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:** Thursday 5 August 2021 9:00am – 18:33pm

**Location:** Zoom Video Conference

## Attendees

Committee members present –

1. Dr Peter Jackson (Chair) Present for all items
2. Dr Paul Arundel (Vice Chair) Present for all items
3. Ms Carrie Gardner Present for all items
4. Mr Francis Pang Present for all items
5. Mr James Avery – TA Member Present for items 1 to 5
6. Mr Jeremy Manuel, OBE Present for all items
7. Ms Karen Samuels (non-voting member) Present for all items
8. Ms Karen Whitehead Present for all items
9. Dr Matt Smith Present for all items
10. Mr Michael Chambers – TA Member Present for items 1 to 5
11. Dr Mudasar Mushtaq – TA Member Present for items 1 to 5
12. Mr Nigel Westwood – TA Member Present for items 1 to 5
13. Professor Philip Beales Present for items
14. Mr Richard Nicholas – TA Member Present for items 1 to 4.2.1
15. Ms Sarah Davis Present for all items
16. Mr Stuart Davies Present for all items

NICE staff present

Nicole Elliott, Associate Director Present for all items

Joanne Ekeledo, Project Manager Present for all items

Sophie McHugh, Administrator Present for all items

Emma Gordon, Administrator Present for all items

Hollie Kemp, Apprentice Administrator Present for items 1 to 5

Lucinda Evans, Coordinator – MIP Present for items 1 to 4.2

Sharlene Ting, Technical Analyst Present for items 1 to 5

Adam Brooke, Technical Advisor Present for items 1 to 5

Carl Prescott, Technical Advisor Present for items 5 to 6

Emma Douch, Technical Analyst Present for items 5 to 6

Heidi Livingstone, PIP Present for items 1 to 4.1.3 & 5 to

Catherine Pank, APM Present for items 5 to 6

Sarah Bromley, Senior Medical Editor Present for items 1 to 5

Pratit Shah, Administrator Present for items 5 to 6

Helen Barnett, Senior Medical Editor Present for items 5 to 6

Ella Livingstone, Technical adviser Present for items 5 to 6

Thomas Strong, HTA Adviser Present for items 5 to 6

External group representatives present

Alexis Llewellyn, Research Fellow, York Present for items 1 to 4.2

Pedro Saramago, Research Fellow, York Present for items 1 to 4.2

Dina Jankovic, Research Fellow, York Present for items 1 to 4.2

Praveen Thokala, Senior Research Fellow, ScHARR Present for items 5 to 5.3

Geoff Holmes, Research associate, ScHARR Present for items 5 to 5.3

Kate Ennis, Research Associate, ScHARR Present for items 5 to 5.3

Emma Hock, Senior Research Fellow, ScHARR Present for items 5 to 5.3

Experts present

Mr Daniel Jennings, Patient Expert, Epilepsy Action Present for items 1 to 4.2

Ms Rebecca Longley Patient Expert, Epilepsy Action Present for items 1 to 4.2

Professor Ley Sander, Clinical Expert, Arvelle Therapeutics Present for items 1 to 4.2

Dr Rhys Thomas, Clinical Expert, Arvelle Therapeutics Present for items 1 to 4.2

Ms Claire Brinkley, Patient Expert,

Children's Liver Disease Foundation Present for items 5 to 5.1.3

Professor Deirdre Kelly, Clinical Expert, Albireo AB Present for items 5 to 5.1.3

Ms Penny North-Lewis, Paediatric Liver Pharmacist,

Royal College of Paediatrics and Child Health Present for items 5 to

Ms Rachel Rhodes, Patient Expert,

Children's Liver Disease Foundation Present for items 5 to

Dr Ayesha Ali, NHSE Present for items 1 to 4.2 and 5 to 5.1.3

## Minutes

### Introduction to the meeting

* 1. The chair welcomed members of the committee and other attendees present to the meeting.

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Thursday 15 July 2021.

### Appraisal of ID1553 Cenobamate for focal onset seizures in epilepsy – STA using the technology appraisal methods and processes. Members from the TA committees join this meeting to supplement the HST membership with some additional roles.

* 1. Part 1 – Open session
     1. The chair welcomed the invited professional experts, external group representatives, members of the public and company representatives from Arvelle Therapeutics.
     2. The chair asked all committee members, professional experts, external group representatives and NICE staff present to declare any relevant interests in relation to the item being considered.

Professor Ley Sanders declared a Direct – non-financial interest as he is the Medical Director of the UK charity Epilepsy Society and the head of the Department of Clinical & Experimental Epilepsy at UCL Queen Square Institute of Neurology.

It was agreed that his declaration would not prevent Professor Ley Sanders from providing expert advice to the committee.

* Dr Reece Thomas declared a Direct – non-financial interest as he is a trustee of Epilepsy Research UK and Disability North, a council member of ILAE – British Chapter and an editorial board member of Seizure, Practical Neurology, Clinical Medicine.

It was agreed that his declaration would not prevent Dr Reece Thomas from providing expert advice to the committee.

* + 1. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Dr Richard Nicholas, Nigel Westwood and Stuart Davies.
  1. Part 2 – Closed session (company representatives, professional experts, external group representatives and members of the public were asked to leave the meeting)
     1. The committee then agreed on the content of the Appraisal Consultation Document (ACD). The committee decision was reached by consensus..
     2. The committee asked the NICE technical team to prepare the Appraisal Consultation Document (ACD) in line with their decisions.

### Evaluation of ID1570 Odevixibat for progressive familial intrahepatic cholestasis

* 1. Part 1 – Open session
     1. The chair welcomed the invited professional experts, external group representatives, members of the public and company representatives from Albireo AB.
     2. The chair asked all committee members, professional experts, external group representatives and NICE staff present to declare any relevant interests in relation to the item being considered.
* Sarah Davis declared a Non-Financial Professional & Personal Interests interest as she is a member of ScHARR-TAG which is acting as the ERG on the appraisal of Odevixibat for progressive familial intrahepatic cholestasis (ID1570). Sarah had no involvement in the preparation of the ERG report and have not discussed this topic with the ScHARR-TAG team preparing the ERG report.
* It was agreed that her declaration would not prevent Sarah Davis from participating in this section of the meeting.
* Professor Diedre Kelly declared a Direct – non-financial interest as she has authored or co-authored a document submitted as an evidence publication to the relevant NICE advisory committee.

It was agreed that her declaration would not prevent Professor Diedre Kelly from providing expert advice to the committee.

* + 1. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Professor Beales, Francis Pang and Karen Whitehead.
  1. Part 2a – Closed session (members of the public, company representatives and professional experts were asked to leave the meeting. The external group representatives remained).
     1. The committee discussed confidential information submitted for this item.
  2. Part 2b – Closed session (External group representatives were asked to leave the meeting).
     1. The committee then agreed on the content of the Evaluation Consultation Document (ECD). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Evaluation Consultation Document (ECD) in line with their decisions.

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Wednesday 15 September 2021 and will start promptly at 9:00am.