E D Acheson (CMO) - part
Dr E L Harris
Dr D Holt
Dr W Miller
Dr J Modle) for EAGA 8
Dr G Pincherle) only
Dr A Smithies
Miss B Weller
Mr A J Williams
Mr T Murray (Admin Secretary)
Dr M Sibellas (Medical Secretary)
Mr D M Bailey (Minutes)

SHHD

Dr R G Covell

DHSS (N Ireland)

Dr N Donaldson

Welsh Office

Dr Ferguson Lewis

Apologies for Absence

1. Apologies had been received from Dr D A J Tyrrell, Chairman of the Advisory Committee on Dangerous Pathogens (ACDP) and Director, MRC Common Cold Unit.

Introduction

2. The Chairman thanked members for responding so quickly to the CMO's invitation to serve on the Expert Advisory Group. He emphasised the importance of the subject on which they were being asked to provide advice, and drew attention to the fact that papers circulated in connection with the Group were not for publication. Meetings should also be regarded as private and the proceedings of the Group be treated in strict confidence.

3. Dr Abrams advised that the names of Dr J D Cash, Consultant Adviser in Blood Transfusion (Scotland) and Dr D B L McLelland Regional Director, Edinburgh and SE Scotland Blood Transfusion Service, should be included in the list of expert members at EAGA1.

4. CMO added his personal thanks to those expressed by Dr Abrams. He stressed the potentially serious epidemiological problem posed by AIDS. The terms of reference drawn up for the Group were very wide; specific issues on which advice was sought included measures necessary - in the field of public health - to control the spread of AIDS. Also CMO hoped for unequivocal advice from the Group on the question of the introduction of a screening test into the NBTS.

Background Paper on AIDS (EAGA2)

5. This paper had been circulated for information prior to the meeting. Dr Pinching pointed out that the paper underestimated the amount of research being carried out into AIDS. In addition to MRC-funded research, much work was being done supported by the pharmaceutical industry and private trusts.

Public Health Implications of AIDS (EAGA3)

6. Dr Galbraith in introducing his paper expressed satisfaction with the present system under which cases of the disease were reported through a variety of channels to CDSC. This system for national monitoring was operating efficiently and should the need arise could be expanded to monitor HTLV III cases as well as the fully expressed cases of AIDS presently being monitored. The efficiency of this system compared favourably with the statutory notification of some sexually transmitted diseases in the USA where large numbers of cases went unreported. Local surveillance posed different problems but these would not be resolved by making the disease statutorily notifiable.

7. The Group proceeded to discuss the practical implications of making AIDS a notifiable disease. It was suggested that problems on maintaining confidentiality could arise if confirmed or suspected cases were reported through normal notification procedures involving local authorities. Problems could also occur in the definition of AIDS for the purpose of amending Regulations.

8. Professor Weiss said that some patients, not necessarily having AIDS as clinically defined, might nevertheless be equally infective. He questioned how it would be possible to apply statutory provisions to control individuals found to be sero-positive who may - at some stage in the past - have been infective, but whose state of infectivity at the present time was unknown.

9. Dr Rodin felt that making AIDS notifiable could heighten public disquiet about the disease and the threat it posed to public health. This would be despite the fact that there was no certainty that the disease posed a risk to the public at large. Professor Adler pointed out that the threat of statutory powers being applied to AIDS sufferers or to suspected cases could alienate 'at risk' groups and the voluntary (sector) organisations like the Terrence Higgins Trust who work with them. This alienation could be counterproductive in achieving the cooperation of at risk groups in health education matters to check the spread of the disease.

10. Accepting the arguments which had been put forward for not making the disease notifiable, the Chairman drew attention to the interest which had focused on the need for Government action to prevent and control the disease. The availability of statutory powers might go some way to reassuring the general public that something was being done. The Group sounded a note of caution about moving too fast with legislation in a field where so many questions remained unanswered. Most cases could be handled through persuasion but if legislation had to be used it could be done by the application of powers within

existing legislation. Preparatory work on amendments to legislation which could be introduced in an emergency situation to allow the detention of an AIDS patient in hospital was one area where action would be warranted. Apart from this there was unanimous opposition from the Group to the idea of making AIDS subject to the range of provisions applying to notifiable diseases.

