# Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Thursday 14 March 2019, 11:37 to 18:12

Venue: National Institute for Health and Care Excellence  
Level 1A, City Tower  
Piccadilly Plaza  
Manchester  
M1 4BT

## **Present**

1.Dr Peter Jackson Present for all notes

2.Prof Ron Akehurst Present for all notes

3.Dr Ayesha Ali Present for all notes

4.Paul Arundel Present for all notes

5.Sarah Davis Present for all notes

6.Stuart Davies Present for all notes

7.Carrie Gardner Present for all notes

8.Dr Shehla Mohammed Present for all notes

9.Francis Pang Present for all notes

10.Matthew Smith Present for all notes

11.Dr Mark Sheehan Present for all notes

12.Dr Glenda Sobey Present for all notes

13.Professor Lesley Stewart Present for all notes

## **In attendance:**

Helen Knight, Programme Director, National Institute for Health and Care Excellence Present for all notes

Sheela Upadhyaya, Associate Director,

National Institute for Health and Care Excellence Present for all notes

Joanne Ekeledo, Project Manager,

National Institute for Health and Care Excellence Present for all notes

Aminata Watson, Technical Analyst,

National Institute for Health and Care Excellence Present for all notes

Ian Watson, Technical Adviser,

National Institute for Health and Clinical Excellence Present for all notes

Ellise Warren, Administrator

National Institute for Health and Clinical Excellence Present for all notes

Johnathan Shepard, ERG Representative Present for notes 1 to 15

Jo Lord, ERG Representative Present for notes 1 to 15

Jasmin Barman-Aksozen, Patient expert Present for notes 1 to 15

Antony Fearn, Patient expert Present for notes 1 to 15

Liz Gill, Patient expert Present for notes 1 to 15

Elisabeth Minder,Clinical Expert Present for notes 1 to 15

Robert Sarkany, Clinical Expert Present for notes 1 to 15

Lesley Rhodes, Clinical Expert Present for notes 1 to 15

Non-public observers:

Helen Barnett, Editor,

National Institute for Health and Clinical Excellence Present for notes all notes

Mandy Tonkinson Public Involvement Adviser,

National Institute for Health and Clinical Excellence Present for notes all notes

Erin Lingard, Apprentice,

National Institute for Health and Clinical Excellence Present for notes all notes

Emily Spencer, Administrator,

National Institute for Health and Clinical Excellence Present for notes all notes

Lorna Dunning, Technical analyst,

National Institute for Health and Clinical Excellence Present for notes all notes

David Thomson, Associate Director,

National Institute for Health and Clinical Excellence Present for notes all notes

Caron Jones, Adviser,

National Institute for Health and Clinical Excellence Present for notes all notes

Dapo Ogunbayo, NIHRIO Present for notes all notes

# Notes

## **Welcome**

1. The Chair welcomed all members of the Committee and other attendees present to the meeting. The Chair reviewed the agenda and timescales for the meeting, which included the evaluations of Afamelanotide for treating erythropoietic protoporphyria [ID927].
2. The Chair welcomed Matt Smith to their first meeting as a member of the Evaluation Committee
3. The Chair informed the Committee of the non-public observers at this meeting:

Helen Barnett

Mandy Tonkinson

Erin Lingard

Lorna Dunning

Caron Jones

David Thomson

Dapo Ogunbayo

1. Apologies were received from Linn Phipps and Jeremy Manuel.

## **Any other Business**

1. None

# Evaluation of Afamelanotide for treating erythropoietic protoporphyria [ID927]

## **Part 1 – Open session**

1. The Chair welcomed the invited experts Jasmin Barman-Aksozen, Antony Fearn, Liz Gill, Elisabeth Minder, Robert Sarkany, Lesley Rhodes, Ayesha Ali, Jo Lord and Johnathan Shepard to the meeting and they introduced themselves to the Committee.
2. The Chair welcomed company representatives from Maria Manley, Lachlan Hay and Sarah Love to the meeting.
3. The Chair asked all Committee members to declare any relevant interests
   1. All declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of Afamelanotide for treating erythropoietic protoporphyria [ID927]
4. The Chair asked all NICE Staff to declare any relevant interests.
   1. All declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of Afamelanotide for treating erythropoietic protoporphyria [ID927].
5. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
   1. All declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of Afamelanotide for treating erythropoietic protoporphyria [ID927].
6. The Chair introduced the lead team, Aminata Thiam and Ian Watson who gave presentations on the clinical effectiveness and cost effectiveness of Afamelanotide for treating erythropoietic protoporphyria [ID927].
7. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
8. The Chair explained that “representatives of the press and other members of the public be excluded from the remainder of this meeting having regard to the confidential nature of the business to be transacted, publicity on which would be prejudicial to the public interest" (Section 1(2) Public Bodies (Admission to Meetings) Act 1960)” and all public attendees left the meeting.

## **Part 2a – Closed session**

1. Discussion on confidential information continued. This information was supplied by the company Maria Manley, Lachlan Hay and Sarah Love. Experts stayed for part two who were Elisabeth Minder, Robert Sarkany, Lesley Rhodes, Jasmin Barman-Aksozen, Liz Gill and Antony Fearn. Jo Lord for the ERG also stayed.
2. The Chair then thanked the experts and company representatives for their attendance, participation and contribution to the evaluation and they left the meeting.

## **Part 2b – Closed Session**

1. The Committee continued to discuss the clinical and cost effectiveness of Afamelanotide for treating erythropoietic protoporphyria [ID927].

* The committee decision was based on consensus.

1. The Committee instructed the technical team to prepare the Evaluation Consultation Document (ECD) or Final Evaluation Determination (FED) in line with their decisions.

# Date, time and venue of the next meeting

1. Thursday 11 April 2019, 10:00am at National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT.