

Epilepsies in children, young people and adults

Committee meeting 06

Date: 28 January 2020

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

Minutes: Final

| Committee members | s present: | | | |
|------------------------------|--|---------------------------|--|--|
| Stephen Ward (Chair) | Present for notes 1 – 12 | | | |
| Arjune Sen (Topic ad | viser) | Present for notes 1 – 12 | | |
| Christina Petropoulos | | Present for notes 1 – 12 | | |
| Janine Winterbottom | | Present for notes 1 – 12 | | |
| Jon Mark Dickson | | Present for notes 1 – 12 | | |
| Lisa O'Brien | | Present for notes 1 – 12 | | |
| Phillip Smith | | Present for notes 1 – 12 | | |
| Rohit Shankar | Present for notes 1 – 12 | | | |
| Lauren Anderson | Present for notes 1 – 12 | | | |
| Sally Gomersall | Present for notes 1 – 12 | | | |
| Sallie Baxendale | | Present for notes 1 – 12 | | |
| Archana Desurkar | | Present for notes 1 – 12 | | |
| Susan Croft (co-opted | l committee member) | Present for notes 1 – 12 | | |
| Trudy Thomas | | Present for notes 1 – 12 | | |
| In attendance: | | | | |
| Angela Cooper | Senior research fellow | Present for notes 1 – 12 | | |
| Gill Ritchie | Guideline lead | Present for notes 1 – 12 | | |
| Margaret Constanti | Senior health economist | Present for notes 1 – 12 | | |
| Joseph Runicles | Information Specialist | Present for notes 11 – 12 | | |
| Rafina Yarde | Research fellow | Present for notes 1 – 12 | | |
| Tamara Diaz | Project manager | Present for notes 1 – 12 | | |
| Caroline Keir | NICE Guideline Commissioning Manager (attended via Skype) | Present for notes 1 – 12 | | |
| Catharine Baden- Daintree | NICE Editor | Present for notes 1 – 12 | | |
| Apologies: | | | | |
| Ashifa Trivedi (co-opt | ed committee member) | | | |
| Ashley Liew (co-opted | d committee member) | | | |
| Gabriella Rands | | | | |

1. Welcome and objectives for the meeting

The Chair welcomed attendees to the sixth meeting of the Epilepsies in children, young people and adults Guideline Committee.

The Chair informed the Committee that there had been apologies from Ashley Liew and Ashifa Trivedi. These are noted on the attendees list.

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

- Review of evidence discussion documents for:
 - Reducing the risk of seizure-related mortality, including Sudden Unexpected Death in Epilepsy (SUDEP), in people with epilepsy
- Presenting and discussing clinical and health economic evidence on
 - Status Epilepticus monotherapy
 - Status Epilepticus add on therapies
 - Repetitive or cluster seizures monotherapy
 - o Repetitive or cluster seizures add on therapies
 - Prolonged seizures monotherapy
- 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 conflict by Philip Smith repeated as Status Epilepticus will be

discussed on the day's agenda. No further action required.

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 | Speaker honoraria for meeting hosted by Bial Pharma. Delivered talk on topic of epilepsy and ageing. | In-Direct Financial | Declare and participate. |
| | | Speaker honoraria for meeting hosted by UCB Pharma. Delivered talk on epilepsy and dementia | In- Direct Financial | Declare and participate. |
| Rohit Shankar | Learning disabilities psychiatrist | Chief Investigator Neuronostics (NIHR Adopted) funded by Innovate grant. December 2019 ongoing | In-Direct Financial | Declare and participate. |
| | | UCB IIS grant for Ep-ID national register (NIHR adopted) –Chief investigator | In-Direct Financial | Declare and participate. |



