

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

**NOTE OF MEETING HELD ON MONDAY 5 JULY 2004 AT 11.00AM,
ROOM 140B SKIPTON HOUSE, ELEPHANT & CASTLE, LONDON, SE1**

Present:

Richard Gutowski	- Department of Health
Julia Stallibrass	- Department of Health
Andre Hare	- Department of Health
Zubeda Seedat	- Department of Health
Frank Hill	- UKHCDO
Charles Hay	- UKHCDO
Sybil Hirsch	- UKHCDO
Rob Hollingsworth	- UKHCDO
Carl Ashworth	- North West SCG
Chris Theaker	- S Yorks & E Midlands SCG
Chris Curtis	- South SCG
Kendal Bird	- South SCG
David Kemsley	- London SCG
Wendy O'Neill	- London SCG
Mick O'Donnell	- West Midlands SCG
Steve Washbourne	- West Midlands SCG
Ruth Taylor	- Haemophilia Society
Chris Hodgson	- Haemophilia Society
Norma Rees	- Royal Free
Ann-Marie Marek	- East Kent Hospital

Welcome, introduction and apologies

1. Richard Gutowski welcomed everyone to the meeting.

Note of the meeting held on 26 April 2004

2. The note of the last meeting was agreed subject to the following amendments:

Para 9 "...UKHCDO *will develop* a web-based system *for subsequent years*...."

Para 10 "....confirmed that the patient cohort *criteria* for 2004/05 is the"

Action, under para 12 ".... UKHCDO to consider how to present the data in a way that would allow members of the Group to undertake a *year on year* comparison"

Matters arising

Report on the first year of the roll-out

3. Members of the Group thanked Mick O'Donnell for producing a report on the first year of the roll-out as discussed at the last meeting. Members were invited to comment on the draft report which would be made available on the DH website.

Action: Members of the group to comment on the draft report.

Reduction to the budget for 2004/05

4. Richard Gutowski confirmed that the recombinant budget for 2004/05 had been cut by £4m by colleagues in the Department (from £21.7m–£17.7m). In discussion members expressed their serious concerns on the impact to the roll-out programme. The key concerns were:

Patients eligibility to treatment. The reduced funding would not be sufficient to cover all the patients who started recombinant products in 2003/04. However, the Group considered that it would be unethical to withdraw recombinant treatment.

The overall impact to PCTs budget. The original funding had been carefully calculated to ensure that PCTs could purchase sufficient stock for all the patients eligible under the roll-out. A reduction in funding would put additional risks on PCTs.

Future funding. Members queried whether there would be further reductions in 2005/06. Although the funding for next year was considerably more, these funds would extend treatment to patients aged over 41 and to inhibitor patients.

National Contract. The reduced volume purchased would affect the price per unit of recombinant product from some manufacturers. As a result, PASA would be unable to reach the required threshold for maximum discount.

5. The Group urged the Department to reconsider its decision. Richard Gutowski agreed to make further representation following the meeting.

Action: The Secretariat to prepare a submission on the implications to the roll-out programme of a reduction to the budget.

Revised allocation to PCTs for 2004-05

6. Following the decision to reduce the recombinant budget, UKHCDO had been asked to recalculate the allocations to PCTs. Sybil Hirsch explained that the revised figures included 12 months allocation for those patients who were eligible, but received no allocation in 2003/04 because their data were not been submitted on time. In addition, for the remainder of the patients, the allocations were based on 10 months supply. This included an uplift of 4% above baseline usage.

7. Some members of the Group did not consider that they could agree to the revised allocations until they were able to verify the data for their PCTs, and undertake an assessment of the risk to PCTs of the reduction in funds. In order to achieve this UKHCDO was asked to recalculate the 2003-4 allocations to take into account the changes in patient circumstances recorded as a result of information received in the

2003-4 audit. These revised allocations (Version 4) will be circulated to the Group. In addition, Mick O'Donnell and Carl Ashworth will send Sybil Hirsch a list of PCT's in their respective consortia so that she could provide them with a patient by patient breakdown of these newly calculated allocations. Mick and Carl will use these to estimate the impact of the reduction in funding to their respective PCT finances. These estimates would be taken as an assessment of the countrywide impact of the reduction in funding.

Action: UKHCDO agreed to revise the calculations and circulate PCT allocations to members of the Group by 16 July.

Action: Mick O'Donnell and Carl Ashworth agreed to send Sybil Hirsch a list of PCT codes, for which she will calculate individual patient allocations and send these to them.

Update on the audit 2003-04

8. Frank Hill provided an update on the audit for 2003/04. It was reported that funding had been allocated for 528 patients. As part of the audit process, UKHCDO asked haemophilia centre directors to supply information on the roll-out. At the time of the meeting 35 out of 40 centres have submitted audit data, comprising 506 patients. Of these 364 patients were being treated with recombinant. 142 patients had no recombinant start date reported. For 120 patients, centres had stated that recombinant treatment had yet to start. For the remaining 22 patients with no start date, centres reported a variety of reasons.

9. Chris Curtis said that some clinicians were unclear about the eligibility criteria. Frank Hill provided clarification; it was noted that UKHCDO did write to all haemophilia centres earlier in the year setting out the eligibility criteria. He agreed to write to haemophilia centres once again as a reminder.

Action: Frank Hill to write to haemophilia centres about the eligibility criteria.

Risk analysis

10. Richard Gutowski introduced Andre Hare from the Economic and Operational Research (EOR) Unit in the Department. He explained that there was some concern about the medium and long-term financial risks to PCTs of the roll-out programme. It was considered that a risk analysis of the roll-out would help to identify issues for consideration, prior to the completion of the roll-out. Some of the risks were around the volatility of the market, the move to weighted capitation in 2006/07, and the high cost of treatment.

11. Andre Hare agreed that colleagues in EOR would consider undertaking a risk analysis. He said that it would be helpful to speak to some members of the group involved with aspects of the implementation.

Action: The Secretariat agreed to provide contact details.

Any other business

12. There was no other business.

Date of next meeting

13. The date of the next meeting will be Monday 6 September at 11am in room 281D
Skipton House