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Your reference
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24 February 1988

Dear Joe

REPORT OF THE ADVISORY GROUP ON THE MONITORING AND SURVEILLANCE OF HIV INFECTION AND AIDS

Following the submission of your report to the CMO on Monitoring and Surveillance, we have been giving a lot of thought to how we can best consider the implications of the recommendations. It is clear that it will take some time to give detailed consideration to all of them, but we would like to sort out how consideration of the report is to be carried forward before we publish it which, as you know, we are committed to doing.

It seems to us that, in the majority of cases, action on taking forward the recommendations will fall to PHLS and CDSC, often in liaison with CD(S)U.

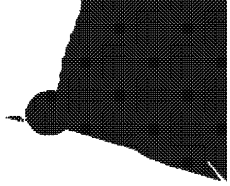
I attach note we have prepared in the AIDS Unit setting out the action that we consider necessary to take for each of the recommendations. I have circulated this to colleagues in the Department. You will see that in a large number of cases we are suggesting that the action required falls to CDSC and/or CD(S)U. I would be most grateful, therefore, if you could let me have your initial comments on the proposed action.

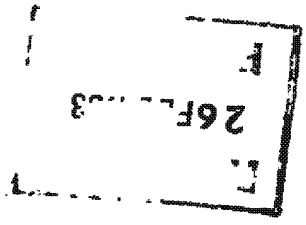
We are holding a meeting here shortly to decide on the action which is needed and I would be very pleased if you and/or someone from CDSC could attend. Perhaps your secretary would let John Griffiths know when you would be available in the next two weeks.

Yours sincerely

GRO-C

A B BARTON
Assistant Secretary





1. The routine laboratory programme for reporting the results of HIV antibody tests and the Denominator Studies should be modified:

1.1 The Denominator Study providing data on HIV antibody positive and negative patients should be extended to include a further 3 to 6 laboratories. Other laboratories prepared to submit relevant data should be free to join the study. (4.4i)

1.2 Procedures for checking the reliability of the data reported under the Denominator programme should be kept under review. (4.4i)

1.3 Similar information on all HIV positive patients should be provided by as many other laboratories as are able to participate. The laboratories should also report the total number of patients tested. (4.4ii)

1.4 All other laboratories should provide data on each positive test together with a report of the total number of patients tested. (4.4iii)

Comment 1. The routine laboratory reporting programme is run by the CDSC of PHLS. PHLS to consider the implications of the above recommendations and to inform the Department of any resource implications and how they can be met.

2. The Denominator Study in England and Wales is funded by the MRC and coordinated by PHLS. The study which is about to begin in Scotland will be funded by ? and coordinated by CD(S)U. PHLS and CD(S)U to prepare costed proposals for MRC on carrying out the recommendation to their funding bodies.

3. PHLS and CD(S)U to keep DHSS and SHHD in touch with developments.

2. The GUM Clinic Study should be extended to involve heterosexual attenders at many of the main GUM clinics in areas of high prevalence. The inclusion of further centres should be kept under review. (4.6)

Comment: The GUM Clinic Study is coordinated by PHLS and funded by the MRC. PHLS to consider the implications of the recommendation and to bring forward costed proposals to MRC. PHLS should also consider the inclusion of further centres in the study.

3. Further information is required to confirm the view that prevalence of HIV infection outside the high risk behaviour groups is at present low in the UK and to provide a baseline which could be used to track prevalence. This further information should in the first place be sought by means of antenatal testing. (4.10)

3.1 Centres participating in antenatal studies should provide compatible basic data and studies in these centres should be co-ordinated. (4.14)

3.2 Three samples of pregnant women should be studied over a period of a year. The clinics selected to take part in antenatal screening should be both in areas where the prevalence of infection and of high risk behaviour in high and in low risk parts of the country. (4.16)

Comment: We propose that this recommendation is accepted in principle. Research Management Division to ask the MRC to consider the implementation of the proposals. Studies are already planned in

Edinburgh and Dundee. The MRC will be in touch with those planning the Scottish studies to talk about the problems they have encountered etc. RM and CMP3 to consult RCOG, RCM about proposals, NHS will also need to be consulted because of resource implications.

4. The needs for further studies in antenatal patients and/or in other groups representative of the general population should be decided in the light of the results of the antenatal testing studies. (4.18)

Comment: The MRC to keep this recommendation in view.

5. Provision should be made for unnamed HIV testing for those who refuse to have their blood tested in named schemes. (4.13)

Comment: The MRC to consider this in development of protocols for the antenatal studies. Legal advice will be required on the arrangements for consent [? from DHSS or MRC lawyers?] ? problem

6. The continued support for the existing cohort studies of homosexual men should be a priority. (4.19)

7. The existing study of prostitutes should continue (4.23)

Comment: The MRC are funding these studies. Invited MRC to note these recommendations.

8. A pilot study in an appropriate prison population should be undertaken. (4.24) Barrow

Comment: The Home Office have reservations about implementing this recommendation. They feel that it would be impossible to convince people that those involved in the study had given true informed consent. [contribution from Home Office to be inserted.]

