

Epilepsies in children, young people and adults

Committee meeting 01

Date: 22/05/2019

Location: NGC Boardroom, 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 – 6)
Arjune Sen (AS) (Topic adviser)		(Present for notes 1 – 6)
Christina Petropoulos (CP)		(Present for notes 1 – 4)
Gabriella Rands (GR)		(Present for notes 1 – 6)
Janine Winterbottom (JW)		(Present for notes 1 – 6)
Jon Mark Dickson (JD)		(Present for notes 1 – 6)
Lauren Anderson (LA)		(Present for notes 1 – 6)
Rohit Shankar (RS)		(Present for notes 1 – 6)
Sally Gomersall (SG)		(Present for notes 1 – 6)
Trudy Thomas (TT)		(Present for notes 1 – 6)
Colin Reilly (CR) – Cooptee		(Present for notes 1 – 6)
Ashley Liew (AL) – Cooptee		(Present for notes 1 – 6)

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

Apologies:

Philip Smith (PS)

Committee member

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the first 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: introducing the National Guideline Centre technical team to the committee, inducting committee members to the guideline development process and discussing the draft protocols for two clinical areas.

2. Introductions

Committee members introduced themselves.

3. Declarations of interest presentation and meeting declarations

The Chair introduced Gill Ritchie, Guideline Lead who gave a presentation on the NICE DOI policy. Meeting attendees were given the opportunity to ask questions about the presentation.

The Chair then circulated the register of declared interests and asked attending Committee members to verbally declare any further interests that may have arisen since recruitment and following the presentation of the policy. 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
Anderson: Lauren	Lay member	Declaration made at recruitment: Informal voluntary support group for parents and carers of children and young people with epilepsy.	Direct non-financial	Declare and participate
Dickson: Jon M.	General Practitioner	Meeting declaration: Chair for the revision of the national paramedic handbook. Guideline on emergency management of seizures published in	Direct Non-financial	Declare and participate

		early May.		
		Declaration made at recruitment: (Chief Investigator) for research into emergency admissions to hospital. 2012-2018. Educational Grant paid by UCB to the University of Sheffield. UCB had no control over the conduct of the study	Indirect financial	Declare and participate
		Declaration made at recruitment: Member of the ILAE	Direct non-financial	Declare and participate
		Declaration made at recruitment: Member of the ILAE GP Society	Direct non-financial	Declare and participate
		Declaration made at recruitment: I am a 'Clinical Advisor' to the RCGP which involves being given the opportunity to comment on issues that may be relevant to general practice. I have not been involved in any substantial pieces of advisory work in this capacity.	Direct non-financial	Declare and participate
		Declaration made at recruitment: Epilepsy Action, member of medical advisory board.	Direct non-financial	Declare and participate
		Declaration made at recruitment: 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-tbc
		Declaration made at recruitment: I am a GP at a research active GP practice where I am directly involved in clinical research e.g. RCTs, post-	Direct Non-financial	Research activities do not include areas considered by this guideline. Declare and participate

		<p>authorisational safety studies. These studies have a mix of academic and commercial sponsors, commercial sponsors include: GSK and Novonordisk.</p>		TBC.
		<p>I am a GP at a research active GP practice where I am directly involved in clinical research e.g. RCTs, post-authorisational safety studies. These studies have a mix of academic and commercial sponsors, commercial sponsors include: GSK and Novonordisk.</p>	Direct Non-financial	
Liew: Ashley	Consultant Paediatric Neuropsychiatrist (Cooptee)	<p>Declaration made at recruitment: Executive Secretary for the Child & Adolescent Intellectual Disability Psychiatry Network whose members see patients with epilepsy relatively frequently</p>	Direct Non-Financial	Declare and participate
		<p>Declaration made at recruitment: Neuropsychiatry representative on the Council for the British Paediatric Neurology Association which represents Paediatric Neurologists who see patients with epilepsy frequently.</p>	Direct Non-financial	Declare and participate
		<p>I have received speaking and travel honoraria from Flynn Pharma and Shire, in relation to psychiatric medication not directly used in the treatment of epilepsy</p>	Direct Financial	TBC?
Rand: Gabiella	Paediatric clinical psychologist	<p>Meeting declaration: Ongoing ketogenic diet study within the department where I work. I have no involvement with the study.</p>	Indirect Financial	Declare and participate

Sen: Arjune	Topic Advisor	Declaration made at recruitment: Grant monies awarded by UCB Pharma for immune modulation study,	Indirect Financial	Declare and participate
		Declaration made at recruitment: Grant monies awarded by Eisai Europe for project investigating anti-epileptic medication post VNS insertion/ surgery (project complete)	Indirect Financial	Declare and participate
		Declaration made at recruitment: Grant monies awarded by Bial for project investigating anti-epileptic medication in older people with epilepsy	Indirect Financial	Declare and participate
		Declaration made at recruitment: UCB Pharma speaker honoraria 5.10.17, 20.4.18, 6.11.18 17.11.18. LivaNova costs to attend invited meeting (accommodation, travel) 29.6.18 GW Advisory Board 20.2.18 Eisai speaker Honoria 9.11.18 16.11.18.	Indirect Financial	All honoraria paid to university and trust. Declare and participate
Reilly: Colin	Paediatric educational psychologist (co-optee)	Declaration made at recruitment: International League Against Epilepsy – Co - Chairperson Paediatric Psychiatric Issues	Direct Financial	Declare and participate
		Declaration made at Recruitment: Epilepsy12 Audit Methodology and Dataset Group - Educational Psychologist member	Direct Non-financial	Declare and participate
Shankar: Rohit	Learning Disabilities Psychiatrist	Meeting declaration: Academic secretary for the intellectual disability faculty of the Royal College of Psychiatrists.	Direct Non-financial	Declare and participate
		Meeting declaration: Attending advisor for the NHS England pathway.	Direct Non-Financial	Declare and participate
		Declaration made at recruitment: A Register	Indirect financial	Declare and participate

