

Epilepsies in children, young people and adults

Committee meeting 06

Date: 01 July 2020

Location: Virtual Meeting: MS Teams Platform

Minutes: Final

Committee members present:		
Stephen Ward (Chair)		Present for notes 1 – 5
Arjune Sen (Topic adviser)		Present for notes 1 – 5
Christina Petropoulos		Present for notes 1 – 5
Janine Winterbottom		Present for notes 1 – 5
Jon Mark Dickson		Present for notes 1 – 5
Lisa O'Brien		Present for notes 1 – 5
Phillip Smith		Present for notes 1 – 5
Rohit Shankar		Present for notes 1 – 5
Sally Gomersall		Present for notes 1 – 5
Sallie Baxendale		Present for notes 1 – 5
Archana Desurkar		Present for notes 1 – 5
Gabriella Rands		Present for notes 1 – 5
Trudy Thomas		Present for notes 1 – 5
In attendance:		
Angela Cooper	Senior research fellow	Present for notes 1 – 5
Gill Ritchie	Guideline lead	Present for notes 1 – 5
Margaret Constanti	Senior health economist	Present for notes 1 – 5
Joseph Runicles	Information Specialist	Present for notes 1 – 5
Rafina Yarde	Research fellow	Present for notes 1 – 5
Tamara Diaz	Project manager	Present for notes 1 – 5
Caroline Keir	NICE Guideline Commissioning Manager (attended via Skype)	Present for notes 1 – 5
Catharine Baden-Daintree	NICE Editor	Present for notes 1 – 5
Apologies:		
Lauren Anderson		

1. Welcome and objectives for the meeting

The Chair welcomed attendees to meeting 12 of the Epilepsies in children, young people and adults Guideline Committee.
 The Chair informed the Committee that apologies from Lauren Anderson. Attendees are listed on the first page of these minutes.
 The Chair outlined the objectives of the meeting, which included: 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.

All interests relevant to this meeting are noted below:

Name	Job title, organisation	Declarations of Interest, when declared (Meeting/Recruitment)	Type of interest	Decision taken
AS	Topic Advisor	We have initiated a global study on epilepsy during COVID-19. This is work being done in collaboration between University of Oxford and the charity SUDEP Action. 30/06/2020	Direct Non-financial	Declare and participate
JW		Cochrane Systematic review protocol Preconception counselling for women with epilepsy a mixed methods review Submitted for publication 20/06/2020	Direct non-Financial	Declare and participate
JW		NIHR RfPB grant Developing a preconception care pathway for women with epilepsy in UK 23/03/2020. Funding made to research department	Indirect Financial	Declare and participate
RS		Grant received NIHR RfPB (Co-applicant) Person centred risk communications - what works best for people with epilepsy and their clinicians (a qualitative study. (11/2019)	Direct Non-Financial	Declare and participate
RS		Grant received Grant from UCB for research on Brivaracetam using the ID AED Register (NIHR study number: 31484) Chief Investigator. (12/2019)	Direct Non-Financial	Declare and participate
RS		Grant received –EU satellite Agency grant looking at technology in clinical care (co-applicant). (11/2019)	Direct Non-Financial	Declare and participate
RS		Grant received /- Grant from Eisai for research on Perampanel influence on	Direct Non-	Declare and

		Autism using the ID AED Register (NIHR study number: 31484) Chief Investigator. (03/2020)	Financial	participate
RS		Grant received - GW Pharma – to extend the Ep-ID register from adults to children with Epidyolex as a pilot molecule. (06/2020)	Direct Non-Financial	Declare and participate
RS		Pharmaco-resistant epilepsy treatment options & Quality of Life – funded by LivaNova accepted onto NIHR portfolio IRAS 272686, CPMS 45575 Chief Investigator	Direct Non-Financial	Declare and participate
RS		Shortlisted for grants waiting results– <ol style="list-style-type: none"> 1. NIHR Phase 2 AI (co-applicant) - Computational Decision Support in Epilepsy using retrospective EEG 2. NIHR RfPB – stage 2 (co-applicant) – RAPID – reduction of antipsychotic medication 3. Small Business Research Initiative (SBRI) stage 2 (chief investigator) – Brain in Hand. 4. Wellcome Grant – stage 3 (07/2020) 	Direct Non-Financial	Declare and participate
RS		Index linked publications since last meeting – <ol style="list-style-type: none"> 1. Boland C, Jalihal V, Organ C, Oak K, McLean B, Laugharne R, Woldman W, Beck R, Shankar R EEG Markers in Emotionally Unstable Personality Disorder-A Possible Outcome Measure for Neurofeedback: A Narrative Review EEG and clinical neuroscience in press 2. Lennard S, Sharpe R, Goodey R, Hudson S, Shankar R Creating capable communities for people with Intellectual Disabilities– challenges and opportunities Journal of Mental Health research in intellectual disabilities in press 3. McCabe J, Wilcock M, Atkinson K, Laugharne R, Shankar R General Practitioners and Psychiatrists Attitudes towards Antidepressant Withdrawal British Journal of Psychiatry (Open) : https://doi.org/10.1192/bjo.2020.48 	Direct Non-Financial	Declare and participate

