NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 7 December 2023

**Location:** Via Zoom and Manchester Office

## 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. Sarah Davis Present for all items
6. Carrie Gardner Present for all items
7. Tina Garvey Items 1.1 to 4.3.2
8. Professor Jonathan Ives Present for all items
9. Stuart Mealing Present for all items
10. Dr Shehla Mohammed Present for all items
11. Sara Payne Present for all items
12. Angharad Shambler Present for all items
13. Professor Ed Wilson Present for all items

NICE staff (key players) present

Jacoline Bouvy, Programme Director Present for all items

Ricard Diaz, Associate Director Present for all items

Vonda Murray, Project Manager Items 1.1 to 4.3.2

Yelan Guo, Health Technology Assessment Adviser Items 1.1 to 4.3.2

Thomas Jarratt, Health Technology Assessment Analyst Items 1.1 to 4.3.2

Celia Mayers, Project Manager Items 5.1 to 5.2.2

Ewa Rupniewska, Health Technology Assessment Adviser Items 5.1 to 5.2.2

Emma Douch, Health Technology Assessment Analyst Items 5.1 to 5.2.2

External assessment group representatives present

Caroline Farmer, Peninsula Technology Assessment Group Items 1.1 to 4.3.2

Ed Wilson, Peninsula Technology Assessment Group Items 1.1 to 4.3.2

Deborah Caldwell, Bristol-Technology Assessment Group Items 5.1 to 5.1.3

Nicky Welton, Bristol-Technology Assessment Group Items 5.1 to 5.1.3

Clinical, Patient & NHS England experts present

Simon Jones, Consultant Paediatric inherited metabolic disease, clinical expert, nominated by NPUK Items 1.1 to 4.3.

Elaine Murphy, Consultant Adult Inherited Metabolic Disease - clinical expert, nominated by Sanofi Items 1.1 to 4.3.2

Toni Mathieson, Patient expert, nominated by NPUK Items 1.1 to 4.3.2

Sally Tungate, Patient expert, nominated by NPUK Items 1.1 to 4.3.2

James Dyson, Patient expert, nominated by NPUK Items 1.1 to 4.3.2

Ayesha Ali, Medical Adviser for Highly Specialised Services at NHS England – commissioning expert Items 1.1 to 4.3.2

Items 5.1 to 5.3.2

Sanjeev Patel, IMF Adviser for Highly Specialised Services at NHS England – commissioning expert Items 1.1 to 4.3.2

Elizabeth Forsythe, Consultant in Clinical Genetics – clinical expert, nominated by Rhythm Pharmaceuticals Items 5.1 to 5.1.3

Dimitri Pournaras, Consultant Bariatric and Metabolic Surgeon – clinical expert, nominated by Obesity & Metabolic Surgery Society Items 5.1 to 5.1.3

Danielle Thomas, Patient expert, nominated by Bardet-Biedl Syndrome UK

Items 5.1 to 5.1.3

Angela Scudder, Patient expert, nominated by Bardet-Biedl Syndrome UK

Items 5.1 to 5.1.3

*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 Anthony Williams.

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Thursday 5 October 2023

### Evaluation of [Olipudase alfa for treating Niemann-Pick disease types A and B [ID3913]](https://www.nice.org.uk/guidance/indevelopment/gid-ta10788)

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Sanofi
     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.
     3. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by Peter Jackson.
  2. Part 2 – Closed session (company representatives, patient, clinical and 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 Final Draft Guidance (FDG). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the 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-ta10788>.

### Evaluation of [Setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome [ID3947]](https://www.nice.org.uk/guidance/indevelopment/gid-ta10834)

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Rhythm 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. 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-ta10834).
     3. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by Peter Jackson.
  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). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the 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-ta10834>.

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Wednesday 10 January 2024 and will start promptly at 9am.