IN CONFIDENCE

MINUTES OF THE FIRST MEETING OF THE EAGA SUB-GROUP ON MONITORING AND SURVEILLANCE HELD ON TUESDAY 28 APRIL 1987

Present

Dr J W G Smith (Chair)
Dr R D Covell
Dr J Cope
Dr N S Galbraith
Professor L Glynn
Professor M Healy
Professor M Marmot

Mrs F Goldhill)
Dr G Greenberg) Secretariat
Mr B Merkel

In Attendance

Sir Donald Acheson

Introduction by Sir Donald Acheson

1 Sir Donald Acheson welcomed the members of the Group and outlined its important role. The Group's objective was to produce a set of recommendations, applicable throughout the UK, for improving the monitoring and surveillance of the epidemic of HIV 1 infection. The Group should not, however, consider the research aspects. That was a matter for the MRC who were represented on the Group so that their attention could be called readily to research issues. All options should be considered principally from the scientific point of view. It was agreed that the Group might need to call upon the help of those with expertise in particular areas, for example, drug abuse. Recommendations were required quickly but it was accepted that two or more meetings might be needed before the Group was able to reach conclusions.

Apologies for Absence

2 Apologies had been received from Professor M Adler and Dr D Reid.

Agenda Item 1: Terms of Reference

3 There were no comments on the terms of reference.

4 The Chairman pointed out that it was hoped that the first meeting would provide the Group with an overview of current surveillance programmes, and a more detailed picture of the current clinical and laboratory monitoring procedures; that the Group would be able to identify where further information on these programmes was needed; and that they might give preliminary consideration to the possibilities for improvements.

Agenda Item 2.i: PHLS Programme - Tabled Paper SMS1(10)

5 Professor Glynn outlined the PHLS programmes. In carrying out their laboratory surveillance of people with HIV antibodies, PHLS supplemented the reporting of data on HIV positive patients with information from a number of sources, including the Needlestick Injury Programme, a study of positive and negative tests in ten PHLS laboratories (denominator study), and Dr Polakoff's collaborative programme involving homosexual and heterosexual people attending STD clinics. The numbers in the surveillance scheme were growing, but as yet there appeared to be little suggestion of major penetration of infection into the heterosexual population. It was agreed that Professor Glynn would produce for the next meeting a written report of the denominator study and that Dr Polakoff be invited to present a paper on the study she had organised.

(Action: Professor Glynn, Secretariat).

6 Professor Healy raised the issue of forecasting, which he considered to be an integral part of any monitoring activities. After a brief discussion, it was decided that this was an item for a future meeting and Professor Healy agreed to consider the information needed by those engaged in mathematical modelling of the epidemic and forecasting, and to present his conclusions to the next meeting.

(Action : Professor Healy).

Agenda Item 2.ii: CD(S)U Programme - Paper SMS1(1)

7 Dr Covell outlined the CD(S)U programme. Much of what Professor Glynn had described was going on in parallel in Scotland and their data was being fed into the national surveillance system. In addition, CD(S)U were pursuing the possibility of reports from other sources, including a system of GP "Spotters". This was a scheme in which GPs in areas of high prevalence would, with the consent of the patient, send for HIV testing blood samples taken for other purposes.

8 During discussion, the Group felt that it was important that CDSC and CD(S)U programmes were compatible and that it would welcome further information on the CD(S)U studies proposed in relation to spotter practices, GUM clinics and ante-natal clinics (see also Agenda Item 6).

(Action: Secretariat).

Agenda Item 2.iii: Other MRC-Supported Programmes - Paper SMS1(2)

9 The Chairman pointed out a number of MRC-funded studies which were relevant to monitoring and surveillance. These are listed at Annex A. Dr Covell agreed to obtain information for the Group on the Forbes, Froebel and Loewe study of AIDS in haemophiliac patients which was being funded by the Scottish Home and Health Department.

(Action: Dr Covell).

10 The Group considered that behavioural information was

relevant to monitoring but that "hard" data would be difficult to obtain. They felt that information about the effectiveness of the public education campaign was needed but it was not clear whether they should become involved in the methodology for obtaining this. It was decided that they should seek EAGA's advice on this matter.

