IN CONFIDENCE

EXPERT ADVISORY GROUP ON AIDS

MINUTES OF THE SIXTH MEETING HELD ON 1 OCTOBER 1985

Present:

Mr B Hayhoe - Minister for Health
Dr E D Acheson - Chairman

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 McClelland
Dr P Mortimer
Dr D Pereira-Gray
Dr J W G Smith
Dr R Tedder
Dr N Thin
Dr D A J Tyrrell
Professor A J Zuckerman

DHSS

Dr E L Harris
Dr D Ower
Dr A Smithies
Dr J Bellamy
Mr C Howard
Miss B Weller
Mr A Williams
Dr M Sibellas - Medical Secretary
Mr T Murray - Secretary
Miss G Woods - Minutes
Dr R G Covell - SHHD
Dr S N Donaldson - DHSS NI
Dr S Palmer - WO

1. Introduction

1.1 The Chairman welcomed Mr Barney Hayhoe (MS(H)) to the meeting.

1.2 Mr Hayhoe said that the measures he had taken were an indication of the priority he attached to the immediate need to control the spread of AIDS. There was a considerable amount of work to be done in communicating information to the specific target groups and to the general public in such a way that it would be understood and acted upon. Unfortunately, the funds necessary for the exercise were subject to constraints this year but bids had been registered for additional resources for the future. The outcome of these bids would be known later this year. MS(H) then expressed his appreciation to members of the EAGA for their invaluable assistance.

1.3 Dr Tedder said he was extremely concerned about the shortfall in the finance required; the London Regions had only been allocated one-third to one-quarter of the amount requested. It was essential that the Government understood that it was necessary to spend money now in order to make savings later on.

1.4 Mr Hayhoe accepted the point but stressed that the decision on overall allocations was not dependant on Health Ministers alone; Ministers collectively had to agree. A strong case for additional monies had been submitted and Health Ministers would continue to argue the need for additional resources. Regions could also be flexible in the deployment of their own allocations and Districts should press their case to Regions.

1.5 Professor Zuckerman said that although only 206 people had contracted clinical AIDS, the situation in reality was much more serious and constituted a national emergency. Mr Hayhoe replied that an inter-Departmental Group was being set up which should ensure that Ministers in other Departments had a much better appreciation of the situation.

(Mr Hayhoe left the meeting at this point.)

2. Agenda Item 1 - Apologies

2.1 Apologies had been received from Dr Ferguson-Lewis and Dr Pinching, Professor Weiss and Mr Wells.

2.2 The Chairman welcomed Dr Joe Smith of PHLS who had succeeded Dr Whitehead and Dr Stephen Palmer who was attending instead of Dr Ferguson-Lewis.

3. Agenda Item 2 - Minutes of the previous meeting held on 30 July

3.1 Subject to the following amendments:

Paragraph 7.2.2

(1) Line 3 should be amended to read "assertions" and not "assumptions";

(2) The inclusion of Dr Pinching's point that "the assessment had included the validity of tests on heat treated sera. As it was not necessarily appropriate for all laboratories to use heat treated sera, the necessity for good performance in heat treated sera was not necessarily a valid reason for excluding a particular system." (Letter dated 5 September to Dr Sibellas refers);

the minutes were agreed.

4. Agenda Item 3 - Matters Arising

4.1 Dr Pinching's letter dated 5 September to Dr Sibellas - EAGA(6)1 referred.

4.1.1 Dr Pinching had suggested that it would be helpful if information was provided on which tests performed as well as recommended tests other than performance on heat treated sera. Dr Smithies said that a report from PHLS containing such data was in print and members would receive copies.

4.2 Draft Guidance for Surgeons, Anaesthetists and Dentists

4.2.1 Dr Ower reported that the guidance was being edited and he hoped the final version would be ready at the end of the week. It would be issued to doctors as part of the Blue Book Series and to dentists under cover of a CDO letter.

4.2.2 It was agreed that members should receive a copy of the final version before it went to print but further comments would not be sought since it was essential that the guidance was issued as quickly as possible.

5. Agenda Item 4 - The Establishment of the Sub-Groups on: EAGA(6)2
(a) The Employment of Health Care Personnel and
(b) AIDS in Renal Units

5.1 Members noted this paper. It was agreed that dates for the second meetings of the two Sub-Groups should be fixed straightaway if arrangements were not in hand. The Chairman expressed hope that decisions would be reached quickly on guidance to be issued.