		<p>for New Anti-Epileptic Drugs In ID/PDD populations 10 years ethics approval Adopted by UK NIHR</p> <p>This is a national Research Register held by Cornwall Partnership NHS Foundation Trust and has a national steering committee. It has 20 National sites registered to recruit molecules.</p> <p>Pharmaceutical companies pay the NHS Trust research support costs to collect real world data of side effects and efficacy of their molecule in people with ID and epilepsy. Sponsorship for researcher assistance has been received from Eisai, UCB, Bial</p>		
		<p>Declaration made at recruitment: Funding for researcher support for projects on behalf of the NHS Trust and Exeter Medical School has been received from LivaNova, Veriton Pharma, Eisai and Desitin</p>	Indirect financial	Declare and participate
		<p>Declaration made at recruitment:</p> <p>Honorarium received for time for preparation of talk for providing training and talks in various Industry supported conferences on the subjects of epilepsy management in people with Intellectual Disability and SUDEP in CPD approved peer group conferences.</p> <p>1. Eisai- European advisory board - the effectiveness and safety of adjunctive perampanel in the routine clinical care of patients with myoclonic seizures</p>	Direct financial	Partial exclusion for pharmacological questions-tbc Any future honorariums will be paid to Trust research fund.

		<p>in Idiopathic Generalised Epilepsy</p> <p>2. Eisai - European Epilepsy Conference symposium – talk on risk management of people with ID and epilepsy</p> <p>3. Desitin – Training on communication skills</p> <p>4. UCB – talk on SUDEP in Cardiff LD meeting</p> <p>UCB – Focus on Epilepsy conference – talk on challenges of management of epilepsy and ID</p>		
		<p>Declaration made at recruitment: I am stakeholder and developer of the 'SUDEP and Seizure Safety Checklist' and the mobile app based on the checklist - EpSMon. The SUDEP Checklist is a joint property of Cornwall Partnership NHS Foundation Trust and SUDEP Action Charity. An expert committee organised by SUDEP Action oversees the Checklist and its update. EpSMon is an e-App developed by Plymouth University with licence from SUDEP Action and Cornwall Partnership NHS Foundation Trust of the Checklist. It is part of the National Innovation Accelerator (NIA) Program. The App is available freely to all PWE in the UK. I have no commercial or financial interests in the product. I am the medical lead for it. The app is free and is administered by the charity SUDEP Action. 2016 - Present</p>	Direct non-financial	Partial exclusion for the new technologies question. tbc
Thomas: Trudy	Adult Pharmacist	Declaration made at recruitment: Working toward Consultant	Indirect financial	Declare and participate

		pharmacy in epilepsy qualification. Partnering with training organisation to review community pharmacy training materials.		
		Declaration made at recruitment: UCB Pharma Health Network Lead for neurology providing local data information to support business plan for consultant pharmacist in epilepsy. In exchange advice is being given on UCB's training materials for community pharmacists.	Direct non-financial	Declare and participate
Winterbottom: Janine	Epilepsy Nurse Specialist	Presented a talk about my epilepsy nurse service the south of England epilepsy nurses, this was sponsored by UCB The payment was made into The Walton Centre Trust's charitable neuroscience fund for future nurse training therefore I received no payment to me personally. 2019	Direct Financial	Declare and participate
		Research grant application. NIHR RfPB application of research proposal concerning preconception care of women with epilepsy.	Indirect financial	Declare and participate
		Speaker fee from UCB pharma paid to the Walton Centre neuroscience fund for epilepsy nurse training.	In-direct financial	Declare and participate
		Declaration made at recruitment: Lead author of Cochrane review 2008; protocol update awaiting editorial approval. Review of qualitative and quantitative evidence of effectiveness of pre-conception counselling for women with epilepsy	Direct nonfinancial	Declare and participate

All committee members noted on the register as not having any declarations and

who have also not declared any additional interests during the day's meeting are not listed above.

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. Presentations

The Chair introduced Caroline Keir and Erin Whittingham, from the NICE team. They delivered presentations on the role of the Guideline commissioning Manager and working with NICE patient involvement.

The Chair invited the NGC technical team members to deliver the following presentations:

- a. Joseph Runicles, the role of the information specialist
- b. Jacqui Real, the role of the research fellow
- c. Margaret Constanti, an introduction to health economics

The committee were given an opportunity to ask the technical team questions about the guideline development process.

The Chair invited the topic advisor, Arjune Sen to deliver a presentation on the Scope and review questions to be addressed for the guideline. The committee was given an opportunity to raise questions on this item.

The Chair invited Angela Cooper to deliver a presentation on the Types of reviews and evidence.

5. Draft Review Protocols

Angela Cooper and Jacqui Real lead the committee's discussions on the following review protocols:

- a. Technologies (New Technologies and SUDEP)
- b. Vagus Nerve Stimulation

The committee contributed to discussions and volunteered to support the technical team on further draft work on these areas.

6. Any other business

There being no further business the meeting ended at 4:00 a.m.

Date of next meeting: 09 July 2019

Location of next meeting: Royal College of Physicians