NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date and time:** Wednesday 8 June 2022

**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 Ron Akehurst Present for all items
4. Sotiris Antoniou Present for all items
5. Annett Blochberger Present for all items
6. Emtiyaz Chowdhury Present for all items
7. Sarah Davis Present for all items
8. Carrie Gardner Present for all items
9. Jeremy Manuel O.B.E Present for all items
10. Francis Pang Present for all items
11. Dr Mark Sheehan Present for all items
12. Professor Lesley Stewart Present for all items
13. Karen Whitehead M.B.E Present for all items
14. Tony Williams Present for all items

NICE staff present

Richard Diaz, Associate Director Present for all items

Daniel Davies, Project Manager Present for all items

Ella Livingstone, Technical Adviser Present for all items

Emily Eaton-Turner, Technical Analyst Present for all items

Lorna Dunning, Health Technology Appraisals Adviser Present for all items

Thomas Strong, Health Technology Assessment Adviser Present for all items

Stephen Norton, Health Technology Assessment Analyst Present for all items

Emma Douch, Health Technology Assessment Analyst Present for all items

Helen Barnett, Senior Medical Editor Present for all items

Mandy Tonkinson, Public Involvement Adviser, PiP Present for items 1 – 4.1.3

Lyn Davies, Coordinator, Corporate Office Present for items 1 – 4.1.3

Rosemary Harris, Appeal Panel Member, NICE (Observing) Present for all items

Emma Gordon, Administrator, TA Present for all items

Laura Kelly, Administrator, COT Present for all items

External assessment group representatives present

Matt Stevenson, SchARR-Tag Present for items 1 – 4.2.1

Sue Harnan, SchARR-Tag Present for items 1 – 4.2.1

Experts present

Ayesha Ali, Commissioning Expert, NHS England. Present for items 1 – 4.1.3

Dr Alex Broomfield, Consultant Paediatrician in Metabolic Medicine, St Mary’s Hospital Manchester. Present for items 1 – 4.1.3

Dr Karolina Stepien, Consultant in Adult Metabolic Medicine, nominated by Chiesi. Present for items 1 – 4.1.3

Onaissa Jamil, Patient Representative, nominated by MPS Society. Present for items 1 – 4.1.3

Sophie Thomas, Head of Advocacy and Patient Services, MPS Society. Present for items 1 – 4.1.3

## Minutes

### Introduction to the meeting

* 1. The chair welcomed members of the committee and other attendees present to the meeting.
  2. Prior to the meeting, apologies were received from Professor Philip Beales, Stuart Davies, Dr Shehla Mohammed & Karen Samuels.

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Wednesday 13 April 2022

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

* 1. Part 1 – Open session
     1. The chair welcomed the invited professional experts, external assessment group representatives, members of the public and company representatives from Chiesi Ltd.
     2. The chair asked all committee members, professional experts, external assessment group representatives and NICE staff present to declare any relevant interests in relation to the item being considered.
* Emtiyaz Chowdhury declared a direct non-financial interest as he is an employee of Parexel, who collaborate with Chiesi. It was agreed that this declaration would not prevent Emtiyaz Chowdhury from participating in this discussion.
* Sarah Davis declared an indirect non-financial interest, as she is a member of ScHARR-TAG, who are acting as the ERG on this topic. It had been agreed with the ScHARR-TAG director that Sarah would not be involved in their work on this topic and would not discuss the topic with ScHARR-TAG members prior to submission their report. It was agreed that this declaration would not prevent Sarah Davis from participating in this discussion.
* Jeremy Manuel declared an indirect non-financial interest as he is a co-founder and Director of the Gauchers Association which forms part of the LSD collaborative to which the MPS Society is also a member. The MPS Society support patients with alpha-mannosidosis. It was agreed that this declaration would not prevent Jeremy Manuel from participating in this discussion.
* Prior to the meeting, Professor Ed Wilson declared a direct financial interest due to his involvement in some of the background analyses and economic modelling that formed a key part of this submission. It was agreed that this declaration would prevent Professor Wilson from participating in this discussion.
* Dr Alex Broomfield declared a direct financial interest, as he has participated in a one-off consultancy for Chiesi Ltd in 2018. It was agreed that this declaration would not prevent Dr Broomfield from providing expert advice in this discussion.
* Sophie Thomas declared various direct non-financial interests, as she has been a patient advocate for MPS Society since 2002 and PPV member of RDAG 03/2021. Sophie Thomas also declared an indirect financial interest, as her organisation has received funding from Chiesi for its patient services, and a direct financial interest as had attended an advisory board organised by Chiesi in 2018. It was agreed that these declarations would not prevent Sophie Thomas from providing expert advice in this discussion.
  + 1. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by the chair, Dr Peter Jackson.
  1. Part 2a – Closed session (company representatives, clinical, patient & NHS experts, and members of the public were asked to leave the meeting).
     1. The committee discussed confidential information submitted for this item.
  2. Part 2b – Closed session (external assessment group representatives were asked to leave the meeting)
     1. The committee then agreed on the content of the Evaluation Consultation Document (ECD) or Final Evaluation Determination (FED). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the documents in line with their decisions and 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 Wednesday 6 July 2022 and will start promptly at 09:30am.