6. Agenda Item 5

6.1 AIDS Surveillance Update EAGA(6)3

6.1.1 Dr Galbraith said that the total number of AIDS cases reported by the end of September had risen to 225; of these one was an intravenous drug abuser. In total four had now contracted the disease through blood transfusions. Two of the blood transfusion cases had been transfused abroad and reported previously; the two new cases, both male had been transfused in England (Manchester and Newcastle). The number of heterosexuals who had contracted AIDS remained at two. With the new CDC classification two HTLV III cases would be considered negative and therefore excluded but several lymphomas would be included.

6.1.2 The discussion then centred on the prevalence of the disease. Dr Smith referred to two surveys being undertaken, the first by Dr Polakoff in collaboration with Genito-Urinary Medicine clinics, the aim of which was to ascertain prevalence in non-homosexual men. He suggested that Dr Polakoff should be invited to give an oral report at the next meeting. The second survey was being carried out in Haemophilia Centres. Dr McClelland asked if data from this survey could be made available before the next meeting.

6.1.3 Professor Adler informed members that monitoring of homosexual men by the Middlesex Hospital had shown an increasing prevalence; more recently heterosexual men and women had been included and their prevalence had remained at zero.

6.1.4 Dr Tyrrell was of the opinion that cases not within the CDC classification should be re-examined. If these persons were carrying the virus a low transmission rate would become important over the years. Monitoring would need to be carried out in case guidance needed to be amended in the light of new evidence regarding changes in the virus.

6.1.5 Professor Bloom said that a prevalence study of haemophiliacs who had had the HTLV III test had been completed. Of 2420 haemophiliacs treated in the last five years in the UK, 865 were positive, all had been treated with Factor VIII or IX. A statistical breakdown of children of school age had revealed the following positivity:

< 5	-	13%
5-9	-	10%
10-19	-	40%

In his own clinic it was policy to use BPL Factor VIII on those under 20 and 4/40 patients in this age group are positive.

The Chairman said the figures were better than he might have expected. Consideration would however have to be given to the post-pubertal child.

6.1.6 Professor Bloom said that of children 4-10 years of age extrapolated against the known number in the country, 73 were positive and of young people under 20, 436 were positive. Dr Craske had also obtained additional data to the effect that 4/90 wives of positive haemophiliacs were also positive. Dr Mortimer said that Dr Evans of the West London clinic had found one patient to be positive out of 2-300 tested. It was difficult to find a non-biased group.

6.1.7 Dr Contreras informed members that a questionnaire was given to all known high risk blood donors who had attended the North London Blood Transfusion Centre. All 50 tested by Dr Tedder were negative.

6.1.8 Dr Cash wondered if the reporting system for AIDS was being effectively co-ordinated. Dr Galbraith replied there were some problems.

It was not known if:

(i) All cases of HTLV III infection and AIDS were reported;

and (ii) some were reported twice.

However, when the system had settled down it would be valuable for showing trends of time and place. It would be useful to be able to see trends of the individual types affected. However, this would involve laboratory staff in a great deal of work. He was already discussing with Dr Smith and Dr Mortimer the case for a more detailed sampling frame. Dr McClelland was doubtful if meaningful data could be provided since no personal details were collected. If they were, duplication of information would be avoided.

6.1.9 Dr Tedder was of the opinion that the National Blood Transfusion Service was in an excellent position to collect epidemiological data on donors who provided 2½ million donations each year.

6.1.10 The Chairman said the introduction of the test would provide the opportunity for extending epidemiological knowledge. It was essential that the most was made of the valuable information gained despite the known bias. Dr Galbraith replied that CDSC did try to ensure details were known and suggested that Dr McEvoy be asked to give a report on the cases outside the risk groups. This was agreed.

6.2 Some problems in the prediction of future numbers of cases of the Acquired Immunue Deficiency Syndrome in the UK — EAGA(6)4

6.2.1 Members noted this paper. Dr Tyrrell pointed out that there was the possibility the virus could change over the years, possibly affecting its pathogenicity and behaviour. Clinical and epidemiological monitoring was therefore necessary and advice would need to be amended accordingly.

Dr Cash thought it was essential that positive blood donations should be stored for co-ordinated research at a later date.

