NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date and time:** Thursday 9 December 2021

**Location:** Via Zoom

## Attendees

Committee members present

1. Dr Peter Jackson [Chair] Present for all items
2. Professor Ron Akehurst Present for all items
3. Dr Paul Arundel Present for all items
4. Professor Philip Beales Items 1 to 4.1.3
5. Sarah Davis Present for all items
6. Stuart Davies Present for all items
7. Carrie Gardner Present for all items
8. Jeremy Manuel Present for all items
9. Dr Shehla Mohammed Items 1 to 4.1.3
10. Francis Pang Present for all items
11. Karen Samuels Present for all items
12. Dr Mark Sheehan Present for all items
13. Matt Smith Present for all items
14. Karen Whitehead Present for all items

NICE staff present

Richard Diaz, Associate Director Present for all items

Daniel Davies, Project Manager Present for all items

Yelan Guo, Health Technology Assessment Adviser Present for all items

Emma Douch, Health Technology Assessment Analyst Present for all items

Catrin Austin, Technical Analyst, Methods and economics Present for all items

Emily Eaton Turner, Technical Adviser, Commercial Risk Assessment Present for all items

Claire Hawksworth, Technical Analyst, Evidence Generation Present for all items

Ella Livingstone, Technical Adviser, Commercial Risk Assessment Present for all items

Thomas Strong, Technical Adviser, Commercial Risk Assessment Present for all items

Hayley Garnett, Senior Medical Editor Present for all items

Heidi Livingstone, Public Involvement Adviser, PIP Items 1 to 4.1.3

Lyn Davies, Coordinator, Corporate Office Items 1 to 4.1.3

Gemma Smith, Coordinator, COT Present for all items

Emma Gordon, Administrator, TA Present for all items

Laura Kelly, Administrator, COT Present for all items

External review group representatives present

Amanda Brand, Peninsula Technology Assessment Group [PenTAG] Items 1 to 4.1.3

Brian O’Toole, Peninsula Technology Assessment Group [PenTAG] Items 1 to 4.1.3

Clinical & patient experts present

Dr Ayesha Ali, Commissioning expert, NHS England Items 1 to 4.1.3

Professor Sadaf Farooqi, Wellcome Trust Principal Research Fellow, Professor of metabolism and medicine, clinical expert nominated by Rhythm Pharmaceuticals, Items 1 to 4.1.3

Dr Pooja Sachdev, Consultant in Paediatric Diabetes and Endocrinology, clinical expert nominated by Royal College of Paediatrics and Child Health, Item 4.1.3

Dr Mars Skae, Consultant Paediatric Endocrinologist, clinical expert nominated by Royal College of Paediatrics and Child Health, Items 1 to 4.1.3

Debbie Potter, Patient expert, nominated by clinical expert Professor Farooqi, Items 1 to 4.1.3

Alex Potter, Patient expert, nominated by clinical expert Professor Farooqi, Items 1 to 4.1.3

## Minutes

### Introduction to the meeting

* 1. The chair Dr Peter Jackson welcomed members of the committee and other attendees present to the meeting.
  2. The chair noted committee member apologies.

### News and announcements

* 1. None

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meetings held on Wednesday 6 October and Wednesday 10 November 2021.

### Evaluation of setmelanotide for treating obesity caused by LEPR or POMC deficiency [ID3764]

* 1. Part 1 – Open session
     1. The chair welcomed the invited clinical and patient experts, the NHS England commissioning expert, external review group representatives, members of the public and company representatives from Rhythm Pharmaceuticals.
     2. The chair asked all committee members, clinical and patient experts, NHS England commissioning expert, external review group representatives and NICE staff present to declare any relevant interests in relation to the item being considered.
* Committee member Dr Shehla Mohammed declared non-financial professional interests as she has been involved as PI in another phase III trial using setmelanotide for a ciliopathy disorder Bardet Biedle Syndrome [BBS] associated with obesity. It was agreed that her declaration would not prevent Dr Mohammed from participating in part one discussions on this appraisal, but she would not be permitted to attend part two confidential discussions.
* Committee member Professor Philip Beales declared non-financial professional interests as he sits on the Rhythm therapeutics scientific advisory board for Bardet-Biedl syndrome [BBS] and alstrom syndrome indications and is Chief Investigator for the UK setmelanotide study for use in BBS. It was agreed that his declaration would not prevent Professor Beales from participating in part one discussions on this appraisal, but he would not be permitted to attend part two confidential discussions.
* Nominated clinical expert Dr Mars Skae declared non-financial professional interests as she has been involved as PI in another phase III trial using setmelanotide for a ciliopathy disorder Bardet Biedle Syndrome [BBS] associated with obesity. It was agreed that her declaration would not prevent Dr Skae from providing expert advice to committee.
  + 1. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Professor Ron Akehurst, Dr Paul Arundel, and Jeremy Manuel.
  1. Part 2 – Closed session [company representatives, clinical and patient experts the NHS England commissioning expert, external review group representatives and members of the public were asked to leave the meeting]
     1. The committee then agreed on the content of the Final Evaluation Determination (FED) or the Evaluation Consultation Document [ECD]. The committee decision was reached by consensus..
     2. The committee asked the NICE technical team to prepare the Final Evaluation Determination (FED) or the Evaluation Consultation Document [ECD] in line with their decisions.
* Further updates will be available on the topic webpage in due course: <https://www.nice.org.uk/guidance/indevelopment/gid-hst10034>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 13 January 2022 and will start promptly at 09.30.