NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Unconfirmed

**Date and time:** Wednesday 6 July 2022

**Location:** Via Zoom Conference Call

## Attendees

Committee members present

1. Dr Peter Jackson (Chair) Present for all items
2. Dr Paul Arundel (Vice Chair) Present for all items
3. Professor Ron Akehurst Present for all items
4. Annett Blochberger Present for all items
5. Emtiyaz Chowdhury Present for all items
6. Stuart Davies Present for all items
7. Sarah Davis Present for all items
8. Carrie Gardner Present for all items
9. Karen Whitehead M.B.E Present for all items
10. Professor Ed Wilson Present for all items
11. Anthony Williams Present for all items

NICE staff present

Helen Knight, Programme Direct, TA/HST Present for all items

Richard Diaz, Associate Director Present for all items

Daniel Davies, Project Manager Present for all items

Vicky Kelly, Technical Adviser Present for all items

Ella Livingstone, Technical Adviser, Commercial Risk Present for items 4.1.3 and 4.2.1

Emily Eaton-Turner, Technical Analyst, Present for all items Commercial Risk

Alan Moore, HTA Analyst Present for all items

Helen Barnett, Senior Medical Editor Present for all items

Catherine Pank, Assistant Project Manager, COT Present for items 4.3 to 4.3.3

Heidi Livingstone, Senior Public Involvement Adviser, PiP Present for items 1 to 4.2.1

Lyn Davies, Coordinator, Cooperate Office Present for items 1 to 4.1.3

Emma Gordon, Administrator, TA Present for all items

Laura Kelly, Administrator, COT Present for items 1 to 4.1.3

External assessment group representatives present

Geoff Frampton, Southampton Health Technology Assessment Centre Present for items 1 to 4.1.3

Jo Lord, Southampton Health Technology Assessment Centre Present for items 1 to 4.1.3

Experts present

Dr Jasmin Barman-Aksözen, Vice President, International Porphyria Patient Network, nominated by International Porphyria Patient Network (IPPN) Present for items 1 to 4.1.3

Professor Lesley Rhodes, Professor of Experimental Dermatology and Consultant Dermatologist, nominated by British Association of Dermatologists (BAD) Present for items 1 to 4.1.3

Anthony Fearn, Patient Expert, nominated by British Porphyria Association Present for items 1 to 4.1.3

Liz Gill, Vice Chairman for British Porphyria Association, nominated by British Porphyria Association Present for items 1 to 4.1.3

## Minutes

### Introduction to the meeting

* 1. The chair welcomed members of the committee and other attendees present to the meeting.
  2. Prior to the meeting, apologies were received from Professor Philip Beales, Jeremy Manuel O.B.E, Dr Shehla Mohammed and Dr Mark Sheehan.

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Wednesday 9 June 2022

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

* 1. Part 1 – Open session
     1. The chair welcomed the invited professional experts, external assessment group representatives, members of the public and company representatives from Clinuvel Ltd.
     2. The chair asked all committee members, professional 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 non-financial professional interest as his employer - Parexel - is a clinical research organisation that works with various manufacturers in the life science industry. Clinuvel UK may be one such manufacturer. Emtiyaz has not been directly involved, nor has any knowledge of any work undertaken by Parexel specifically for the technology under consideration. It was agreed that this declaration would not prevent Emtiyaz Chowdhury from taking part in this discussion.
* Professor Lesley Rhodes declared various indirect 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. Professor Rhodes has also published multiple original manuscripts on sunlight related health effects and photoprotective agents. Furthermore, Professor Rhodes also declared a direct financial interest, as principal investigator for clinical trials of melanotropic peptides with commercial partners (Mitsubishi Pharma and Clinuvel Ltd.) It was agreed these declarations would not prevent Professor Rhodes from providing expert advice in this discussion.
* Prior to the meeting, Anthony Fearn declared an indirect financial interest as he is a BPA Committee Member and supports the European Porphyria Network EPNET with development of their website content. It was agreed that this declaration would not prevent Anthony Fearn from providing expert advice in this discussion.
  + 1. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by the chair, Dr Peter Jackson.
  1. Part 2 – Closed session (company representatives, clinical & patient 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 Determination (FED). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Final Evaluation Determination (FED) in line with their decisions.
* The committee asked the NICE technical team to prepare the documents in line with their decisions and 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 September 2022 and will start promptly at 09:00am for 09:30am.