NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 13 July 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. Professor Philip Beales 5.1.1 to 5.3.2
4. Annett Blochberger Present for all items
5. Emtiyaz Chowdhury Present for all items
6. Sarah Davis Present for all items
7. Carrie Gardner Present for all items
8. Stuart Mealing Present for all items
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

Jasdeep Hayre, Associate Director Items 1.1 to 4.3.2

Richard Diaz, Associate Director Items 5.1 to 5.3.2

Celia Mayers, Project Manager Items 1.1 to 4.3.2

Leena Issa, Project Manager Items 5.1 to 5.3.2

Rufaro Kausi, Health Technology Assessment Adviser Items 1.1 to 4.3.2

Alan Moore, Health Technology Assessment Adviser Items 5.1 to 5.3.2

Emma Douch, Health Technology Assessment Analyst Items 1.1 to 4.3.2

Sharlene Ting, Health Technology Assessment Analyst Items 5.1 to 5.3.2

Jacoline Bouvy, Programme Director Present for all items

External assessment group representatives present

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| Nicky Welton, Bristol Technology Assessment Group | Items 1.1 to 4.2.1 |
| Jelena Savovic, Bristol Technology Assessment Group | Items 1.1 to 4.2.1 |
| Gurdeep Sagoo, Newcastle Technology Assessment Review Group | Items 5.1 to 5.2.2 |
| Katie Thomson, Newcastle Technology Assessment Review Group | Items 5.1 to 5.2.2 |
| Hosein Shabaninejad, Newcastle Technology Assessment Review Group | Items 5.1 to 5.2.2 |

Clinical, Patient & NHS England experts present

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| 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 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 |
| Suresh Vijay, Consultant Paediatric Inherited Metabolic Disorders – Clinical expert, nominated by Alexion Pharma UK | Items 5.1 to 5.1.3 |
| Simon Jones, Consultant paediatric inherited metabolic disease – Clinical expert, nominated by Alexion Pharma UK (and The MPS Society) | Items 5.1 to 5.1.3 |
| Sophie Thomas, Patient expert, nominated by The MPS Society | Items 5.1 to 5.1.3 |
| Lee-Ann Lorimer, Patient expert, nominated by The MPS Society | Items 5.1 to 5.1.3 |
| Ayesha Ali, Medical adviser for Highly Specialised Services at NHS England – commissioning expert | Items 1.1 to 4.1.3, Items 5.1 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, Dr Peter Jackson, welcomed members of the committee and other attendees present to the meeting.
  2. The chair noted apologies from Jonathan Ives, Philip Beales, Dr Shehla Mohammed and Tina Garvey.

### News and announcements

* 1. The chair informed the committee of a change to the August meeting from hybrid to virtual.
  2. The committee were reminded of two public consultations open on the NICE website.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Thursday 8 June 2023

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

* 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 evidence presented to the committee. This information was presented to the committee by Dr Paul Arundel, Sara Payne and Sarah Davis.
  2. Part 2a – Closed session (members of the public, patient and clinical experts, and company representatives 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 sebelipase alfa for treating Wolman disease [ID3995]

* 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 Alexion Pharma.
     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-hst10047).
     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 (two of the company representatives, patient and clinical experts, external assessment group representatives and members of the public were asked to leave the meeting).
     1. A representative of Alexion Pharma gave a brief statement to the committee
  3. Part 2b – Closed session (the representative of Alexion Pharma left 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-hst10047>

### Date of the next meeting

* The meeting scheduled for Thursday 3 August 2023 has been cancelled.
* The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 14 September 2023 and will start promptly at 9:15am.