National Surveillance of AIDS - HTLV III Infection

11. Dr Galbraith briefly introduced his paper (EAGA 3(iii)). Dr Rodin raised the question of preventing patients with AIDS, or individuals who are sero-positive, from donating blood, and Dr Gunson asked specifically about means of monitoring potential donors, who might be infective, moving from one BTS Region to another. In the case of hepatitis B, there existed a system of notification between Regions. A number of issues needed to be considered and it was agreed that a small working group would be set up to consider the matter.

AIDS Counselling (EAGA 4)

12. There was general agreement that a need existed for AIDS counselling, and that a policy on this (where, when and by whom should be carried out etc) needed to be developed.

13. Haemophilia Centres and STD Clinics would provide some counselling - and indeed were already doing so - but would be constrained by the level of resources available. Much excellent work in this field had been done at St Mary's, Paddington; this work would make it a possible choice as a national centre for training health professionals in AIDS counselling if such a facility was thought to be necessary. For many people however especially amongst those found to be sero-positive by the Blood Transfusion Service, reference to an STD Clinic would be inappropriate.

14. Dr Pereira Gray stressed that counselling should not be regarded as an "optional extra", but as a function which had to be fully integrated into the medical care of AIDS cases. GPs would have a vital role to play in this, and their training in counselling in other fields would be valuable in this.

15. Following discussion, the Group concluded that counselling must be available at the point when an individual is first told that he has AIDS, and/or a positive test for HTLV III antibody, and should preferably be provided by the person who imparts this information. The person (or service) which instigates the screening test, and gives out the result - whether this be the NBTS, or STD Clinic, or hospital - must take responsibility for the consequences, including counselling. The provision of effective counselling could, however have significant resource implications.

16. Mr Wells said that AIDS patients would seek help and support from the whole range of health-carers, and that the development of counselling skills was just as important for nurses and other health-care professionals as it was for doctors. Dr Pereira-Gray again stressed the importance of involving the general medical practitioners, though it was generally recognised that the actual counselling would be best provided by an expert in the field. The STD Clinic would be an appropriate centre in many cases, but whatever the circumstances of a particular case there would always be a need for those involved to work together as a team - and for the GP to be in close liaison with the expert counsellor.

17. At the Chairman's suggestion it was agreed that a small working group be set up to consider the problems of AIDS counselling, and to provide a written paper on the subject for the next meeting of the EAGA. The working group would consist of Professor Adler, Dr Gunson, Miss Jenner, Dr Pereira-Gray, Dr Pinching and Professor Zuckerman. Dr Abrams would Chair this group. [Secretary's Note. Professor A Geddes and Dr J Green (St Mary's) have since agreed to join the working group.]

The Availability of the AIDS Screening Test (EAGA 5)

18. Professor Weiss said that work was currently being carried out with Wellcome Diagnostics to develop a screening test, but there were still problems to be solved and he was not able to say when the test would become available. Professor Zuckerman said that tests were also being carried out at his laboratory and that the results of the American Dupont and Travenol tests might be available within a few months. Comparisons would be made with the test being developed by Professor Weiss and Dr Tedder.

19. The Chairman reminded members that the November meeting of the BTS Advisory Group on AIDS had concluded that a screening test for all blood donors should be made available as soon as possible. He asked whether the EAGA endorsed this view.

20. There was general support for the introduction of a blood donor screening test as soon as practicable.

21. On the type of test to be used, Dr Gunson said there was an overwhelming preference for the use of the radioimmunoassay test in the NBTS, whilst Professor Zuckerman stressed the need, first, for evaluation of other tests, including the ELISA test. The Chairman said that DHSS would ensure that all tests were evaluated.

