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 10 November 2021

**Location:** Via Zoom

## Attendees

Committee members present

1. Dr Paul Arundel (Topic 1 Chair) Present for all items
2. Dr Peter Jackson (Topic 2 Chair) Items 1 to 5.1.3
3. Professor Ron Akehurst Present for all items
4. Sotiris Antoniou Present for all items
5. Sarah Davis Present for all items
6. Jeremy Manuel Items 1 to 4.3.2 & 5.1.3 to 5.2.2
7. Francis Pang Items 1 to 5.1.3
8. Dr Mark Sheehan Present for all items
9. Matt Smith Present for all items
10. Professor Lesley Stewart Present for all items
11. Karen Whitehead Items 1 to 4.3.2

NICE staff present

Richard Diaz, Associate Director Present for all items

Daniel Davies, Project Manager Present for all items

Carl Prescott, Health Technology Assessment Adviser Items 1 to 4.3.2

Joanna Richardson, Health Technology Assessment Adviser Items 5 to 5.2.2

Emma Douch, Health Technology Assessment Analyst Items 1 to 4.3.2

Nigel Gumbleton, Health Technology Assessment Analyst Items 5 to 5.2.2

Helen Barnett, Senior Medical Editor Items 1 to 4.3.2

Hayley Garnett, Senior Medical Editor Items 5 to 5.2.2

Ella Livingstone, Technical Adviser, Commercial Risk Assessment Items 1 to 4.3.2

Thomas Strong, Technical Adviser, Commercial Risk Assessment Item 4.1.3

Emily Eaton-Turner, Technical Adviser, Commercial Risk Assessment Items 5 to 5.2.2

Steven Norton, Technical Analyst – Managed Access Items 5 to 5.2.2

Heidi Livingstone, Public Involvement Adviser, PIP Items 1 to 4.2.1 & 5 to 5.1.3

Lucinda Evans, Coordinator, Corporate Office Items 1 to 4.2.1 & 5 to 5.1.3

Gemma Smith, Coordinator, COT Present for all items

Emma Gordon, Administrator, TA Items 1 to 5.1.3

Louise Jones, Administrator, TA Items 5 to 5.2.2

External review group representatives present

Emma Hock, School of Health and Related Research (ScHARR) Items 1 to 4.2.1

Praveen Thokala, School of Health and Related Research (ScHARR) Items 1 to 4.2.1

Geoff Holmes, School of Health and Related Research (ScHARR) Items 1 to 4.1.3

Robert Wolff, Kleijnen Systematic Reviews Ltd Items 5 to 5.1.3

Hannah Penton, Kleijnen Systematic Reviews Ltd Items 5 to 5.1.3

Clinical & patient experts present

Ayesha Ali, Commissioning expert, NHS England, Items 1 to 4.2.1 & 5 to 5.1.3

Claire Brinkley, Patient expert nominated by Children’s Liver Disease Foundation,

Items 1 to 4.2.1

Professor Deirdre Kelly, Professor of Paediatric Hepatology, clinical expert nominated by Albireo AB, Items 1 to 4.2.1

Penny North - Lewis, Paediatric Liver Pharmacist, clinical expert nominated by Royal College of Paediatrics & Child Health, Items 1 to 4.2.1

Rachel Rhodes - Nealson, Patient expert nominated by Children’s Liver Disease Foundation, Items 1 to 4.2.1

Professor Richard Thompson, Professor of Molecular Hepatology & Honorary Consultant in Paediatric Hepatology, clinical expert nominated by Albireo AB, Items 1 to 4.2.1

Clare Barklam, Patient expert nominated by Childhood Tumour Trust, Items 5 to 5.1.3

Dr Karine Lascelles, Consultant Paediatric Neurologist, clinical expert nominated by British Paediatric Neurology Association (BPNA), Items 5 to 5.1.3

Vanessa Martin, Patient expert nominated by Childhood Tumour Trust, Items 5 to 5.1.3

Dr Grace Vassallo, Consultant Paediatric Neurologist, clinical expert nominated by AstraZeneca, Items 5 to 5.1.3

Observers present

Victoria Charlton, Department of Global Health and Social Medicine, Kings College London, Items 5 to 5.2.2

## 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 committee member apologies.

### News and announcements

* 1. None

### Minutes from the last meeting

* 1. The chair noted the minutes of the committee meeting held on Wednesday 6 October 2021. It was agreed these minutes would be confirmed at the next meeting scheduled for Thursday 9 December 2021.

