

**The Forward Planning & Monitoring Group: Roll-Out of Recombinant Treatment for Adult Haemophilia Patients**

- |                       |                              |
|-----------------------|------------------------------|
| 1 ✓ Richard Gutowski  | - Department of Health ✓     |
| 2 ✓ Julia Stallibrass | - Department of Health ✓     |
| 3 ✓ Frank Hill        | - UKHCDO ✓                   |
| 4 ✓ Charles Hay       | - UKHCDO ✓                   |
| 5 ✓ Sybil Hirsch      | - UKHCDO ✓                   |
| 6 ✓ Rob Hollingsworth | - UKHCDO ✓                   |
| 7 ✓ Carl Ashworth     | - North West SCG ✓           |
| 8 ✓ Chris Theaker     | - S Yorks & E Midlands SCG ✓ |
| 9 ✓ Chris Curtis      | - South SCG ✓                |
| 10 ✓ Kendal Bird      | - South SCG ✓                |
| 11 ✓ David Kemsley    | - London SCG ✓               |
| 12 ✓ Wendy O'Neill    | - London SCG ✓               |
| 13 ✓ Mick O'Donnell   | - West Midlands SCG ✓        |
| 14 ✓ Steve Washbourne | - West Midlands SCG ✓        |
| 15 ✓ Ruth Taylor      | - Haemophilia Society ✓      |
| 16 ✓ Chris Hodgson ✓  |                              |
| 17 Emily Costello     | - PASA                       |

17.

✓ 18 Norma Rees - Royal Free. norma.Rees@

19 Andre Hore.

GRO-C

✓ 20 Annemarie Meretz. East Kent Hospital

Ann Marie. Meretz @

GRO-C

24 Sept.  
inhibitors  
mts.

(2)

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

**NOTE OF MEETING HELD ON MONDAY 26 APRIL 2004 AT 11.00AM,  
ROOM 125A SKIPTON HOUSE, ELEPHANT & CASTLE, LONDON, SE1**

### **Present:**

Richard Gutowski	- Department of Health
Julia Stallibrass	- Department of Health
Frank Hill	- 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
Zubeda Seedat	- Department of Health

### **Welcome, introduction and apologies**

1. Richard Gutowski welcomed everyone to the meeting. Apologies were received from Charles Hay, Chris Hodgson, and Peter Graham.

### **Note of the meeting held on 9 February**

2. Richard Gutowski thanked Frank Hill for producing a note of the key decisions and actions arising from the meeting on 9 February.

### **2003/04 allocations to PCTs**

3. Richard Gutowski explained that the roll-out had been delayed in 2003/04 due to a judicial review, which had implications for the roll-out of the recombinant programme. In addition, patient data had to be collected to enable the UKHCDO to calculate the funding to be allocated to PCTs, this process took longer than anticipated, with some centres not responding promptly.

4. PCTs were notified of their allocations for 2003/04 in the first week of March 2004. In early January, Haemophilia Centre Directors were advised to order 5 months supply of stock for their patients (this would enable Trusts to purchase 3 months stock to be used in 2003/04 and purchase and carry forward 2 months stock into 2004/05). On the advice of finance colleague, funding had been initially

provided on a Cash Limited Allocation basis, but later confirmed on a Resource Limited Allocation basis.

5. The Group was informed that Melanie Johnson, the Minister for Public Health had asked to be kept informed of the roll-out and to ensure that the monies allocated to PCTs was fully spent.

6. Some PCTs had indicated that their auditors had expressed concern about current stock holdings. Frank Hill agreed to produce a note on behalf of the UKHCDO setting out why it is regarded as good clinical practice to hold stocks of recombinant. Julia Stallibrass agreed to obtain advice from finance colleagues on this issue.

**Action:** Frank Hill agreed to produce a note to be circulated to commissioners on the holding of recombinant stock.

**Action:** Julia Stallibrass agreed to confirm this advice and circulate to commissioners.

7. Frank Hill confirmed that some PCT allocations did not include funding for all eligible patients, this was because patient information had not been submitted on time to the UKHCDO. Frank Hill had spoken to those Haemophilia Centre Directors where patients had not received an allocation in 2003/04 to provide an explanation. He confirmed that all patients who were eligible for treatment would receive an allocation in 2004/05. Julia Stallibrass suggested that UKHCDO should produce a short note to explain why some centre did not receive the full allocation, this would make the whole process more transparent.

**Action:** Frank Hill agreed to draft a note which set out why 49 patients who were eligible for recombinant treatment did not receive an allocation in 2003/04.

8. Mick O'Donnell suggested that it would be helpful for the Group to document all the decisions made during 2003/04 prior to start of the roll out programme. This could be included on the DH Website.

**Action:** Mick O'Donnell agreed to produce a draft report for consideration by members of the Group.

#### **Audit of data for 2003/04**

9. Frank Hill confirmed that the audit process for 2003-04 would be kept simple as discussed at the last meeting. Rob Hollingsworth explained that UKHCDO have ~~will~~ developed a web-based system which would enable all Haemophilia Centres to complete information about the roll-out electronically.

**Action:** UKHCDO to provide an update at the next meeting.

#### **Provisional allocations to PCTs for 2004/05**

10. Richard Gutowski thanked the UKHCDO for calculating the allocations to PCTs for 2004/05. Sybil Hirsch confirmed that the patient cohort for 2004/05 is the same as 2003/4. The figures have been calculated to enable Trusts to purchase 10 months stock and reflects growth in usage of 10%. It is assumed that there would be at least 2 months stock at the end of 2003/04 to carry forward to 2004/05.

11. In discussion the group agreed that those patients who did not receive an allocation last year, but for whom information is now complete, should be allocated funding for 12 months supply for 2004-2005.

**Action:** Sybil Hirsch agreed to recalculate the cost for these patients.

12. David Kemsley suggested that it would be helpful if the data could be presented which would enable the Group to make a comparison between the two financial years, this would also begin the process to help identify trends in funding. In discussion, it was suggested that UKHCDO could expand the worksheets with the information that had already been provided to commissioners at the end of the last financial year.

**Action:** UKHCDO to consider how to present the data in a way that would allow members of the Group to undertake a comparison.

13. David Kemsley expressed concerns about the long term costs and impact to PCTs in the future. He considered that the financial implications had not been fully worked out. He suggested that the Department should commission a risk analysis of the roll-out programme. Frank Hill indicated that UKHCDO had already undertaken some work to model the programme. Richard Gutowski agreed to speak to colleagues in the Economic and Operational Research (EOR) unit about undertaking a risk analysis.

**Action:** Richard Gutowski to speak to EOR about the viability of undertaking a risk analysis.

14. Members of the Group again emphasised the need for shared risk arrangements.

15. Richard Gutowski confirmed that the funding allocation for 2005/06 was £53.4m. It was agreed that the FP&M Group should have early discussion about the data for next year. A decision will also need to be made about the treatment of inhibitor patients

#### **Audit for 2004/05**

16. UKHCDO expect to collect audit data. It was hoped that this would use monthly returns of data from Centres to commissioners.

**Action:** Frank Hill agreed to provide an update at the next meeting.

**Any other business**

17. There was no other business

**Date of the next meeting**

18. The date of the next meeting will be Monday 5 July at 11am in room 140B Skipton House.