

Epilepsies in children, young people and adults

Committee meeting 02

Date: 09/07/2019

Location: The Long Room, Royal College of Physicians, 11 St. Andrews Place, Regent's Park, London, NW1 4LE

Minutes: Final

Committee members present:	
Stephen Ward (SW) (Chair)	(Present for notes 1 – 9)
Arjune Sen (AS) (Topic adviser)	(Present for notes 1 – 9)
Christina Petropoulos (CP)	(Present for notes 1 – 9)
Gabriella Rands (GR)	(Present for notes 1 – 9)
Lisa O'Brien (LOB)	(Present for notes 1 – 9)
Janine Winterbottom (JW)	(Present for notes 1 – 9)
Jon Mark Dickson (JD)	(Present for notes 1 – 9)
Sally Gomersall (SG)	(Present for notes 1 – 9)
Trudy Thomas (TT)	(Present for notes 1 – 9)
Phillip Smith (PS)	(Present for notes 1 – 9)

In attendance:		
Angela Cooper	Senior Research Fellow	(Present for notes 1 – 9)
Caroline Keir	Guideline Commissioning Manager, NICE	(Present for notes 1 – 9)
Gill Ritchie	Guideline Lead	(Present for notes 1 – 9)
Jacqui Real	Senior Research Fellow	(Present for notes 1 – 9)
Joseph Runicles	Information Specialist	(Present for notes 1 – 4 & 6 – 9)
Margaret Constanti	Senior Health Economist	(Present for notes 1 – 9)
Rafina Yarde	Research Fellow	(Present for notes 1 – 9)
Tamara Diaz	Project Manager	(Present for notes 1 – 9)

Apologies:	
Archana Desurkar	Paediatric Neurologist
Rohit Shankar	Learning Disabilities psychologists
Lauren Anderson	Lay member

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the second meeting on Epilepsies in children, young people and adults.

The Chair informed the Committee that apologies had been received. These are noted above.

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

- Leading introductions for the benefit of newly joining members of the committee.
- Delivering a presentation on minimum important differences and seeking committee feedback in this regard.
- Presenting, discussing and editing draft review protocols for the areas of the guideline to be commissioned to Cochrane and protocols that will be reviewed by the NGC Epilepsies technical team.
- Discussing the economic priorities for the guideline.

2. Introductions

Committee members introduced themselves.

3. Declarations of interest presentation and meeting declarations

The Chair confirmed that, for the purpose of managing conflicts of interest, the matters under discussion were:

- Ketogenic diet
- Psychological therapies
- AEDs in the treatment of status epilepticus

The Chair asked attending Committee members to verbally declare any interests that may have arisen since the last meeting, and that in addition new members joining the committee inform the committee of their declarations made at recruitment. All interests declared at recruitment and during the meeting are noted below for those present:

Name	Job title, organisation	Declarations of Interest, when declared (Meeting/Recruitment)	Type of interest	Decision taken
Lisa Obrien	Nurse (Paediatric)	Fee received for providing a presentation at a Complex Epilepsy Study Day at Young Epilepsy ran by Nutricia about "Supporting Families with Safety Issues". Nutrica produces ketogenic diet products.	Direct Financial	Declare and participate for discussion of protocol. Partial exclusion will be required when considering recommendations on this topic.
		Travel and accommodation costs to attend a conference in Belgium ran by LivaNova about VNS therapy.	Direct Financial	Declare and participate
		Employee of Young Epilepsy as Head of Health and Epilepsy Nurse Specialist. No involvement with research activity or advocacy work on behalf of the charity.	Direct Non-financial	Declare and participate
		Support by different drug representatives to sponsor an Epilepsy Nurse Specialist group I attend on a monthly basis.	Indirect Financial	Declare and participate
Janine Winterbottom	Nurse (Adult)	Update on earlier declaration. NIHR grant application on pre-conception	Indirect Financial	Non-specific. Declare and participate.

		counselling for women with epilepsy moved to stage 2 in the application process.		
Phil Smith	Neurologist (Adult)	Research grant and author of SANAD II.	Direct non-financial	SANAD is not being considered by this committee. Partial exclusion may be required during joint committee discussions on pharmacological treatments.
		President of Joint Neurosciences Council.	Direct non-financial	Not specific to epilepsy. Declare and participate
		Chair Epilepsy Action Advisory Council for Wales.	Direct non-financial	Has stood down early from this role. Declare and participate
		MHRA Expert Panel on Sodium Valproate	Direct non-financial	Declare and participate
		Co-editor of Practical Neurology	Direct non-financial	Declare and participate
Jon Mark Dickson	General Practitioner	Update of last declaration: Chief Investigator of the ESPENTE project. Grant paid to the University of Sheffield (commissioned by Epilepsy Action) to undertake a mapping review of the evidence-base for epilepsy specialist nurses.	Indirect financial	The specialist epilepsy nurse review is not being considered by this committee – Declare and participate
Arjune Sen	Topic Advisor	Member of the Medical Advisory	Direct non-financial	Declare and participate

		Board for Ring Chromosome 20 foundation UK		
		Grant monies awarded by UCB for trial investigating EEG (SEIZE IT) To start in 2020	Indirect financial	Declare and participate
		Grant monies awarded by UCB for study on outcomes registry in people with Epilepsy treated With VNS (CORE-VNS)	Indirect financial	Declare and participate

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

4. Minutes of the previous meeting

The GC approved the minutes of Guideline Committee meeting 1.

5. Minimum Important differences

Jacqui Real delivered a methodological presentation on the measurement of minimum important differences that will be used when considering outcomes reported in evidence reviews across clinical areas addressed within the guideline. The committee had an opportunity to discuss and agree on appropriate MID's for a range of clinical outcomes. The Chair co-led discussions and presented a diagram to support the presentation.

6. Draft Review Protocols: Cochrane commissions

Angela Cooper presented draft protocols for reviews on the following topics. The committee discussed and amended the protocols, with the assistance of the Cochrane epilepsy reviewing teams who had joined the meeting remotely:

- Protocol 5.2. Effectiveness of ketogenic diet: Update of Cochrane review - effectiveness of a ketogenic diet in drug resistant epilepsy
- Protocol 7.2. Effectiveness of psychological interventions: Update of Cochrane review - psychological treatments for people with epilepsy

7. Health economic priorities

Margaret Constanti delivered a presentation on cost effectiveness and decision analytic modelling. The committee was then led through a discussion on the health

economic modelling prioritisation and the economic plan. Committee members considered the suggested priorities for this guideline.

8. Draft Review Protocols: reviews

Angela Cooper and Jacqui Real presented draft protocols for upcoming reviews on the clinical area listed below, the committee discussed and amended the protocol:

- Protocol 3.8 a&b: Effectiveness of AEDs in the treatment of status epilepticus

These reviews will be completed by the NGC technical team. The Chair asked for volunteers to support the draft work on this area.

9. Any other business

There being no further business the meeting ended at 1600.

Date of next meeting: 03 September 2019

Location of next meeting: Royal College of Physicians