NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 14 September 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. Emtiyaz Chowdhury Present for all items
4. Sarah Davis Present for all items
5. Tina Garvey Present for all items
6. Dr Warren Linley Present for all items
7. Professor G.J. Melendez-Torres Items 5.1.1 to 5.2.2
8. Dr Shehla Mohammed Items 5.1.1 to 5.2.2
9. Sara Payne Present for all items
10. Carole Pitkeathley Items 5.1.1 to 5.2.2
11. Peter Wheatley-Price Items 1.1 to 4.3.2
12. Alan Thomas Items 1.1 to 4.3.2
13. Professor Ed Wilson Items 1.1 to 4.3.2

NICE staff (key players) present

Jasdeep Hayre, Associate Director Items 1.1 to 4.3.2

Celia Mayers, Project Manager Items 1.1 to 4.3.2

Rufaro Kausi, Health Technology Assessment Adviser Items 1.1 to 4.3.2

Emma Douch, Health Technology Assessment Analyst Items 1.1 to 4.3.2

Richard Diaz, Associate Director Items 5.1.1 to 5.2.2

Vonda Murray, Project Manager Items 5.1.1 to 5.2.2

Ewa Rupniewska, Health Technology Assessment Adviser Items 5.1.1 to 5.2.2

Owen Swales, Health Technology Assessment Analyst Items 5.1.1 to 5.2.2

Jacoline Bouvy, Programme Director Present for all items

External assessment group representatives present

Jelena Savovic, Bristol TAG Items 1.1 to 4.2.1

Nicky Welton, Bristol TAG Items 1.1 to 4.2.1

Sue Harnan, ScHARR Items 5.1.1 to 5.1.3

Matthew Stevenson, ScHARR Items 5.1.1 to 5.1.3

Clinical, Patient & NHS England experts present

Elizabeth Forsythe, Consultant in Clinical Genetics – clinical expert, nominated by Rhythm Pharmaceuticals Items 1.1 to 4.1.3

Dimitri Pournaras, Consultant Bariatric and Metabolic Surgeon – clinical expert, nominated by the Obesity & Metabolic Surgery Society Items 1.1 to 4.1.3

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

Items 1.1 to 4.1.3

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

Items 1.1 to 4.1.3

Ayesha Ali, Medical Adviser for Highly Specialised Services at NHS England – commissioning expert Items 1.1 to 4.1.3,

Items 5.1.1 to 5.1.3

Sophie Thomas, Patient expert, nominated by the MPS Society,

Items 5.1.1 to 5.1.3

Alexander Broomfield, Consultant Metabolic Medicine – clinical expert, nominated by Central Manchester Foundation Trust Items 5.1.1 to 5.1.3

Julia Hennermann, Head of the Dept. for Inborn Errors of Metabolism – clinical expert, nominated by Chiesi Items 5.1.1 to 5.1.3

Sanjeev Patel, IMF Adviser for Highly Specialised Services at NHS England – commissioning expert Items 5.1.1 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 Peter Jackson, welcomed members of the committee and other attendees present to the meeting.
  2. The Chair noted apologies from Angharad Shambler, Annett Blochberger, Anthony Williams, Carrie Gardner, Jonathan Ives, Philip Beales and Stuart Mealing.

### News and announcements

* 1. The committee were reminded of the next meeting being a hybrid meeting on Thursday 5 October 2023

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Thursday 13 July 2023

### Evaluation of setmelanotide for treating obesity and hyperphagia in Bardet-Biedl syndrome [ID3947]

* 1. Part 1 – Open session
     1. The Chair, Dr Peter Jackson, 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 The Chair.
  2. Part 2a – Closed session (company representatives, clinical and patient experts, and members of the public were asked to leave the meeting).
     1. The committee discussed confidential information submitted for this item.
  3. Part 2b – Closed session (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: <https://www.nice.org.uk/guidance/indevelopment/gid-ta10834>

### Evaluation of velmanase alfa for treating alpha-mannosidosis [ID800]

* 1. Part 1 – Open session
     1. The Chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Chiesi.
     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-hst10010).
     3. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by The Chair.
  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: <https://www.nice.org.uk/guidance/indevelopment/gid-hst10010>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 5 October 2023 and will start promptly at 9:00am. Please note the meeting is no longer hybrid as planned and is now virtual only.