

## Epilepsies in children, young people and adults

### Committee meeting 04

**Date:** 22 October 2019

**Location:** Boardroom, NGC Offices, Royal College of Physicians, 11 St. Andrews Place, Regent's Park, London, NW1 4LE

**Minutes:** Final

<b>Committee members present:</b>		
Stephen Ward (Chair)		Present for notes 1 – 9
Anna Miserocchi		Present for note 6
Arjune Sen (Topic adviser)		Present for notes 1 – 9
Christina Petropoulos		Present for notes 1 – 9
Gabriella Rands		Present for notes 1 – 9
Gareth Payne (cooptee)		Present for notes 1 – 9
Janine Winterbottom		Present for notes 1 – 9
Jon Mark Dickson		Present for notes 1 – 9
Lisa O'Brien		Present for notes 1 – 9
Phillip Smith		Present for notes 1 – 9
Rohit Shankar		Present for notes 1 – 9
Aswin Chari		Joined meeting for item 6
Trudy Thomas		Present for notes 1 – 9
<b>In attendance:</b>		
Angela Cooper	Senior research fellow	Present for notes 1 – 9
Gill Ritchie	Guideline lead	Present for notes 1 – 9
Margaret Constanti	Senior health economist	Present for notes 1 – 9
Joseph Runicles	Information Specialist	Present for notes 6 – 9
Rafina Yarde	Research fellow	Present for notes 1 – 9
Tamara Diaz	Project manager	Present for notes 1 – 9

<b>Apologies:</b>
Ashley Liew
Lauren Anderson
Sally Gomersall
Sallie Baxendale
Archana Desurkar

<b>1. Welcome and objectives for the meeting</b>
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The Chair welcomed attendees to the fourth meeting of the Epilepsies in children, young people and adults Guideline Committee.

The Chair informed the Committee that there had been apologies from Sally Gomersall, Lauren Anderson, Sallie Baxendale, Archana Desurkar and Ashley Liew. Additionally, Aswin Chari would be joining the meeting by Skype. Anna Miserocchi would join mid meeting for protocol and review discussions. These are noted in the attendees list.

The Chair outlined the objectives of the meeting, which included:

Review of Linking evidence to recommendations documents for new technologies and vagus nerve stimulation

- Presenting and discussing clinical and health economic evidence on **reducing the risk of seizure-related mortality, including Sudden Unexpected Death in Epilepsy (SUDEP), in people with epilepsy.**
- Presenting, discussing and editing draft review protocols.

## 2. Declarations of interest: committee declarations

The Chair confirmed the matters under discussion, for the purpose of managing conflicts of interest, and asked attending Committee members to verbally declare any interests that may have arisen since the last meeting.

Previously declared conflicts by Dr. Rohit Shankar required that he step out of the room during discussions on SUDEP evidence review.

All interests declared during the meeting are noted below:

Name	Job title, organisation	Declarations of Interest, when declared (Meeting/Recruitment)	Type of interest	Decision taken
Arjune Sen	Topic Advisor	Contributed to publishing the following <a href="https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies">https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies</a>	Specific Direct Non-financial	Declare and participate
Rohit Shankar	Learning disabilities psychiatrist	15.10.2019 Talk to Neurologists in Southwest on results of NIHR Ep-ID register for Lacosamide real world effect on people with ID and epilepsy – program sponsored by UCB. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust.	Specific Indirect Financial	Declare and participate

		10.10.2019 Southwest Paediatric conference – Invited to give a talk on SUDEP and children – conference sponsored by various drug companies. No payment as invite was from the South West Interest in Paediatric Epilepsy group	Specific Direct non - financial	Declare and participate
		02.10.2019 Invited keynote ILAE British Chapter – SUDEP communication – No payment	Specific Direct Non-financial	Declare and participate
Janine Winterbottom	Epilepsy Specialist Nurse	10.09.2019 Attendance at UCB Pharma sponsored teaching session inviting Dr Marcus Reuber Consultant Neurologist from Sheffield to present patient audit on Eslicarbazepine	Specific Direct Non-financial	Declare and participate
Philip Smith	Adult Neurologist	Editorial on Status epilepticus has been published in the New England Journal of Medicine.	Specific Direct Non-Financial	Declare and participate
Anna Misserochi	Neurological Surgeon	Awarded grant from Medtronic. This medical manufacturer provides lasers for surgeries. The surgery this equipment is used for is not currently offered in the UK.	Non-specific Direct Financial	Declare and participate

The Chair and a senior member of the Developer’s team noted that the above interests, declared during the meeting, did not prevent attendees from fully participating in the day’s meeting.

**3. Minutes of the previous meeting**

The GC approved the minutes of Guideline Committee meeting 3.

**4. Draft discussion documents**

The group was referred to the circulated documents summarising their discussions on the following areas and agreed that the content was an accurate reflection of meeting discussions:

- Vagus Nerve Stimulation
- New Technologies

**5. Draft Review: Reducing the risk of seizure related mortality including SUDEP**

Rafina Yarde presented the evidence review for the clinical question on, Reducing the risk of seizure related mortality including SUDEP. There was no economic

evidence for this question. The committee considered and discussed the evidence.

## **6. Draft review protocols**

Angela Cooper led the group's discussions on the following draft protocols and the committee discussed and amended each item:

3.7a prolonged seizures: monotherapy

3.7b prolonged seizures: adjunct

Aswin Chari, Anna Miserocchi and Joseph Runicles joined the meeting for discussions on the draft review protocols for the following areas:

- 6.5 Referral for surgery
- 5.1 Effectiveness of surgical intervention

## **7. Health economics: surgery modelling**

Margaret Constanti delivered a presentation and led discussions on the economic priorities for the guideline. Further discussions focussed on surgery modelling.

## **8. Draft review protocols: Information and Transition**

Angela Cooper presented draft protocols for the clinical areas listed below, the committee discussed and amended each protocol:

- 2.2 Information and support
- 10.1 Transition from children to adult services.

## **9. Any other business**

There being no further business the meeting ended at 1600.

Date of next meeting: 10 December 2019

Location of next meeting: NGC Board room, Royal College of Physicians