# Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Tuesday 21 May 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 all notes

2.Paul Arundel Present for all notes

3.Sarah Davis Present for all notes

4.Stuart Davies Present for all notes

5.Carrie Gardner Present for all notes

6.Jeremy Manuel Present for all notes

7.Dr Shehla Mohammed Present for all notes

8.Francis Pang Present for all notes

9.Linn Phipps Present for all notes

10.Dr Mark Sheehan Present for all notes

11.Dr Glenda Sobey Present for all notes

12.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

Orsolya Balogh, Technical Lead

National Institute for Health and Care Excellence Present for only 1- 9

Richard Diaz, Technical Adviser

National Institute for Health and Clinical Excellence Present for only 1- 9

Paul Tappenden, ERG Present for only 1- 8

John Stevens, ERG Present for only 1- 8

Professor Philip Hawkins, Clinical expert Present for only 1- 8

Dr Carol Whelan, Clinical expert Present for only 1- 8

Vincent Nicholas, Patient expert Present for only 1- 8

Dr Ayesha Ali, NHSE Commissioning expert Present for only 1- 8

Mr Hollins Lin, Company representative Present for only 1- 8

Dr Raul Arocho, Company representative Present for only 1- 8

## **Non-public observers:**

Karen Samuels, AWTTC Present for only 1- 9

Lucy Stacey, WHSSC Present for only 1- 9

# 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 Patisiran for treating hereditary transthyretin amyloidosis.
2. The Chair informed the Committee of the non-public observers at this meeting: Karen Samuels and Lucy Stacey.
3. Apologies were received from Professor Ron Akehurst and Sotiris Antoniou.

Any other Business

1. None

# Evaluation of Patisiran for treating hereditary transthyretin amyloidosis [ID1279]

## **Part 1 – Open session**

1. The Chair welcomed the invited experts: Professor Philip Hawkins, Dr Carol Whelan, Vincent Nicholas, Carlos Heras-Palou, Dr Ayesha Ali, Paul Tappenden and John Stevens to the meeting and they introduced themselves to the Committee.
2. The Chair welcomed company representatives from Alnylam Pharmaceuticals to the meeting.
3. The Chair asked all Committee members to declare any relevant interests
	1. All present committee members except Sarah Davis 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 Patisiran for treating hereditary transthyretin amyloidosis.
	2. Sarah declared a non-personal specific financial interest as part of his team had produced the assessment report for this evaluation, although he had not been directly involved.

 8.2.1 It was agreed that this declaration would not prevent Sarah Davis from participating in this section of the meeting.

1. 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 Patisiran for treating hereditary transthyretin amyloidosis.
2. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
	1. All except Carlos Heras-Palou 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 Patisiran for treating hereditary transthyretin amyloidosis.
	2. Carlos Heras-Palou declared a personal non-specific financial interest as he holds shares in healthcare industries but not for any of the manufacturer for this evaluation.
		1. It was agreed that this declaration would not prevent Carlos Heras-Palou from participating in this section of the meeting
3. 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
4. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
5. 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.
6. 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. Clinical and patient experts, ERG and company representatives excused.

1. The Committee continued to discuss the clinical and cost effectiveness of Patisiran for treating hereditary transthyretin amyloidosis.
	1. The committee decision was based on consensus.
2. 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

1. Thursday 25 July 2019 10am – 5pm at National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT