# Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Tuesday 12 February 2019

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

# Present:

1.Dr Peter Jackson Present for topic 1,2,3

2.Professor Ron Akehurst Present for topic 1 only

3.Paul Arundel Present for topic 1,2,3

4.Sarah Davis Present for topic 1,2,3

5.Stuart Davies Present for topic 1,2,3

6.Carrie Gardner Present for topic 1,2,3

7.Jeremy Manual Present for topic 1,2,3

8.Dr Shehla Mohammed Present for topic 1,2,3

9.Francis Pang Present for topic 1,2,3

10.Linn Phipps Present for topic 1,2,3

11.Dr Mark Sheehan Present for topic 1,2,3

12.Dr Glenda Sobey Present for topic 1,2,3

13.Professor Lesley Stewart Present for topic 1,2,3

# 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

Yelan Guo, Technical Adviser

National Institute for Health and Clinical Excellence Present for Topic 1

Ellise Warren, Administrator

National Institute for Health and Clinical Excellence Present for all notes

Thomas Paling, Technical Lead

National Institute for Health and Clinical Excellence Present for all notes

Eleanor Donegan, Technical Advisor

National Institute for Health and Clinical Excellence Present for topic 2

Aminata Thiam, Technical Lead

National Institute for Health and Clinical Excellence Present for topic 2

Christian Griffiths, Technical Advisor

National Institute for Health and Clinical Excellence Present for topic 3

Orsolya Balogh, Technical Lead

National Institute for Health and Clinical Excellence Present for topic 3

Nasuh Buyukkaramikli, ERG Representative

(Kleijnen Systematic Reviews Ltd) Present for topic 1

Marie Westwood, ERG Representative

(Kleijnen Systematic Reviews Ltd) Present for topic 1

John Stevens, ERG Representative

(ScHARR) Present for topic 2

Paul Tappenden, ERG Representative (ScHARR) Present for topic 2

Aline Navega Biz, ERG Representative (ScHARR) Present for topic 2

Graham Scotland, ERG Representative

(Aberdeen HTA Group) Present for topic 3

Dwayne Boyers, ERG Representative

(Aberdeen HTA Group) Present for topic 3

Rebecca Sanders, Patient Expert Present for topic 1

Tania Watson, Patient Expert Present for topic 1

Anna Stears, Clinical Expert Present for topic 1

Tricia Tan, Clinical Expert Present for topic 1

Professor Philip Hawkins, Patient expert Present for topic 2 & 3

Vincent Nicholas, Patient Expert Present for topic 2 & 3

Carol Whelan, Clinical expert Present for topic 2 & 3

Carlos Heras-Palou, Patient Expert Present for topic 2 & 3

Ayesha Ali, NHS Commissioning Expert Present for 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 Metrelptin [ID861], Patisiran [ID1279] and Inotersen [ID1242].
2. The Chair informed the Committee of the non-public observers at this meeting: Helen Barnett, Ann Greenwood, Mandy Tonkinson, Mark Rasburn, Alan Moore, Heather Stegenga, Trudie Willingham, Carl Boswell and Sarah Bromley

## **Any other Business**

1. None

# Evaluation of Metrelptin [ID861]

## **Part 1 – Open session**

1. The Chair welcomed the invited experts: Rebecca Sanders, Tania Watson, Anna Stears, Tricia Tan, Professor Philip Hawkins, Vincent Nicholas, Carol Whelan, Carlos Heras-Palou, and Ayesha Ali to the meeting and they introduced themselves to the Committee.
2. The Chair welcomed company representatives from Aegerion to the meeting.
3. The Chair asked all Committee members to declare any relevant interests

6.1 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 Metrelptin [ID861]

1. The Chair asked all NICE Staff to declare any relevant interests.

7.1 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 Metrelptin [ID861]

1. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.

8.1 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 Metrelptin [ID861].

1. The Chair introduced the lead team, Sotiris Antonia, Carrie Gardner and Linn Phipps who gave presentations on the clinical effectiveness and cost effectiveness of Metrelptin [ID861].
2. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
3. 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.
4. The Chair then thanked the experts and company representatives for their attendance, participation and contribution to the evaluation and they left the meeting.

## **Part 2 – Closed session**

1. Discussion on confidential information continued. This information was supplied by the company.
2. The Committee continued to discuss the clinical and cost effectiveness of Metrelptin [ID861].
3. The committee decision was based on consensus.
4. The Committee instructed the technical team to prepare the Final Evaluation Determination (FED) in line with their decisions.

# Evaluation of ID1279 Patisiran for treating hereditary transthyretin amyloidosis

## **Part 1 – Open session**

1. The Chair welcomed the invited expert’s assessment group representatives and observers the meeting and they introduced themselves to the Committee.
2. The Chair welcomed company representatives from Alnylam Pharmacueticals to the meeting.
3. The Chair asked all Committee members to declare any relevant interests

19.1 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 ID1279 Patisiran for treating hereditary transthyretin amyloidosis

1. The Chair asked all NICE Staff to declare any relevant interests.

20.1 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.

1. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.

21.1 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 ID1279 Patisiran for treating hereditary transthyretin amyloidosis

1. The Chair introduced the key themes arising from the consultation responses to the Evaluation Consultation Document (ECD) received from consultees, commentators and through the NICE website.
2. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
3. 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.
4. The Chair then thanked the experts and company representatives for their attendance, participation and contribution to the evaluation and they left the meeting.

## **Part 2 – Closed session**

1. Discussion on confidential information continued. This information was supplied by the company.
2. The Committee continued to discuss the clinical and cost effectiveness.
3. The committee decision was based on consensus.
4. The Committee instructed the technical team to prepare the Evaluation Consultation Document (ECD) in line with their decisions.

# Evaluation of ID1242 Inotersen for treating hereditary transthyretin amyloidosis

## **Part 1 – Open session**

1. The Chair welcomed the invited experts, assessment group representatives and observers to the meeting and they introduced themselves to the Committee.
2. The Chair welcomed company representatives from Akcea Therapeutics to the meeting.
3. The Chair asked all Committee members to declare any relevant interests

32.1 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 ID1242 Inotersen for treating hereditary transthyretin amyloidosis.

1. The Chair asked all NICE Staff to declare any relevant interests.

33.1 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 ID1242 Inotersen for treating hereditary transthyretin amyloidosis

1. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.

34.1 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 ID1242 Inotersen for treating hereditary transthyretin amyloidosis

1. The Chair introduced the key themes arising from the consultation responses to the Evaluation Consultation Document (ECD) received from consultees, commentators and through the NICE website.
2. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
3. 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.
4. The Chair then thanked the experts and company representatives for their attendance, participation and contribution to the evaluation and they left the meeting.

## **Part 2 – Closed session**

1. Discussion on confidential information continued. This information was supplied by the company.
2. The Committee continued to discuss the clinical and cost effectiveness.

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

# Date, time and venue of the next meeting

Thursday 14 March 2019 at National Institute for Health and Care Excellence,Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT