

NOTE OF THE RECOMBINANT CLOTTING FACTORS WORKING GROUP HELD AT 11:00AM ON FRIDAY 11 JULY 2003, ROOM 136B SKIPTON HOUSE

Present:

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| Richard Gutowski | Department of Health - Chairman |
| Karin Pappenheim | Haemophilia Society |
| Chris Hodgson | Haemophilia Society |
| Dr Charles Hay | UKHCDO |
| David Kemsley | London & SE Haemophilia Consortium |
| Dr Susan Schonfield | Croydon PCT |
| Mick O'Donnell | Haemophilia Commissioner – West Midlands |
| Steve Davies | NHS Purchasing & Supply Agency |
| Emily Costello | NHS Purchasing & Supply Agency |
| Howard Stokoe | NHS Purchasing & Supply Agency |
| Dr Claire Bradford | Newcastle PCT |
| Carl Ashworth | Haemophilia Commissioner – Manchester |
| GRO-A | Patient Representative |
| Dr Mark Winter | Haemophilia Alliance |
| Andrew Whittome | Guy's & St Thomas' |
| Zubeda Seedat | Department of Health |

WELCOME, INTRODUCTIONS AND APOLOGIES

1. Richard Gutowski introduced himself as the new head of the blood policy team. He would be taking over as Chairman of the Working Group.
2. Apologies were received from Dr Denise O'Shaughnessy, Mike Maunder, Sophie Heiser, Trudi Mann, Joanne Wells, Frank Hill, and Christine Harrington.

MINUTES OF THE PREVIOUS MEETING

3. The note of the last meeting was agreed, subject to the following amendment at para 8 (bullet 5):

'If companies are asked for a price reduction for volume, they may require a minimum commitment. However, there were potential problems with this approach *because companies may require a minimum commitment*'.

MATTERS ARISING

4. (Para 4) Data from the Macfarlane Trust indicated there were 351 haemophilia patients with HIV in England registered with the Trust, whereas revised figures from the UKHCDO indicated that there were 419 haemophilia patients with HIV. Charles Hay agreed to follow this up with the Macfarlane Trust. It was estimated that the cost of placing all of these patients on recombinant would be £14m. However, it was envisaged that 50-60% of HIV patients would receive recombinant products in the early stages of the roll-out.

Action: Charles Hay to contact the Macfarlane Trust.

5. (Para 15) DH had agreed the job description prepared by the UKHCDO for the project manager post to assist with data management for the roll-out of recombinant products. A copy of the job advert would be circulated for information.

Action: Secretariat to circulate a copy of the job description.

DRAFT IMPLEMENTATION TIMETABLE

6. The group was asked to consider the draft timetable. The Secretariat agreed to revise the timetable in light of discussion at the meeting.

Action: Secretariat to re-draft the implementation timetable.

PROGRESS REPORT ON THE NATIONAL TENDER

7. PASA provided an update on the tender process. The deadline date for tenders had passed on 1st July. PASA tabled, in confidence, a summary of the prices quoted by the drug companies for each of the three years. There was agreement that the contract should be based on the existing volume usage and market patterns.

8. PASA reported that they expected to confirm by mid- August the volume banding for each company. Subject to their agreement, it was expected that the call-off contract would be in place by early September.

UKHCDO DATA COLLECTION AND ANALYSIS

9. UKHCDO had received patient data from the majority of haemophilia centres. However, 25 centres had not yet responded. UKHCDO continued to remind these centres. The validation process with lead commissioners would help to close gaps in the data. For example, data indicated that some patients were registered with more than one centre.

10. It would be made clear to lead commissioners, that as part of the validation process, they would be asked to check the data on the number of patients within each PCT.

ALLOCATION OF FUNDS TO PCTs

11. In discussion, it was mentioned that the use of recombinant products in the treatment of patients was not constant. The group had to try and reflect what happened in practice, when the baseline funding is agreed. It was suggested that the group would benefit from commissioning work, on a mapping exercise to help gain a picture of the position in three years time and provide a clear base to make decisions. The DH's Economic Operational Research unit may be able to assist with this work.

MONITORING OF PHASING PROCESS

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12. Richard Gutowski proposed that a sub-group should be set up to help drive forward monitoring arrangements. Members were asked to consider themselves for nomination.

ANY OTHER BUSINESS

13. The group were made aware of recent comments that the decision by the group to roll-out recombinant products on the basis of age was discriminatory, and contravened NHS guidance.

DATE OF NEXT MEETING

14. The next meeting would be at 11:00am on Tuesday 9 September 2003 in room 140B Skipton House.