9. Request forms for HIV antibody tests should indicate whether or not the patient has recently visited a country with a high prevalence of HIV infection. Central recording and analysis of the data should include this factor for all HIV positives. Similar information should continue to be recorded in the Denominator and GUM clinic studies. (4.26)

Comment: PHLS to consider this recommendation and advise on any resource implications and how they will be met.

9.1 The leaflets which are now available to travellers and which contain advice about AIDS and HIV, should advise that travellers who expose themselves to risks should have an HIV test upon their return to the UK and, if negative, another test after a suitable period to allow for possible seroconversion. (4.27)

Comment: The AIDS Unit to follow this recommendation. How?

10. The acquisition of information concerning non-homosexual and possible non-sexual spread of HIV requires particular emphasis in the surveillance of the infection (4.29)

10.1 The national surveillance centres (CDSC and CD(S)U) should be encouraged to plan and conduct or collaborate in the follow-up of seropositive patients who are not in recognised risk behaviour groups, in order to determine possible previously unrecognised routes of infection and contributory factors. (4.31)

10.2 With due regard to the difficulties and sensitivities involved encouragement should be given to careful surveillance of suitable groups of contacts of HIV positive subjects to record relevant aspects of behaviour and the results of periodic serotesting. (4.32)

10.3 In all reported cases of AIDS or suspected AIDS where the patient does not admit to known high risk behaviour the patient should, with the clinician's permission, be interviewed by an experienced CDSC or CD(S)U doctor, nurse or health adviser, primarily to establish the route by which the patient might have been infected in order to identify a new and unrecognised route of transmission. (6.7)

Comment: It is for the National Surveillance Centres - CDSC and CD(S)U - to take forward these recommendations, and assess resource implications. In the case of 10.2, CDSC and CD(S)U will need to put research proposals to the MRC.

11. Clinicians in all specialities should continue to be made aware of the need to report cases of AIDS and to complete the standard questionnaire. (6.2)

12. The liaison between CDSC staff and AIDS working groups in health authorities and between CD(S)U and their equivalents in Scotland should continue in order to maintain full reporting of AIDS cases and verification of reports. (6.2)

Comment: CDSC and CD(S)U have been asked to consider these recommendations, to propose how they can be taken forward, indicating any resource implications and how they will be met.

13. Identification of cases should be improved by cooperation between designated local physicians and CDSC to compare nationally reported cases with those known locally. Similar arrangements should be made in Scotland. (6.2)

14. Assistance in the identification of cases and help for the clinicians in completion of questionnaires should be provided where necessary by local community physicians and by specialist staff including infectious disease physicians and staff from CDSC and CD(S)U. (6.2)

Comment: CDSC and CD(S)U to consider these recommendations. DHSS (AIDS Unit) consult the Joint Consultants Committee and the Community Medicine Consultative Committee about the recommendations.

15. All cases accepted as meeting the agreed case definition of AIDS should be followed-up by inquiry to the reporting physician to ensure that all deaths are recorded. (6.8)

Comment: CDSC and CD(S)U to consider the resource implications of this recommendation.

16. High priority should be given to the development of programmes for monitoring AIDS related conditions in a sample of clinical centres in association with the national surveillance centres. (6.5)

Comment: DHSS (AIDS Unit and RM) to consider this recommendation with PHLS, the MRC and some of the main treatment centres. See also recommendation 18.

17. CDSC and CD(S)U should undertake a continuing evaluation of the accuracy of the date admitted to them. (6.6)

Comment: CDSC and CD(S)U to consider the resource implications of this recommendation.

18. A more detailed follow-up of a sample of AIDS patients should be made to determine the clinical conditions subsequently experienced by these patients and the demand made on health care facilities. (6.9)

Comment: This recommendation to be considered under recommendation 16 above.

19. Surveillance schemes for AIDS should (like the HIV antibody reports) be used as a basis for studies about transmission to contacts. (6.10)

20. A properly staffed and equipped AIDS Data Unit should be established in the PHLS AIDS Coordinating Centre at Colindale. (7.2)

21. The PHLS AIDS Coordinating Centre should make appropriate data on HIV infection and AIDS available through the Joint Academic Network (Janet) with due regard to confidentiality. (7.3)

22. The current monthly tabulations on AIDS and HIV reports should be supplemented by a more comprehensive quarterly report (the "Quarterly" AIDS bulletin), with a commentary on changes in the data over time and geographically and with information about important publications from the UK and overseas. (7.4)

23. Relevant academic departments should be invited to contribute research reports to the proposed Quarterly AIDS bulletin. (7.4)

24. There should be annual reviews of HIV infection in the CDR "AIDS supplement" series and in the CD(S)U AIDS supplement. (7.4)

Comment: CDSC and CD(S)U to consider the resource implications of these recommendations.

25. The national surveillance of STDs and hepatitis B should continue as an important, though indirect, aspect of HIV surveillance. (8.5)

Comment: CDSC and CD(S)U to note. There is, of course, no proposal to stop the national surveillance of STDs and hepatitis B.

26. Well planned studies to gain greater understanding of drug misusers and of sexual behaviour in the United Kingdom should be accorded high priority by bodies funding such research.

Comment: The MRC to consider this recommendation in respect of the proposed studies in drug misusers. The ESRC to consider it in considering the proposal on studies of sexual behaviour.