Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

**Topics for discussion:**

**Volanesorsen for treating familial chylomicronaemia syndrome [ID1326] - ECM1**

Date and Time: Thursday 28 November 2019 10am

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.Paul Arundel Present for all notes

4.Sarah Davis Present for all notes

5.Stuart Davies Present for all notes

6.Carrie Gardner Present for all notes

7.Jeremy Manual Present for all notes

8.Dr Shehla Mohammed Present for all notes

9.Francis Pang Present for all notes

10.Linn Phipps Present for all notes

11.Dr Mark Sheehan Present for all notes

In Attendance:

Helen Knight, Programme Director

National Institute for Health and Care Excellence Present for all notes

Melinda Goodall, 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 Analyst

National Institute for Health and Care Excellence Present for all notes

Yelan Guo, Technical Adviser

National Institute for Health and Clinical Excellence Present for all notes

Rashida Akhtar, Administrator

National Institute for Health and Clinical Excellence Present for all notes

Ayesha Ali, NHS England commissioning expert Present for notes 1-8

Non-public observers:

Karen Samuel, AWTTC Present for notes all notes

David Wright, DHSC Present for notes 1-8

Harsimran Sarpal, NIHR Present for all notes

Chika Ejikeme, NICE Present for all notes

Aideen Dunne, Public Health Trainee Present for notes 1-8

Nicole Elliot, NICE Present for notes 1-8

Karen Facey, IMPACT HTA Present for all notes

Frances Trenholme, IMPACT HTA Present for all notes

Elena Nicod, IMPACT HTA 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 evaluation of Volanesorsen for treating familial chylomicronaemia syndrome.
2. Apologies were received from Glenda Sobey

Any other Business

1. None

Notes from the last meeting

Evaluation of [Insert long form title of first topic]

Part 1 – Open session

1. The Chair welcomed the invited experts: Dr Charlotte Dawson, Dr Handrean Soran and Dr Fredrik Karpe (Clinical experts), Karishma Patel, and Jill Prawer (Patient experts), and Sarah Watson as the NHSE commissioning expert 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
   1. Paul Arundel, Carrie Gardner, Francis Pang, Linn Phipps, Mark Sheehan, Lesley Stewart, Shehla Mohammed, Stuart Davis, Ron Akehurst, Jeremy Manuel, and Sotiris Antonoiu, 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 Volanesorsen for treating familial chylomicronaemia syndrome.
   2. Sarah Davis declared a non-direct interest as follows: “I am a member of ScHARR-TAG which is acting as the ERG for this topic. It has been agreed with the ScHARR-TAG director that I will not discuss this topic with the ERG until after the ERG report is submitted to NICE”. Also, Matt Smith declared an indirect interest too as follows: “I am employed by Public Health England and part of my role is to support NHSE to commission specialised services. However, my role does not support the commissioning of NHSE highly specialised services.”

6.2.1 It was agreed that the declarations would not prevent Matt Smith or 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 Volanesorsen for treating familial chylomicronaemia syndrome.
2. The Chair introduced the lead team, Sarah Davis, Paul Arundel and Linn Phipps. who gave presentations on the clinical effectiveness and cost effectiveness of Volanesorsen for treating familial chylomicronaemia syndrome.
3. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
4. 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.
5. 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 Volanesorsen for treating familial chylomicronaemia syndrome.
   1. The committee decision was based on consensus.
3. The Committee instructed the technical team to prepare the Evaluation Consultation Document (ECD) or Final Evaluation Determination (FED) in line with their decisions.