

hep124

RESTRICTED - POLICY

Dr Metters

From Roger Scofield

Date 7 March 1995

copies
Dr Rejman
Dr Nicholas
Dr Melia
Mr Kelly
Mr Burrage
Ms Sandillon

HEPATITIS C LOOK BACK

1 I attach draft minutes of the second meeting of the look back working party, together with a Chairman's brief/ annotated agenda for the third meeting. As agreed with you yesterday I have circulated the draft minutes and outline agenda with other papers for the meeting 14 March.

R M T Scofield

CA OPU

EH303 Ext: GRO-C

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**NOTES OF DECISIONS AND ACTIONS FROM THE SECOND MEETING OF
HEPATITIS C LOOK BACK WORKING PARTY**

Held 24 February 1995

Present

A list of those attending is attached.
Apologies were received from Prof Zuckerman and Dr Rejman

Minutes of first meeting

These were agreed

Matters arising

The Chairman reviewed developments since the last meeting. Feedback from the Field was largely supportive of the decision to go ahead with the look back exercise and the advice made available by EPINET. Some had not received this and others were concerned about possible cost implications. There was an interest in using data emerging for epidemiological purposes. This was sensible but it was more important to press ahead with the task.

Dr Metters had been in touch with PHLS and agreement had been reached with the NBA over the way in which the results of tests undertaken on patients referred by GPs etc and found HCV antibody positive might be reported to NBA. PHLS proposed not to make any charges for such tests carried out up to 10 February. They were considering whether this date might be extended.

He had not been able to contact Dr Bogle to seek any further views from GMSC but would try again when Dr Bogle returned to the country.

Dr Robinson reported that the preliminary procedural guidance had been received by the Transfusion Services who were proceeding accordingly. There had been well over 12,000 calls to the help line but these were now tailing off. They might be triggered again any time the media ran a feature on hepatitis C.

Dr Gillan said that progress in Scotland was similar to that in England. Prof. Cash's working party had met and were getting hepatologists involved.

Guidance on look back

There was detailed discussion of the draft procedural guidance. All the points raised have been carried forward into the revised draft to be considered at the next meeting.

Prof. Cash had raised a number of points all of which had been dealt with. It would not be possible to start the next phase of the look back on March 1 as he had suggested but it was hoped that final guidance could be issued shortly after the next meeting.

It was important to get legal opinion on the drafts for publication. NBA had already received legal advice on the drafts they had submitted.

The guidance should be written in as simple a form as possible. Whilst it should be focused on the look back exercise on blood transfusion recipients a note should be included on the risk situation for those who had received blood products or solid organs or human tissue. It might be helpful for the transfusion centres to gather consultants from local blood banks together to brief them on the procedure and to identify any special issues.

Although the look back procedure would provide a UK-wide approach there needed to be some flexibility to acknowledge variations between the four countries. The pro forma should be provided in order to record as much of the relevant information as possible. It was accepted that in some cases doctors might not complete all the details requested.

Guidance on counselling / Guidance on treatment options

There was detailed discussion of the two papers presented by Dr Gillon and Prof Thomas. It was agreed that they should be merged into one piece of guidance covering both aspects. Otherwise there would inevitably be a certain amount of overlap.

The text was edited to ensure consistency between the various documents and in some places it was simplified to make it suitable for those who had only a limited knowledge of the subject.

All other comments were fed into the revised version to be considered at the next meeting.

Guidelines on the diagnosis and management of chronic disease in haemophilia.

Members took note of this paper which had been prepared by the UKHCDO.

Date of next meeting

It was agreed that the working party's business should be the principle item on the agenda of the full MSBT meeting which had been set for 14 March 1995.

CA OPU
3 March 1995

SECOND MEETING OF HEPATITIS C WORKING PARTY

24 February 1995

Attendance List

Dr Metters (Chairman)

Dr D Gorst
Dr R Mitchell
Dr E A Robinson
Prof Howard Thomas
Dr R Warren
Dr J Gillon
Dr A Keele
Dr E Mitchell
Dr D Westmoreland

Departmental officials

Dr H Nicholas
Dr N Melia
R M T Scofield

RESTRICTED - POLICY
THIRD MEETING OF THE WORKING PARTY ON THE
HEPATITIS C LOOK BACK EXERCISE
to be held 14 March 1995

AGENDA

- 1 Apologies for absence.
- 2 Minutes of second meeting
- 3 Matters arising
- 4 Guidance on look back procedures, including
standard letters and proforma
- 5 Guidance on counselling and treatment options
- 6 Commissioning of further work
- 7 Any other business
- 8 Date of next meeting

CA OPU
7 March 1995

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**THIRD MEETING OF THE WORKING PARTY ON THE
HEPATITIS C LOOK BACK EXERCISE**

to be held 14 March 1995

Chairman's Brief

Date, Time and Venue To be held Tuesday 14 March 1995 at 11.00 am in room 310 at Eileen House. Coffee will be available on arrival and a working lunch will be provided in room EH303. This meeting has replaced the full meeting of the MSBT which had been called for that date. Those "stood down" were told that they would be welcome but that the look back would be the only agenda item.

Briefing Meeting Tuesday 14 March at 10.30am in EH303

Secretariat Dr Rejman will be present. Dr Nicholas is on leave. Do you wish Dr Melia to attend? Roger Scofield will attend and Dave Burrage will act as secretary with administrative help from Mary Sandillon.

Agenda A simple outline agenda is attached which has been circulated to the members.

The remainder of the brief is in the form of an annotated agenda which seeks to identify the main points which will need to be addressed.

R M T Scofield

CA OPU

EH03 Ext GRO-C

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SECOND MEETING OF THE WORKING PARTY ON THE
HEPATITIS C LOOK BACK EXERCISE

ANNOTATED AGENDA

1 Apologies for absence.

Dr Nicholas

2 Minutes of first meeting

The minutes were largely of the introduction. Points made on the guidance documents were taken into account in the rewrites.

No comments received to date

3 Matters arising;

Haemophilia paper. We tended to skate over this last time. Does anyone have any further comments?

PHLS. The instructions and issue of payments are still not entirely clear. We hope they will confirm no charges for tests up to end March at least.

Dr Bogle (GMS). He has been invited to comment on the draft guidance and letters etc.

NBA. Any developments?

Scotland. Are they going ahead and if so have they come across any new issues?

4 Guidance on look back procedures

The guidance circulated concentrates on the look back arising out of donors who came forward after 1991 and were found positive. A note is provided about infection through blood products, solid organs or human tissues.

Model letters. These are now more user friendly and appear to hang together.

Pro forma for recording all information which needs to be collected. Dr Westmoreland clearly thinks that we are asking for too much information. Perhaps we should just acknowledge that not everyone will provide all the answers but we need to aim to get what we can. Likewise there has to be some flexibility in how the guidance is interpreted. The main task will fall to

RTCs and blood banks who will be more likely to understand the need than others.

Testing of stored samples in Scotland and at North Thames. See my minute to Charles Blake and Dr Rejman. We are due to speak with Anita James in Sol C4 on Monday to take this forward.

Other possible routes of infection - need for look back exercise? eg, tissues and organs; semen, eggs and embryos; haemodialysis; reversal of warfarin; Guillan Barre syndrome trials. Do we need to be more pro active? The points are covered in the guidance. Should there be a general encouragement for consultants to look out for possible infection by such routes and refer their patients to a liver clinic if they have cause to believe they have been infected in this way. Next steps??

Other ethical issues ref advice to GPs without consent;
information to next of kin.

Publication of the guidance The aim is presently to send out an HSG with a short covering note to which will be attached the various pieces of guidance and proforma. Supplies of the actual forms will go to the RTCs via the Blood Transfusion Services. We need to agree the date of issue.

Date for implementation. We need to decide the date for carrying forward the steps below the dotted line in respect of NBA. This needs to fit in with the issue of the HSG.

5 Guidance on counselling and treatment options

The revised guidance embraces all the points made at the last meeting.

We are awaiting advice from Prof Thomas on two points.

It was agreed that those issues which are more properly the responsibility of consultants rather than GPs should be kept "below the line" for information. The treatment part of the guidance is primarily for GPs.

6 Commissioning of further work.

This depends largely on the outcome of the various agenda items above.

Improved estimates of the numbers infected -
appointment of epidemiologist jointly by PHLS/NBA -
need for early best estimate and proposals for how the numbers will be refined over time.

7 **Any other business.**

None advised at this stage.

8 **Date of next meeting**

No dates yet fixed. Depends on work commissioned.

Also note need to complete look back exercise by late Summer.

CA OPU
7 March 1995