### Evaluation of odevixibat for treating progressive familial intrahepatic cholestasis [ID1570]

* 1. Part 1 – Open session
     1. The chair welcomed the invited clinical and patient experts, external review group representatives, the NHS Commissioning representative, 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.
* Committee member Sarah Davies declared non-financial professional and personal Interests as she is a member of ScHARR-TAG which is acting as the ERG on this appraisal. Sarah confirmed she was not involved in the preparation of the ERG report.
* It was agreed that her declaration would not prevent Sarah from participating in this section of the meeting.
* Nominated patient experts Clare Brinkley and Rachel Rhodes - Nealson declared indirect interests as CLDF has received funding from Albireo Pharmaceuticals for 2021 in the amount of GBP 26,000. This support is an unrestricted grant to support the CLDF’s mission and pillars, including generating information for the patient community, providing support to families through different programs, advocacy work, and providing research grants to scientists working in liver disease.
* It was agreed that their declaration would not prevent them from providing expert advice to committee.
* Nominated clinical expert Professor Deirdre Kelly declared financial interests as she is an expert advisor at Albireo advisory board and 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 Kelly from providing expert advice to committee.
* Nominated clinical expert Professor Richard Thompson declared financial interests as he has received payments for speaking engagements and sitting on advisory boards, he is the author or co-author of documents (manuscripts, abstracts) submitted as an evidence publication to the relevant NICE advisory committee and is a member of the PEDFIC studies Global Steering Committee and Principal Investigator.
* It was agreed that his declaration would not prevent Professor Thompson from providing expert advice to committee.
  + 1. The Chair led a discussion of the consultation comments presented to the committee.
  1. Part 2a – Closed session (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 (company representatives, clinical & patient experts and external review group representatives were asked to leave the meeting)
     1. The committee then agreed on the content of the Evaluation Consultation Document (ECD) or the Final Evaluation Determination (FED). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Evaluation Consultation Document (ECD) or the Final Evaluation Determination (FED) 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-hst10043>

### Evaluation of selumetinib for treating symptomatic and inoperable plexiform neurofibromas associated with type 1 neurofibromatosis in children aged 3 years and over [ID1590]

* 1. Part 1 – Open session
     1. The chair Dr Peter Jackson welcomed the invited clinical and patient experts, external review group representatives, the NHS Commissioning representative, members of the public and company representatives from AstraZeneca.
     2. The chair asked all committee members, clinical and patient experts, external review group representatives, the NHS Commissioning representative and NICE staff present to declare any relevant interests in relation to the item being considered.
* Committee member Sotiris Antoniou declared financial interests as he has attended talks on unrelated topic sponsored by AstraZeneca.
* It was agreed that his declaration would not prevent Sotiris from participating in this section of the meeting.
* Nominated patient expert Clare Barklam declared financial interests as she has attended a patient charter workshop/working group hosted by AstraZeneca who have also provided an educational grant to CTT for education.
* It was agreed that her declaration would not prevent Clare from providing expert advice to committee.
* Nominated patient expert Vanessa Martin declared financial interests as she is chair of the Childhood Tumour Trust and has received an educational grant recently from Astra Zeneca and has attended a patient advocacy group advisory board with them too.
* It was agreed these declarations would not prevent Vanessa from providing expert advice to committee.
* Nominated Clinical expert Dr Karine Lascelles declared financial interests as she has attended an advisory board and has contributed to 2 workshops for AstraZeneca in 2021.
* It was agreed these declarations would not prevent Dr Lascelles from providing expert advice to committee.
* Nominated clinical expert Dr Grace Vassallo declared financial interests as she has recently been paid for contributions to masterclasses for AstraZeneca.
* It was agreed these declarations would not prevent Dr Vassallo from providing expert advice to committee.
  + 1. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by the Lead team - Matt Smith, Sarah Davis and Dr Mark Sheehan.
  1. Part 2 – Closed session (company representatives, clinical and patient experts, external review group representatives and members of the public were asked to leave the meeting).
     1. The committee then agreed on the content of the Evaluation Consultation Document (ECD) or the Final Evaluation Determination (FED). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Evaluation Consultation Document (ECD) or the Final Evaluation Determination (FED) 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-hst10045>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 9 December and will start promptly at 09.30.