7. Agenda Item 6

7.1 CMO letter on the introduction of the test for the antibody to HTLV III — EAGA(6)5

7.1.1 The Chairman explained that the second in the Blue Book series had been distributed to all doctors in England; a parallel exercise had taken place in Scotland, Wales and Northern Ireland. The booklet described the arrangements for testing and repeated previous advice on the precautions doctors needed to take when taking samples of blood from an at risk individual. It also contained simplistic advice on the counselling of a positive patient. He was sceptical about the number of doctors who would read the booklet since he was aware of a recent survey of London general practitioners which showed a considerable degree of ignorance about HTLV III infection and AIDS. This indicated they had not read the first Blue Book. It was essential that GPs knew of developments since some people who feared they had come into contact with the virus would go to their GP first for advice. Whilst the General Medical Services Committee would be asked for advice on the dissemination of information to GPs, he asked Dr Pereira Gray to let the Department have his initial views.

7.1.2 Although the draft of the second Blue Book had been seen by members Dr Pereira Gray expressed his concern at not being specifically consulted about the role of the GP. He thought it was important for there to be flexibility in the arrangements for testing since some patients would not want to go to a GUM clinic, others would seek treatment from GPs outside their home areas and others would seek private treatment. If arrangements were not flexible, a number of patients would be missed. There were problems with clinics in that they only opened at certain times and therefore a referral did not mean immediate attention. The problem was exacerbated by the fact that there would be periods when a consultant was not available.

7.1.3 Dr Thin asked whether the PHLS would be carrying out all initial testing and if so by what means were GPs to get the samples to the laboratory, or would the laboratories be taking the samples of blood? Dr Mortimer replied that it would be difficult for the PHLS to do all the sampling; methods of collection varied locally. Appendix 1 of the Blue Book contained advice on the packaging and posting of samples. (Dr Smithies pointed out that paragraph 7 contained a reference to this matter.)

7.1.4 On the question of whether GPs would be reluctant to undertake sampling Dr Pereira Gray thought there would be a division. Professor Bloom thought most of the sampling would be devolved to the laboratories of the local hospital. Professor Geddes described the system in operation in Birmingham whereby the GPs sent their patients to the Infectious Disease Unit (there was only one GUM clinic servicing five Health Districts) where they were bled and the sample was then passed on to the Virus Reference Laboratory. The GP was informed of the result and the patient was given the option of being counselled by the GP or at the Infectious Disease Unit. Many preferred the latter. He felt the complexities of counselling were being over-estimated; he thought that any GP or consultant should be capable of counselling patients. He undertook counselling himself but had not been on the St Mary's course. The counselling he gave basically consisted of an explanation of the significance of a positive test and its health implications and secondly the risks to other people. Many patients asked if they could return with their relatives for further counselling.

7.2 Open access facilities for HTLV III antibody testing EAGA(6)

7.2.1 Dr Ower said his paper was self-explanatory. The conclusions had already been covered in the previous discussion. With regard to the recommendation of a publicity campaign, the Department was actively engaged in discussions with an advertising agency, which had already drawn up initial proposals.

7.2.2 Dr Cash questioned the wisdom of open access facilities provided on an anonymous basis since it was necessary from a public health point of view to maximise the data base on the prevalence of the disease and to provide guidance for positive patients in order to control its spread. It was therefore necessary for alternative sites to be provided for those who did not want to see their GP, these could be provided by GUM clinics (although he felt there was still a stigma attached to these clinics) so Infectious Disease Units were to be preferred.

7.2.3 Dr Thin stated his predecessor had arranged for Genito-Urinary clini staff to work in General Out-Patients half a day a week. Whilst this might be seen as a dilution of resources it was a possible solution. He was concerned about the possibility of anonymous 'walk-in' clinics in the UK, since the data considered essential for national surveillance could not be collected. Dr Ower said he was hoping to obtain information on the type of data collected by such clinics in Denmark and America. The Chairman understood there were anonymous clinics in Holland and he would obtain information when he visited the country shortly. Dr Cash said the American Association of Blood Banks had suggested the workload of anonymous clinics was small.

8. Agenda Item 7 - Resources

8.1 Mr Murray reported that a team of Departmental officials had met representatives of the Thames Regions to discuss the resource implications of dealing with AIDS. From the information obtained it had been possible to assess both the short-term situation and the long-term implications. Mr Hayhoe had recently announced that additional monies would be available this year and a letter would be sent to the Thames Regions informing them of their allocation. Additional support this year was for:

(i) Out-patient services.