22. With regard to testing "on demand", Dr Tedder felt that ideally a screening test should be available to anyone seeking it. Departments of Genito-Urinary Medicine would probably be the most appropriate centres. GPs would also need to have access to testing facilities. Professor Bloom said that haemophiliacs - as a group - should have ready access to screening test facilities, and provision of such a service for them should be less difficult than for the population at large because they formed a finite group. Dr McLelland thought that it would be impossible to separate, as a matter of policy, NBTS testing and STD clinic test

23. A sub-group was set up comprising Drs Gunson, McLelland, Mortimer, Pinching, Rodin and Tedder to consider the various aspects of screening tests for AIDS, in particular the best way of introducing the service when the tests become available. Dr Smithies would Chair this group.

AIDS Guidelines for Clinical and Laboratory Staff (EAGA 6)

24. The Group considered the Advisory Committee on Dangerous Pathogens' Interim Guidelines on AIDS, issued in December 1984. Miss Jenner drew attention to para 15 on page 5 of the Guidelines which referred to those who may be directly exposed to the tissue and body fluids of AIDS patients, and those undertaking laboratory work on the HTLV III virus, being asked to volunteer serum samples. Referring to the earlier discussion of screening test availability, Miss Jenner suggested that this was a group of staff who should be considered for screening.

25. The ACDP Guidelines had very considerable consequences for laboratories, not least of which were the financial implications. The facilities required to meet the recommendations were not currently available everywhere, and they would be expensive to introduce. The question was raised whether laboratories should regard all HTLV III antibody samples as dangerous. This was thought to be unrealistic.

26. The relevance of the Guidelines to Infectious Disease Units was questioned. Dr Pinching expressed the view that nothing in the Guidelines should be seen as affecting the overriding importance of patient care. The Chairman said that comments on the interim Guidelines, should be sent to the ACDP Secretariat.

Prevention and Health Education (EAGA 7)

27. The Chairman drew the Group's attention to the leaflets on AIDS issued by the Health Education Council, and the Terrence Higgins Trust, and to the draft leaflet produced by DHSS for the National Blood Transfusion Service. He sought views on these leaflets and asked what further action could, or should, be taken, bearing in mind the need to avoid any accusation of increasing public anxiety.

28. Professor Zuckerman was concerned at the reference to specific countries (Haiti) in the list of at-risk groups in the HEC leaflet. He thought this could well give a misleading picture and recommended that it be deleted from any reprint of the leaflet.

29. The blood-donor leaflet was not considered sufficiently forceful. It needed some redrafting particularly with regard to its objective of persuading homosexuals not to donate blood. Consideration should be given to the introduction of some means by which the "closetted" homosexual - possibly faced at a visit to a NBTS Centre with advice not to give blood - could unobtrusively withdraw from the system.

30. Regarding further action, Dr Galbraith drew attention to the recent 15% reported increase in IV drug abusers, and the fact that 2-3% of these were HTLV III positive. References to AIDS should be made in the literature being prepared as part of the current drug-abuse campaign.

31. Dr Pinching suggested that since a proportion of AIDS cases are drug addicts who have shared needles, there could be some merit in examining the possibility of providing free needles and syringes.

32. It was also suggested that greater use might be made of the national press, and possibly the involvement of publicity agencies, to try to ensure that AIDS publicity is directed in a way which the Department would find more beneficial to its aims and objectives. It was agreed that a member of the Department's Information Division should be invited to the next meeting of the Group.

Transplantation and AIDS (EAGA 8(i)) and Artificial Insemination and AIDS (EAGA 8(ii))

33. The Group considered papers submitted by the Department on these issues. It was unanimously agreed that in this context the same considerations applied to organ donors and to semen donors (for Artificial Insemination by Donor) as applied to blood donors".

People in the high-risk groups for AIDS should be asked not to carry organ-donor cards, and semen donation for AID should not be accepted from those in the at-risk groups.

Next Meeting

34. 13 March 1985 at 10.30 am, in room 1114, Euston Tower (286 Euston Road, NW1).

February 1985

EAGA Secretariat