NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Wednesday 12 June 2024

**Location:** Via Zoom

## Attendees

Committee members present

1. Dr Paul Arundel (Chair) Present for all items
2. Professor Iolo Doull (Vice Chair) Present for all items
3. Emtiyaz Chowdhury Present for all items
4. Sarah Davis Present for all items
5. Carrie Gardner Present for all items
6. Professor Jonathan Ives Present for all items
7. Stuart Mealing Present for all items
8. Dr Shehla Mohammed Items 1.1 to 4.2.2
9. Sara Payne Present for all items
10. Angharad Shambler Present for all items
11. Professor Ed Wilson Present for all items

NICE staff (key players) present

Jacoline Bouvy, Programme Director Items 1.1 to 4.2.2

Jasdeep Hayre, Associate Director Present for all items

Celia Mayers, Project Manager Present for all items

Jo Richardson, Health Technology Assessment Adviser Items 1.1 to 4.2.2

Ross Wilkinson, Health Technology Assessment Analyst Items 1.1 to 4.2.2

Claire Hawksworth, Health Technology Assessment Adviser Items 5.1 to 5.2.2

Kirsty Pitt, Health Technology Assessment Analyst Items 5.1 to 5.2.2

External assessment group representatives present

Ana Duarte, Centre for Reviews and Dissemination and Centre for Health Economics – York

Items 1.1 to 4.1.3

Mark Simmonds, Centre for Reviews and Dissemination and Centre for Health Economics – York Items 1.1 to 4.1.3

Rebecca Bresnahan, Liverpool Reviews and Implementation Group (LRiG)

Items 5.1 to 5.1.4

James Mahon, Liverpool Reviews and Implementation Group (LRiG)

Items 5.1 to 5.1.4

Clinical, Patient & NHS England experts present

Liz Brownnutt, Chief Executive Officer at Batten Disease Family Association (BDFA) - patient expert, nominated by BDFA Items 1.1 to 4.1.3

Lucy Carroll, Parent - patient expert, nominated by BDFA Items 1.1 to 4.1.3

Gail Rich, Parent - patient expert, nominated by BDFA Items 1.1 to 4.1.3

Dipak Ram, Consultant Paediatric Neurologist – clinical expert, nominated by BioMarin (company) and BDFA Items 1.1 to 4.1.3

Paul Gissen, Clinical Professor in Paediatric Metabolic Medicine & Honorary Consultant - clinical expert, nominated by BioMarin (company) and BDFA

Items 1.1 to 4.1.3

Ayesha Ali, Medical Advisor, Highly Specialised Services at NHSE – nominated by NHSE

Items 5.1 to 5.1.4

Kirstie Purnell - patient expert, nominated by AMEND Items 5.1 to 5.1.4

Jonathan Wadsley, Consultant Clinical Oncologist – clinical expert, nominated by Eli Lilly

Items 5.1 to 5.1.4

Kee Howe Wong, Consultant Clinical Oncologist – clinical expert, nominated by Eli Lilly

Items 5.1 to 5.1.4

Peter Clark, CDF Clinical lead – NHSE Items 5.1 to 5.2.2

*Please note that alongside the attendees listed in this document, there were additional NICE Staff present in this meeting. These attendees were not involved in the decision making or discussions.*

## Minutes

### Introduction to the meeting

* 1. The chair welcomed members of the committee and other attendees present to the meeting.
  2. The chair noted apologies from Tina Garvey.

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Wednesday 8 May.

### Evaluation of cerliponase alfa for treating neuronal ceroid lipofuscinosis type 2 (review of HST12) [ID6145]

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from BioMarin.
     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. Declarations for this appraisal can be found on the Topic Register of Interest (TROI) on the topic webpage, [here](https://www.nice.org.uk/guidance/indevelopment/gid-ta11047).
     3. The chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Sarah Davis (cost), Sara Payne (lay) and Shehla Mohammed (clinical).
  2. Part 2 – Closed session (company representatives, patient and clinical 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 Draft Guidance (DG) or Final Draft Guidance (FDG). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Draft Guidance (DG) or Final Draft Guidance (FDG) 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-ta11047>.

### Appraisal of selpercatinib for advanced thyroid cancer with RET alterations that has not been treated with systemic therapy [ID6132]

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Eli Lilly.
     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. Declarations for this appraisal can be found on the Topic Register of Interest (TROI) on the topic webpage, [here](https://www.nice.org.uk/guidance/indevelopment/gid-ta11391).
     3. The chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by the chair, Paul Arundel.
  2. Part 2 – Closed session (company representatives, patient and clinical 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 Draft Guidance (DG) or Final Draft Guidance (FDG). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Draft Guidance (DG) or Final Draft Guidance (FDG) 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-ta11391>.

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 15 August 2024 and will start promptly at 9:30am.