(Action: Chairman).

11 Other useful sources of monitoring data might come from European colleagues. European figures and methods would put the UK ones into context. Professor Glynn would produce a paper on this for the next meeting, and Dr Covell would produce an analysis of reports given by various countries at the WHO Meeting which he attended recently in Munich. The Chairman added that the monthly update of AIDS cases be included in the papers for future meetings of the subgroup.

(Action: Professor Glynn, Dr Covell, Secretariat).

Agenda Item 2.iv: Blood Transfusion Service Programme

12 It was agreed that Dr Greenberg would write to Dr Gunson for a report on the Blood Transfusion Service Programme.

(Action: Secretariat).

Agenda Item 2.v: Haemophiliac Centres Programme - Paper SMS1(3) and 1(9)

13 The Chairman spoke to these papers. Although haemophiliacs were only a small group, they could provide data on incubation periods and risks of transmission. The paper provided useful figures, including data on infection in sexual partners of haemophiliacs, although not on sexual practices, and on the safety of heat-treated Factor VIII. The Group agreed that an expert on haemophilia, Dr Rizza, should be invited to present the detailed picture to the Group. It was appreciated, however, that clinicians caring for haemophilia patients worked, of necessity, under particular constraints which might affect monitoring. The Group considered that questions of the safety of Factor VIII, although most important, were probably outside its terms of reference.

(Action: Secretariat).

Agenda Item 2.vi: Intravenous Drug Abusers - Paper SMS1(4)

14 The Chairman asked for Dr McLelland's 1986 Report to be circulated to Members.

(Action: Secretariat).

15 The Group found that it was difficult to move forward on this issue since it lacked specific expertise in the area of drug abuse. It was agreed that Dr Greenberg and Professor Marmot would meet with Departmental officials who had expertise in this area to discuss what should be provided to assist the Group at its next meeting.

(Action: Dr Greenberg, Professor Marmot).

Agenda Item 3: The Clinical Reporting System - Paper SMS1(5)

16 Dr Galbraith spoke to this paper. There were two problems with the reporting system; first, ignorance of the system amongst some physicians, and second the fact that, owing to pressure of work, some testing centres had insufficient time to complete the report forms. CDSC were working to rectify the first problem, which included dispelling the fears of physicians that reporting cases would endanger patient confidentiality.

17 The surveillance data was now on computer and duplicates had been identified and removed. CDSC were also carrying out checks to try and ensure the completeness and accuracy of the data, but they were against mandatory reporting of AIDS cases lest this proved counter-productive. During discussion, concern was expressed about CDSC's increasing workload and the need for additional funding and accommodation to enable them to cope with it.

Agenda Item 4: HIV Antibody Surveillance - Paper SMS1(10)

18 Members discussed the aims of the reporting system, for example, whether it should be aimed at providing both data needed to establish the general picture of HIV infection in the UK and data enabling the identification of particular problem areas. Professors Glynn and Marmot and Dr Greenberg would formulate a view on this in time for the next meeting. The Group considered that it was essential to clarify whether steps were needed to improve the reporting system, and Professor Glynn was invited to prepare a report for the next meeting, setting out any possible gaps in the surveillance system. Professor Glynn mentioned the availability of some software which could improve the quality of the data sent to the surveillance centre and ne agreed to provide further information for the next meeting.

(Action: Professor Glynn, Professor Marmot, Dr Greenberg).

19 It was suggested that the PHLS denominator study originated by Dr C L Miller should be considered at the next meeting. (See also para 5).

Agenda Item 5: Studies by Dr Polakoff and Professors Miller and Adler

20 It was agreed that Dr Polakoff's AIDS Survey in STD Clinic Patients (see also para 5) and Professors Miller's and Adler's Study on Heterosexual Transmission would be taken as items at the next meeting.

(Action: Dr Greenberg).