(ii) Counselling services including those provided by the Haemophilia Regional Services

(iii) The voluntary sector.

(iv) Developmental work for the National Health Education Campaign which was to take place next year.

8.2 The Chairman said the virology departments of the London Teaching Hospitals were concerned that additional monies had previously been allocated to the PHLS for testing purposes, whilst they would receive no financial assistance for the additional testing work they would have to carry out. Dr Smith replied that the PHLS had been given funds to promote a national service although the teaching hospitals did probably require special consideration, [illegible]

8.3 Professor Zuckerman said that a number of clinical virologists were concerned about the possibility of lengthy delays between the sending off of samples to PHLS laboratories and receipt of results. Dr Mortimer could not accept there were lengthydelays. There were four PHLS laboratories in London which would be carrying out testing procedures. There would be a need in some instances for teaching hospitals to carry out a test for a patient, but the principal testing services would be provided by the PHLS laboratories. In all cases, the confirmatory test would be done by PHLS. Dr Smith thought the problem was mainly confined to London.

8.4 Dr Tedder said the ophthalmic hospital would want the results of the HTLV III tests within three days. Professor Zuckerman was of the opinion that internal blood donor panels in teaching hospitals required rapid screening; he therefore felt that primary testing could be done in these hospitals. Dr Tedthought the virologist needed to be geographically close - close to the site if not actually on site.

8.5 Dr Tyrrell said the MRC Working Party had formed two Sub-Committees to assist in the work of epidemiological analysis and therapy in connection with protocols for the trials of new drugs. As a consequence of these MRC projects, there would be some co-operation needed from those providing care and services.

9. Agenda Item 8 - Health Education

9.1 Minutes of the meeting of the Working Group on Drug Abusers held on 11 September — EAGA(6)7

Minutes of the meeting of the Working Group on Health Education in Relation to AIDS held on 24 September (tabled) — EAGA(6)8

9.1.1 The Chairman informed members that two meetings of both groups had been held, the aim of which was to obtain advice as to how to target information to the 'at-risk' groups in a way they would accept. Drug abusers were an especially difficult group to target on since they had no respect for their own health. However, it did appear that they were concerned with the effect of drug abuse on other people. This information had been given to the agency which was now tackling the problem of how to translate the objectives into approaches acceptable to this group. There were no plans for the Working Group on Drug Abusers to meet again. Dr Tyrrell was concerned that information should be directed at drug abusers before the become infected. The Chairman replied that that would be one of the aims of the campaign.

9.1.2 The Chairman reported that the Working Group on Health Education in relation to AIDS was considering the promotion of the use of the condom. Such promotions were being made in Holland and in parts of America; and their use was already recommended by the Haemophilia Society. Both Blue Books referred to their use. There were however, practical problems : condoms tended to split during anal intercourse. Research was being undertaken into the matter in Holland and information about it would be obtained.

9.2 Health Education Campaign

9.2.1 The Chairman informed the Group that the advertising agency TBWA had drawn up initial proposals for a health education campaign. As soon as Ministers had taken a decision on general policy, the assistance of the Group would be required to help determine the approaches to be made to each specific group and to the general public.

10. Agenda Item 9 - AIDS counselling - situation report EAGA(6)9

10.1 Dr Sibellas spoke to this paper. The aim was to promote training for a pool of counsellors on a UK basis. The courses would not stop once testing was introduced but would be on-going. There would be a special one day course for GPs. Health authorities had been asked to nominate candidates and the NHSTA which was responsible for the administration of the course had been told to select people initially from districts with AIDS patients.

10.2 Dr Cash was concerned that the appropriate persons were not being nominated and those that were would not be directly involved in counselling. Dr Tyrrell hoped that those who had trained at St Mary's would assume responsibility for training others within their own Regions. Mr Murray replied that the development of effective counselling services at local level would be a matter raised as part of the Regional review mechanism. The Chairman said that in the meantime officials would look into the question of selection procedures. The need to evaluate the training programme had also been recognised as a priority.

10.3 Dr Thin reported that health advisers outside London were concerned because very little information was available to them. The Chairman concluded that there was a need for 3-4 courses to be mounted outside London; Dr Cash understood that the St Mary's team were prepared to organise courses at other centres.

