THE FORWARD PLANNING & MONITORING GROUP: ROLL-OUT OF RECOMBINANT TREATMENT FOR ADULT HAEMOPHILIA PATIENTS

NOTE OF MEETING HELD ON MONDAY 6 SEPTEMBER 2004 AT 11.00AM, ROOM 137B SKIPTON HOUSE, ELEPHANT & CASTLE, LONDON, SEI

Present:

Richard Gutowski	- Department of Health
Julia Stallibrass	- Department of Health
Stephen Dobra	- Department of Health
Zubeda Seedat	- Department if Health
Frank Hill	- UKHCDO
Charles Hay	- UKHCDO
Sybil Hirsch	- UKHCDO
Chris Theaker	- S Yorks & E Midlands SCG
Kendal Bird	- South SCG
Lucie Waters	- London SCG
Bridget Emanuel	- London SCG
Wendy O'Neill	- London SCG
Ruth Taylor	- Haemophila Society
Chris Hodgson	- Haemophilia Society

Welcome, introduction and apologies

1. Richard Gutowski welcomed everyone to the meeting. Apologies were received from Carl Ashworth, Mick O'Donnell, and Steve Washbourne.

Note of the meeting held on 5 July 2004

2. The note of the meeting held on 5 July was agreed.

Matters arising

Report of the first year of the roll-out

3. Subject to final comments the report on the first year of the roll-out will be published on the DH website. Julia Stallibrass offered to send the final report to members of Local Specialised Commissioning Groups (LSCGs) and Specialised Commissioning Groups (SCGs).

Action: Secretariat to publish the report on the DH website.

Action: Julia Stallibrass to circulate to the LSCGs and SCGs.

Risk analysis

4. Richard Gutowski introduced Stephen Dobra from the Economic and Operational (EOR) Unit in the Department. Stephen Dobra informed members that he had spoken to some members of the Group involved with the roll-out. He tabled a paper which set out some of the issues that had been raised in discussion. This included:

- Price/volume of recombinant products
- Impact of new product development
- Impact of the international market
- Increased costs
- Risks arising from National/local contracts

5. Members of the Group agreed that the paper helpfully summarised the key issues for consideration. In discussion members emphasised the need to quantify the risks for individual PCT's. The treatment of inhibitor patients should also be considered. It was suggested that Stephen Dobra should attend the next meeting of the Inhibitors Working Group.

6. In discussion, the Group proposed that a national contract should be put in place for all clotting factors once the current contract expires in March 2006. PASA agreed to explore options for implementing a national contract, and to put forward proposals at the next meeting. Julia Stallibrass agreed to update commissioners so as to minimise the negotiation of local tenders.

Action: Stephen Dobra to progress work on the scoping study.

Action: PASA to examine options for negotiating a national contract for all clotting factors and Julia Stallibrass to update LSCGs and SCGs about this work.

Definitions of eligibility and guidance notes

7. Following discussion at the last meeting about the eligibility criteria, UKHCDO provided a paper which defines the eligibility criteria and provides guidance notes. It was agreed that the paper should be published on the DH website. Julia Stallibrass agreed to send a copy to LSCGs and SCGs.

Action: Secretariat to publish the paper on the recombinant website.

Action: Julia Stallibrass to circulate to LSCGs and SCGs.

Allocations to PCTs for 2004/05

8. Members were reminded that the proposed budget cut to the recombinant budget had been re-instated. Members of the Group agreed the allocation of funding to PCTs as calculated by UKHCDO. Richard Gutowski confirmed that Cash Limit Adjustments and Resource Limit Adjustments would be made to PCTs at the earliest opportunity. Sybil Hirsch confirmed that she would provide each lead commissioner contact with details of the resource/cash limit adjustment to PCTs within their respective consortia, together with a patient by patient breakdown.

9. It was noted that Mick O'Donnell had requested that the allocations for West Midlands should be calculated by weighted capitation and not patient usage because of the local risk sharing arrangements in place in West Midlands.

Action: Secretariat to arrange Cash Limit Adjustments and Resource Limit Adjustments to PCTs.

Action: Sybil Hirsch to provide a breakdown of patient information, by PCT for lead commissioners.

Allocations to PCTs for 2005/06

10. Frank Hill informed members that the Group should aim to agree the allocations for 2005/06 by January 2005, so that the allocations can be made to PCTs by 1 April. It was agreed that UKHCDO would progress work on calculating the allocations for 2005/06. Preliminary allocations will be sent to all lead commissioners in December for agreement. When these figures have been agreed, the final figures will be calculated based on the database as at December 31 2004.

Action: UKHCDO to calculate the allocations for 2005/06.

Final report on the audit: 2003/04

11. Sybil Hirsch provided an update on the audit for 2003/04. It was noted that 380 patients were reported as having been issued with recombinant factor products. 148 patients had no recombinant start date reported. Analysis of the data indicated that the mean number of units used in the baseline year in the non-starters was 37718 compared to 132943 for the 380 patients reported to have started. The Group agreed that a short summary of the audit results should be published on the DH website.

Action: UKHCDO to produce a short report for publication on the DH website

Audit of 2004/05

12. Sybil Hirsch reported that the first phase of the audit for 2004/05 was underway, this covered the period April-June. As part of the audit, Haemophilia Centres had been asked to provided data on monthly usage of recombinant. UKHCDO agreed to provide an update at the next meeting.

Action: UKHCDO to update members on the audit for 2004/05.

Any other business

13. There was no other business

Date of next meeting

14. The date of the next meeting will be Thursday 13 January 2005 at 11am.