NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 10 October 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. Annett Blochberger Present for all items
4. Emtiyaz Chowdhury Present for all items
5. Carrie Gardner Present for all items
6. Tina Garvey Items 1 to 4.3.2
7. Professor Jonathan Ives Present for all items
8. Professor Dusko Ilic Present for all items
9. Stuart Mealing Items 1 to 4.3.2
10. Sara Payne Present for all items
11. Angharad Shambler Items 1 to 4.1.3
12. Professor Ed Wilson Present for all items

NICE staff (key players) present

Jacoline Bouvy, Programme Director Items 5 to 5.2.2

Lorna Dunning, Associate Director Present for all items

Celia Mayers, Project Manager Present for all items

Christian Griffiths, Health Technology Assessment Adviser Items 1 to 4.3.2

Caron Jones, Health Technology Assessment Adviser Items 1 to 4.3.2

Alan Moore, Health Technology Assessment Adviser Items 5 to 5.2.2

Cara Gibbons, Health Technology Assessment Analyst Present for all items

External assessment group representatives present

Fiona Beyer, Newcastle NIHR TAR Team, Newcastle University, Items 1 to 4.2.1

Cristina Fernandez, Newcastle NIHR TAR Team, Newcastle University, Items 1 to 4.2.1

Peter Auguste, Warwick Evidence Items 5 to 5.1.4

Emanuela Castelnuovo Warwick Evidence Items 5 to 5.1.4

Paul Tappenden, Decision Support Unit Items 5 to 5.1.4

Mon Mon Yee, Decision Support Unit Items 5 to 5.1.4

Clinical, Patient & NHS England experts present

Susan Walsh, Patient expert, nominated by Immunodeficiency UK, Items 1 to 4.1.3

Sophie Hodgson Smith, Patient expert, nominated by Immunodeficiency UK, Items 1 to 4.1.3

Siobhan Burns, Professor of Translational Immunology, clinical expert, nominated by Pharming Group N.V, Items 1 to 4.1.3

Austen Worth, Consultant in Paediatric Immunology, clinical expert, nominated by NHS England, Items 1 to 4.1.3

Ayesha Ali, Medical Advisor, Highly Specialised Services, NHS England, Items 1 to 4.1.3

Funmi Dasaolu, Patient expert, nominated by Anthony Nolan & Sickle Cell Society, Items 5 to 5.1.4

Harveen Ubhi, Head of Policy and Public Affairs at Anthony Nolan, patient expert, nominated by Anthony Nolan, Items 5 to 5.1.4

Ben Carpenter, Consultant Haematologist, clinical expert, nominated by Vertex, Items 5 to 5.1.4

Emma Drasar, Consultant Haematologist, clinical expert, nominated by Anthony Nolan & Sickle Cell Society, Items 5 to 5.1.4

Josh Wright, Consultant Haematologist, clinical expert, nominated by Anthony Nolan & Sickle Cell Society, Items 5 to 5.1.4

Dr Sanjeev Patel, Innovative Medicines Fund Clinical lead, NHS England, Items 5 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 Dr Shehla Mohammed.

### News and announcements

* 1. None

### Evaluation of leniolisib for activated phosphoinositide 3-kinase delta syndrome in people 12 years and over [ID6130] (ECM1)

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Pharming Group N.V.
     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-hst10059/documents).
     3. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Annett Blochberger, Professor Ed Wilson and Tina Garvey
  2. Part 2a – Closed session (members of the public, company representatives and experts 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-hst10059>

### Appraisal of exagamglogene autotemcel for treating sickle cell disease [ID4016] (ACM3)

* 1. Part 1 – Open session
     1. The chair Dr Paul Arundel welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Vertex.
     2. The chair noted apologies from Angharad Shambler and Tina Garvey.
     3. 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-ta11249/documents).
     4. The Chair led a discussion of the consultation comments presented to the committee.
  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-ta11249>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 7 November 2024 and will start promptly at 9am.