NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 03 April 2025

**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 Items 1.1 to 4.2.2
4. Carrie Gardner Present for all items
5. Tina Garvey Items 1.1 to 4.2.2
6. Professor Jonathan Ives Present for all items
7. Professor Dusko Ilic Present for all items
8. Dr Natalia Kunst Items 1.1 to 4.2.2
9. Dr Guy Makin Items 1.1 to 4.2.2
10. Stuart Mealing Present for all items
11. Dr Shehla Mohammed Items 1.1 to 4.2.2
12. Sara Payne Present for all items
13. Professor Ed Wilson Present for all items

NICE staff (key players) present

Lorna Dunning, Associate Director Items 1.1 to 4.2.2

Leena Issa, Project Manager Items 1.1 to 4.2.2

Michelle Green, Health Technology Assessment Adviser Items 1.1 to 4.2.2

Madiha Adam, Health Technology Assessment Analyst Items 1.1 to 4.2.2

Rich Diaz, Associate Director Items 5.1 to 5.2.2

Vonda Murray, Project Manager Items 5.1 to 5.2.2

Joanna Richardson, Health Technology Assessment Adviser Items 5.1 to 5.2.2

Ross Wilkinson, Health Technology Assessment Analyst Items 5.1 to 5.2.2

Jacoline Bouvy, Programme Director, Medicines Evaluation Items 5.1 to 5.2.2

External assessment group representatives present

Julian Higgins, Bristol Technology Assessment Group, University of Bristol Items 1.1 to 4.1.3

Nicky Welton, Bristol Technology Assessment Group, University of Bristol Items 1.1 to 4.1.3

Mark Simmonds, Centre for Reviews and Dissemination and Centre for Health Economics, York Items 5.1 to 5.1.3

Ana Duarte, Centre for Reviews and Dissemination and Centre for Health Economics, York Items 5.1 to 5.1.3

Clinical, Patient & NHS England experts present

Deborah Tweddle, Professor of Paediatric Oncology & Honorary Consultant in Paediatric & Adolescent Oncology, Clinical expert, nominated by Norgine Items 1.1 to 4.1.3

Juliet Gray, Professor in Paediatric Oncology, Clinical expert, nominated by Norgine Items 1.1 to 4.1.3

Nicholas Bird, Parent and Chair of Trustees, Patient expert, nominated by Solving Kids’ Cancer Items 1.1 to 4.1.3

Amanda Berriman, Parent, Patient expert, nominated by Solving Kids’ Cancer Items 1.1 to 4.1.3

Peter Clark, CDF Clinical lead, NHSE Items 1.1 to 4.1.3

Dipak Ram, Consultant Paediatric Neurologist, Clinical expert, nominated by BioMarin and Batten Disease Family Association (BDFA) Items 5.1 to 5.1.3

Paul Gissen, Clinical Professor in Paediatric Metabolic Medicine & Honorary Consultant, Clinical expert, nominated by BioMarin and BDFA Items 5.1 to 5.1.3

Liz Brownnutt, Chief Executive Officer at BDFA, Patient expert, nominated by BDFA Items 5.1 to 5.1.3

Lucy Carroll, Parent, Patient expert, nominated by BDFA Items 5.1 to 5.1.3

Gail Rich, Parent, Patient expert, nominated by BDFA Items 5.1 to 5.1.3

Sanjeev Patel, IMF Clinical lead, NHS England 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, Dr Paul Arundel, welcomed members of the committee and other attendees present to the meeting.
  2. The Chair noted apologies from Angharad Shambler, Annett Blochberger, Dr Shehla Mohammed (topic 2) and Tina Garvey (topic 2).

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Thursday 13 March 2025.

### Appraisal of Eflornithine for treating high-risk neuroblastoma with complete or partial response after immunotherapy [ID4060]

* 1. Part 1 – Closed session
     1. The Chair welcomed the invited experts, external assessment group representatives and company representatives from Norgine.
     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-ta10990/documents).
     3. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Tina Garvey, Dr Guy Makin and Professor Ed Wilson.
  2. Part 2 – Closed session (company representatives, Clinical, Patient and NHSE experts and external assessment group representatives 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: [Project information | Eflornithine for treating high-risk neuroblastoma with complete or partial response after immunotherapy [ID4060] | Guidance | NICE](https://www.nice.org.uk/guidance/indevelopment/gid-ta10990)

### Evaluation of Cerliponase alfa for treating neuronal ceroid lipofuscinosis type 2 (MA 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-hst10061/documents).
     3. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by Dr Paul Arundel.
  2. Part 2 – Closed session (company representatives, Clinical and 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 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: [Project information | Cerliponase alfa for treating neuronal ceroid lipofuscinosis type 2 (MA review of HST12) [ID6145] | Guidance | NICE](https://www.nice.org.uk/guidance/indevelopment/gid-hst10061)

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 22 May 2025 and will start promptly at 9am.