NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Wednesday 18 January 2023

**Location:** Via Zoom

## Attendees

Committee members present

1. Dr Peter Jackson (Chair) Present for all items
2. Dr Paul Arundel (Vice Chair) Present for all items
3. Annett Blochberger Present for all items
4. Emtiyaz Chowdhury Present for all items
5. Stuart Davies Present for all items
6. Sarah Davis Present for all items
7. Carrie Gardner Present for all items
8. Tina Garvey Present for all items
9. Professor Jonathan Ives Present for all items
10. Jeremy Manuel O.B.E Present for all items
11. Dr Stuart Mealing Items 1 to 4.1.3
12. Dr Shehla Mohammed Present for all items
13. Sara Payne Present for all items
14. Karen Whitehead M.B.E Present for all items
15. Anthony Williams Present for all items
16. Professor Ed Wilson Present for all items

NICE staff (key players) present

Richard Diaz, Associate Director Present for all items

Daniel Davies, Project Manager Present for all items

Victoria Kelly, Health Technology Assessment Adviser Present for all items

Dilan Savani, Health Technology Assessment Analyst Present for all items

Helen Barnett, Senior Medical Editor Present for all items

Heidi Livingstone, Senior Public Involvement Adviser Items 1 to 4.1.3

Wajeeha Asmin, Administrator, TA Present for all items

Liam Murray, Administrator, COT Present for all items

NICE staff (observers) present

Thomas Strong, Associate Director - Managed Access Present for all items

Sarah Wilkes, Technical Analyst Present for all items

Sandra Robinson, Assistant Project Manager, MIP Items 1 to 4.1.3

Ruby Jennison, Administrator, TA Items 1 to 4.1.3

External assessment group representatives present

Joanne Lord, Southampton Health Technology Assessments Centre Items 1 to 4.1.3

Dr Jonathan Shepherd, Southampton Health Technology Assessments Centre Items 1 to 4.1.3

Clinical, Patient & NHS England experts present

Dr Ayesha Ali, Medical Advisor in Highly Specialised Services, NHS England Items 1 to 4.1.3

Jasmin Barman, Patient Expert nominated by the International Porphyria Patients Network, Present for all items

Antony Fearn, Patient Expert nominated by the British Porphyria Association Items 1 to 4.1.3

Elizabeth Gill, Patient Expert nominated by the British Porphyria Association Items 1 to 4.1.3

Dr Sanjeev Patel, Medical Advisor, NHS England Items 1 to 4.1.3

Lesley Rhodes, Clinical Expert nominated by Clinuvel Items 1 to 4.1.3

## Minutes

### Introduction to the meeting

The chair, Dr Peter Jackson, welcomed members of the committee and other attendees present to the meeting.

The chair noted apologies from Professor Philip Beales.

### News and announcements

None.

### Minutes from the last meeting

The committee approved the minutes of the committee meeting held on Thursday 15 December 2023

### Evaluation of Afamelanotide for treating erythropoietic protoporphyria [ID927]

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Clinuvel Pharmaceuticals
     2. The chair asked all committee members and experts, external assessment group representatives and NICE staff present to declare any relevant interests in relation to the item being considered.
* Emtiyaz Chowdhury declared a professional interest as he is an employee of Parexel, who may collaborate with this manufacturer. He has not personally been involved with any activities with regards to alfamelanotide. It was agreed that his declaration would not prevent Emtiyaz from participating in discussions on this evaluation.
* Dr Stuart Mealing declared a professional interest as in his previous role as part of his job, he designed and built an early version of the economic model that will probably form part of the company’s evidence package and also provided strategic consultancy and support. This was all more than five years ago. It was agreed that these declarations would allow Dr Mealing to attend the public discussion but prevent him from attending the closed discussion and decision making in part two.
* Professor Lesley Rhodes declared direct financial interests as she directs a research programme on sunlight effects on health, including several projects on dietary and systemic photoprotection, vitamin D, skin cancer, photosensitivity and other related areas. This programme has received funding from: Cancer Research UK, Department of Health, NIHR, European Union, BBSRC, AICR, Wellcome Trust, British Skin Foundation and Industry. The accounts are held by the University of Manchester and Salford Royal Hospital; She has published multiple original manuscripts on sunlight related health effects and photoprotective agents; She is principal investigator for clinical trials of melanotropic peptides with commercial partners (Mitsubishi Pharma and Clinuvel Ltd). It was agreed that her declaration would not prevent Professor Rhodes from providing expert advice to the committee.
* No further interests were declared for this evaluation.
  + 1. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by The Chair.
  1. Part 2 – Closed session (company representatives, professional experts, external assessment group representatives and members of the public were asked to leave the meeting)
     1. The committee then agreed on the content of the Evaluation Consultation Document (ECD) or Final Evaluation Document (FED). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Evaluation Consultation Document (ECD) or Final Evaluation Document (FED) 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-hst10009>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 9 February 2023 and will start promptly at 10:00am.