Agenda Item 6: The Issues - SMS1(7) and (8)

21 Dr Smith introduced these papers which had been prepared by the Department. Any form of mandatory screening would pose considerable practical problems and might lead to concealment of the infection. There was also the difficulty concerning the "window period". It was agreed that mandatory screening should not be regarded as a realistic, practicable

option. Other options for consideration, however, included named or anonymised testing in pregnant women; named or anonymised testing of a sample of patients seen in general practice; and named or anonymised testing of a sample of hospital patients. The Group's initial thoughts on these options, as expressed in discussion, are outlined in the following paragraphs.

22 There were logistical problems over the voluntary testing of pregnant women. A vast number of tests would probably have to be carried out for very few positive results. However, this was one option for monitoring sexually active age groups, although it would provide data only for women who were pregnant, and those not attending for ante-natal care would be missed. It was noted that a pilot scheme involving informed consent and low-key counselling was being set up in ante-natal clinics in Edinburgh and Dundee and it was thought that studies were also going on at University College Hospital and at Kings. The Secretariat would make enquiries about these studies. Any full scale study eventually recommended should include a pilot phase: this would help highlight points to be taken into account in a full study such as reactions to an "opt-out" scheme and the likelihood of refusals; it might also give an indication of the prevalence of infection; and it would help to estimate the size of studies which might be needed.

(Action : Secretariat)

23 Professor Marmot suggested that information about HIV infection in sexually active age groups might be obtained by studying partners of people who were already infected, recipients of blood products, prostitutes, heterosexual drug abusers in areas of low and high incidence, attenders at Family Planning Clinics, pregnant women and new born children of infected mothers.

24 Voluntary testing of hospital patients was considered to be a useful potential sources of information about the prevalence of HIV infection. A concise outline of how this could be approached should be prepared in order to help the Group formulate recommendations which might include proposals for mounting studies. It was agreed that that Dr Greenberg would do this.

(Action : Dr Greenberg)

25 On the issue of recruiting volunteers for testing, possibly through GPs, the Group felt that this might become an easier option when saliva tests become available. However, at the moment, the number of blood samples taken by GPs was very small and there was difficulty over a biased sample. The GP "Spotters" Study planned for Scotland would, nevertheless, give an indication of the feasibility of this approach.

26 Professor Glynn raised the question of whether the options for gaining better information could be considered solely from a scientific point of view. He felt that the ethical and legal arguments also needed to be considered and it was agreed that he would provide a paper on this issue for the next meeting.

(Action : Professor Glynn)

27 The Group felt that there were considerable advantages to schemes for anonymous testing, without consent, of blood samples taken for other purposes, but with the patient's identifying details removed. Age, sex and district would be retained. Such testing could provide a good estimate of the numbers infected and the extent and spread of the epidemic, and provide valuable information for mathematical modelling. It could not be used to identify new risk groups, although the information it provided could indicate what studies were needed to reveal such groups. The ethical problems were well recognised, however, and it was agreed that the advantages and disadvantages should be set out clearly in the report which the Group would produce.

Agenda Item 7. Agenda for the Next Meeting

28 The Group appreciated that high priority had to be given to the preparation of recommendations to EAGA. It might, however, be necessary to present a first report of the main recommendations on monitoring before considering questions relating to, for example, studies of drug abusers and of sexual behaviour. The drafting of the report would depend heavily on the Secretariat who, it was agreed, would prepare a draft outline for the next meeting, and, in as much as was possible at this stage, an outline of the logistics or expected benefits of the three major possible appropriate for further surveillance, namely pregnant women, hospital patients and patients seen in general practice.

(Action : Secretariat)

29 Items for further consideration included:

* Improving the existing surveillance systems;
* "Spotter" GPs and Genito-Urinary Clinics in Scotland;
* Dr Polakoff's AIDS survey in STD clinic patients;
* The denominator study;
* Data needed for mathematical modelling;
* AIDS and HIV in haemophiliacs;
* Drug Abusers;
* Blood Transfusion Service;
* Professors Miller and Adler's study on heterosexual transmission;
* Report from Professors Glynn and Marmot on how to improve laboratory reporting;
* Reports from by Dr Covell on the Forbes, Froebel and Lowe study and the position in other European countries;
* Outline of Group's report.

Date of Next Meeting

26 The next meeting would be held on Friday, 12 June 1987, starting at 9.30.