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NOTE OF RECOMBINANT CLOTTING FACTORS WORKING GROUP HELD AT 1PM ON WEDNESDAY 19 MARCH 2003, ROOM 578D SKIPTON HOUSE

Present:

Charles Lister	Department of Health – Chair
Chris Hodgson	Haemophilia Society
Karin Pappenheim	Haemophilia Society
Dr Frank Hill	UKHCDO
Dr Charles Hay	UKHCDO
Christine Harrington	RCN Haemophilia Nurses Association
David Kemsley	London & SE Haemophilia Consortium
Dr Susan Schonfield	Croydon PCT
Mick O'Donnell	Haemophilia Commissioner – West Midlands
Neil Brent	South Gloucestershire PCT
Mike Maunder	Haemophilia Commissioner – North Tyneside
Steve Davies	NHS Purchasing & Supply Agency
Howard Stokoe	NHS Purchasing & Supply Agency
Zubeda Seedat	Department of Health

WELCOME, INTRODUCTIONS AND APOLOGIES

1. Charles Lister welcomed everyone to the first meeting of the Working Group.

2. Apologies were received from Carl Ashworth, GRO-B, Dr Claire Bradford Sophie Heiser, Trudi Mann and Dr Mark Winter.

REMIT AND MEMBERSHIP

3. It was agreed that the remit should be extended to include the need for the group to be maintained to advise on phasing in years 2 and 3.

4. David Kemsley suggested that membership should include a business manager from a provider Trust. Members of the group agreed to identify a suitable representative.

Action: Secretariat to provide a revised draft remit for the next meeting and to add a business manager to the membership.

OVERVIEW & OBJECTIVES FOR THE MEETING

5. Charles Lister said the money announced in February was to provide patients with recombinant Factor VIII, IX and, where clinically indicated, VIIa. It was unclear whether the funding allocated would be sufficient to place all patients on recombinant by 2005/06 given rising usage and uncertainties around the pricing of third generation products. Any additional funding required from 2006/07 to complete the transition would need to be considered in the context of the next spending review.

6. The aim of the meeting was to identify the issues that needed to be resolved in order to arrive at a phasing strategy; to take at least a preliminary view on as many of these issues as possible; to identify data requirements and to agree an action plan. The final recommendations of the Group would have to be agreed with DH Central Finance and with Ministers.

UKHCDO DATA ON CURRENT USAGE

7. Dr Hay presented data on the current usage of recombinant clotting factors; the estimated annual cost as a result of increased usage; and options for staging the roll out.

8. No firm conclusion was reached on how recombinant VIIa should be included in the phasing process. One option was to start with patients suffering from factor VII deficiency and to play in the use of VIIa in the treatment of inhibitors in year 3.

Action: Dr Hay agreed to circulate a copy of the presentation to members of the group.

PATIENT PRIORITY ORDER

9. The Group considered two options:

i) phasing by age group, youngest first;

ii) giving priority to patients infected with HIV. The UKHCDO had received a letter from the Birchgrove Group stating the case for this option. A copy was circulated to members of the Group to inform the discussion.

10. Data presented by UKHCDO showed that an age based strategy could have all haemophilia A and B patients on recombinant by the start of 2005/06.

11. Prioritisation of patients with HIV would also have to be staged. There were roughly 500 patients with HIV almost all on plasma derived factor VIII. The cost of placing all of them on recombinant would be around £18m, more than available in 2003/04.

12. Given that almost all haemophilia patients over age 22 had hepatitis C, HIV or had been exposed to vCJD, and could all make a case to be given priority, the Group concluded that age banding was as equitable as way forward as any. Members regretted that it would not be possible to put all patients onto recombinant immediately. However, the age banding proposal put forward by UKHCDO would result in all patients being placed on recombinant by the start of 2005/06, only two years away.

13. It was agreed that the Group should produce a statement, to be made public, explaining the reasons for their recommendation. In particular, members should be able to demonstrate that due consideration was given to treating patients equitably.

Action: Secretariat to draft a statement setting out the Group's conclusions for consideration at the next meeting.

PURCHASING STRATEGY

14. Members were in favour of setting up a national contract for recombinant factor VIII & IX bought with the new funding. The alternative was for each individual centre to tender separately. It was agreed that a national contract would provide greater transparency and ensure that maximum benefit was obtained from the new money. Once a national contract was established for the three years of the phasing period, it would be possible to extend this to cover all recombinant clotting factor purchases in England.

15. It was noted that products delivered direct to patients' homes by suppliers did not attract VAT. Scotland's recombinant programme had reportedly saved a great deal of money in this way.

16. Steve Davies said that PASA would be willing to set up a national framework contract with all the manufacturers of recombinant. No restriction would therefore be placed on clinicians and patients in their choice of product. Timing would depend to a large extent on the front-end decision making process, but could be speeded up by use of accelerated tendering. This could be justified by the urgency around getting the first new patients on recombinant in 2003/04 but would require approval from PASA's Chief Executive.

17. Members agreed that wider consultation was needed before proceeding with a national contract. It was agreed that the secretariat would ask Julia Stallibrass to seek the views of the specialist services advisory group. Frank Hill also agreed to invite urgent comments from UKHCDO members.

18. It was agreed that a small sub-group would be set up to support PASA in the management of the tendering process. Volunteers were sought from the Group.

Action: Dr Hay to consult UKHCDO members on the proposal for a national contract; secretariat to consult Specialised Services Advisory Group; members to volunteer for a tendering sub-group.

ALLOCATION OF FUNDS TO PCTS

19. Charles Lister confirmed that funding for recombinant could not be ring-fenced. However, it would be necessary for DH to issue guidance to PCTs on the number of new patients to be placed on recombinant each year. The guidance would also need to state explicitly that funding was only for the cost of t5he phased roll out, not for the increasing cost of treating patients already receiving recombinant (currently rising by around 15% pa).

20. A decision was needed on how the funding should be allocated to PCTs. Members were strongly of the view that the money should not be allocated on a capitation basis given the uneven distribution of the haemophilia population. It would therefore have to be linked to the number of patients per PCT or StHA. A further option considered was the allocation of money to lead PCTs

21. There were still gaps in the existing data collected by the UKHCDO. Frank Hill agreed that the UKHCDO would ask Centres to identify patients within each PCT, and to categorise this information by age. This would help the Group agree the amount to be allocated to PCTs. It was agreed that Mick O'Donnell, and Frank Hill would prepare a discussion document around issues on data collection, which would help the Group reach a decision on the funding mechanism

Date of next meeting

22. The date of the next meeting is 10:00am on Thursday 10 April 2003.