11. Agenda Item 10 - Jet Gun and the transmission of Hepatitis B and AIDS EAGA(6)10

11.1 Professor Zuckerman explained that the immunisation programme in West Germany had been suspended because of the risk of infection through the use of jet guns. Further consideration was now being given to the matter and it was possible the decision would be reversed. The view of CDC and the US Army Board was that there was no risk.

11.2 In the following discussion several members expressed reservations about the use of jet guns. It was agreed that the matter should be referred to the Joint Committee on Vaccination and Immunisation.

12 Agenda Item 11. - Papers for Information

12.1 The Location of Human T-Lymphotropic Virus Type III from the tears of a patient with Acquired Immuno Deficiency Syndrome EAGA(6)11

12.1.1 Dr Ower queried whether guidance would need to be issued to opticians since they could be at risk and if so how it could best be done. Professor Zuckerman said the American Public Health Service had issued advice in the Weekly Epidemiological Record dated 20 September. It was agreed copies should be sent to members prior to the next meeting.

12.1.2 The Chairman said the issue would be discussed initially with the relevant divisons within the Department and a report would be made at the next meeting.

12.2 The transmission of Human T-cell lymphotropic virus Type III (HTLV III) by artificial insemination by donor EAGA(6)12

12.2.1 Dr Modle said the Australian paper had raised a number of questions:

(1) Whether stored semen might be preferrable to fresh semen since the donor could be sero-tested, before the semen was used.

(2) How long after a test could AIDS be ruled out.

(3) Was there a need to test the donors of semen already in store, and if this could not be done whether that semen should be rejected.

Present Departmental advice disseminated via the Royal College of Obstetricians and Gynaecologists to fellows and members was to the effect that semen donors should be excluded if from a high risk group.

12.2.2 Dr Mortimer was of the opinion that donors should be asked directly about possible homosexual behaviour and any new guidance should emphasise this aspect.

12.2.3 Dr Contreras agreed that men who had been homosexual should not be allowed to donate semen and that all donors should sign a statement to the effect they had never participated in homosexual practices. The consensus was that frozen semen should be used.

12.2.4 There was general agreement that the donor should be tested six months after donating and the semen only used if the test was negative, although Dr Tedder said that after three months the risk would only be in the region of 5%. It was agreed that any guidance which might be issued would have to be compatible with that of the Blood Transfusion Service. The Chairman said that it would be necessary to discuss the matter with those involved in artificial insemination since what members were suggesting was tantamount to a six month embargo on their work.

12.3 AIDS and Haemophilia : Morbidity and Mortality Well-Defined Population EAGA(6)13

12.3.1 This paper was noted.

12.4 Education and foster care of children infected with Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus EAGA(6)14

12.4.1 The Chairman said interim advice had been given to the Department of Education and Science but had yet to be accepted by their Ministers. Further consideration would have to be given regarding pre-school, mentally handicapped and disturbed children.

13. Agenda Item 12 - Public Health (Infectious Diseases)Regulations 1985 Use of detention provisions EAGA(6)15

13.1 Mr Murray explained that the Regulations had been used for the first time recently to detain an AIDS patient who was bleeding heavily. The patient later made an application for the rescinding of the order which was granted without opposition from the Health Authority since the patient's condition had improved and he had agreed to remain in hospital on a voluntary basis. In answer to a query Mr Murray advised that the local authority could have opposed the rescinding of the order if the patient had remained in a dangerously infectious state but it could not be guaranteed that the case would always go in favour of the authority in such a situation.

13.2 Professor Geddes said that an AIDS patient had been detained in Birmingham under Section 2 of the Mental Health Act. There had been difficulties in finding a hospital to take him. He suggested that as there were now signs the HTLV III virus could affect the brain, HTLV III sufferers might require psychiatric treatment. It was agreed that this should be an item for future discussion.

14. Agenda Item 13 - Any other business

14.1 Dr Contreras said that AIDS patients should be asked if they had donated blood within the last five years so a follow-up could be done. Dr Tedder said the scheme should be extended to cover all HTLV III positive patients..

14.2 Dr Cash said that Insurance Companies in the United Kingdom had already decided that persons who were antibody positive would not be able to take out policies. The Chairman replied that the Inter-Departmental Group, which would include representatives from the Department of Trade and Industry was to consider the problem.

15. Agenda Item 14 - Date of next meeting

15.1 The next meetingswould be on Tuesday 26 November and Friday 23 January.