| | | January 2020 Ongoing | | |
|-------------|--------------|---------------------------------|-------------|--------------|
| | | RSM invited talk SUDEP & ID | Direct non- | Declare |
| | | – no honorarium 11.11.2019 | Financial | and |
| | | | | participate. |
| | | UCB talks on Lacosamide and | In-Direct | Declare |
| | | ID from Ep-ID Register | Financial | and |
| | | findings – all honorarium paid | | participate. |
| | | to NHS Trust | | |
| | | 19.11.2019 | | |
| | | 09.12.2019 | | |
| | | Bristol Medical cannabis | Direct non- | Declare |
| | | conference talk on epilepsy | Financial | and |
| | | and cannabis – no honorarium | | participate. |
| | | 28.11.2019 | | |
| | | RCPsych workshop in Belfast | Direct non- | Declare |
| | | - no honorarium 6.12.2019 | Financial | and |
| | | | | participate. |
| | | Advisory committee member | Direct | Declare |
| | | ational Confidential Enquiry | Financial | and |
| | | into Patient Outcome and | | participate. |
| | | Death (NCEPOD) 08.01.2020 | | |
| | | ongoing | | |
| | | NIHR grant (co-applicant) | In-Direct | Partial |
| | | SUDEP seizure safety | Financial | exclusion |
| | | communication 04.12.2019 | | for the |
| | | ongoing | | SUDEP |
| | | | | risk factors |
| | | | | question |
| | | | | tbc |
| Philip | Adult | Editorial on Status epilepticus | Direct Non- | Declare |
| Smith | Neurologist | has been published in the New | Financial | and |
| | | England Journal of Medicine. | | participate |
| Christina | Neurological | Co-Author – "Practical aspects | Direct | Declare |
| Petropoulos | Surgeon | of childhood epilepsy | non- | and |
| | | BMJ 2019; 367 doi: https://doi. | Financial | participate |
| | | org/10.1136/bmj.l6096 (Publis | | |
| | | hed 11 November 2019) – My | | |
| | | original contribution was | | |
| | | before joining the committee | | |
| | | Talk given to group of GPs | Direct | Declare |
| | | "Paediatric Epilepsy What GPs | non- | and |
| | | need to know" – unpaid | Financial | 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 4.

4. Draft discussion documents

The group's discussion of evidence related to the following topic, had been summarised and circulated for their consideration:

• Interventions to reduce seizure related mortality including SUDEP This item was agreed as an accurate reflection of meeting discussions.

5. NICE Editor's Presentation: drafting recommendations

A presentation on drafting recommendations was given for the committee's information.

6. Draft Review: Status epilepticus monotherapy

The evidence was presented for the following clinical question: What antiepileptic drugs (monotherapy) are effective in the treatment of status epilepticus? The committee considered and discussed the evidence.

7. Draft Review: Status epilepticus add on

The evidence was presented r for the following clinical question: What antiepileptic drugs (add-on therapy) are effective in the treatment of status epilepticus? The committee considered and discussed the evidence.

8. Draft Review: Repetitive or cluster seizures monotherapy

The evidence was presented for the following clinical question: What AEDs (monotherapy) are effective in the treatment of repeated seizures or clusters of seizures? The committee considered and discussed the evidence.

9. Draft Review: Repetitive or cluster seizures monotherapy

The evidence was presented for the following clinical question: What AEDs (add-on therapy) are effective in the treatment of repeated seizures or clusters of seizures? The committee considered and discussed the evidence.

10. Draft Review: Prolonged seizures

The evidence was presented for the following clinical question: What AEDs (monotherapy) are effective in the treatment of prolonged seizures? . The committee considered and discussed the review question.

11. Draft review protocols

The committee discussed and amended the draft review protocol on:

When should monitoring be carried out for people with epilepsy? How should monitoring be carried out for people with epilepsy, and who should do it?

12. Any other business

There being no further business the meeting ended at 1600.

| Date of next meeting: | *24 March 2020 |
|---------------------------|---|
| | 25 March 2020 |
| | |
| | *(At a later date, post meeting, the committee were advised of the subsequent cancellation of the meeting scheduled for 24 March) |
| Location of next meeting: | NGC Board room, Royal College of Physicians |