		<p>4. Sun, J, Perera B, Henley W, Ashby S, Shankar R. Seizure and Sudden Unexpected Death in Epilepsy (SUDEP) characteristics in an urban UK intellectual disability service. <i>Seizure - European Journal of Epilepsy</i> https://doi.org/10.1016/j.seizure.2020.05.004</p> <p>5. Allard, J, Henley W, Snoeijs-Schouwenaars F, Ool J, Tan I, Schelhaas H J,, Majoie M, Hudson S, McLean B, Shankar R, European perspective of perampanel response in people with Intellectual Disability <i>Acta Neurologica Scandinavica</i> https://doi.org/10.1111/ane.13261</p> <p>6. Watkins L, Dyer OM, Lawthom C, McGuire M, Thomas R, Shankar R The evidence for switching dibenzazepines in people with epilepsy" <i>Acta Neurologica Scandinavica</i> https://doi.org/10.1111/ane.13248</p> <p>7. Allard J, Henley W, Mclean B, Sellers A, Hudson S, Rajakulendran S, Pace A, Pashley S., Maguire M, Mohan M, Ellawela S, Tittensor P, Ram S, Bagary M, Shankar R Lacosamide in the general population and in people with intellectual disability: Similar responses? <i>Seizure</i> https://doi.org/10.1016/j.seizure.2020.02.013</p> <p>8. Angus- Leppan H, Moghim M, Cock H, Kinton L, Wells M, Shankar R Valproate risk form - surveying 215 clinicians involving 4775 encounters <i>Acta Neurologica Scandinavica</i> doi: 10.1111/ANE.13231</p> <p>9. Sawhney I, Zia A, Yazdi B, Shankar R Awareness of bone health risks in people with epilepsy and Intellectual Disability <i>British Journal of Learning Disabilities</i> DOI:10.1111/bld.12321</p> <p>10. Smart C, Page G, Shankar R et al. Keep Safe: The when, why and how of epilepsy risk communication <i>Seizure</i> in press</p> <p>11. Burrows L, Lennard S, Hudson S, McLean B, Jadav M, Henley W, Sander JW, Shankar R Interventions</p>		
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		<p>reducing unnecessary emergency department attendances for seizures: a scoping review Seizure https://doi.org/10.1016/j.seizure.2020.01.012</p> <p>12. Zabel A, Gamman L, Webb A, Goodey R, Shankar R Transforming Care in Cornwall: A review of the quality of the lives of people with learning disabilities a decade post discharge from hospital Br J Learn Disabil https://doi.org/10.1111/bld.12316</p> <p>13. Lance Watkins, Máire O'Dwyer, Michael Kerr, Mark Scheepers, Ken Courtenay & Rohit Shankar (2019) Quality improvement in the management of people with epilepsy and intellectual disability: the development of clinical guidance, Expert Opinion on Pharmacotherapy, DOI: 10.1080/14656566.2019.1695780</p> <p>14. Sharpe R, Curry W, Brown R, Shankar R A public health approach reducing health inequalities among autistic adults British Journal of General Practice 2019; 69 (688): 534-535.</p> <p>15. Shankar R, et al Bridging the gap of risk communication and management using the SUDEP and Seizure Safety Checklist Journal: Epilepsy & Behavior https://doi.org/10.1016/j.yebeh.2019.07.020</p> <p>16. Newman C, Ashby S, McLean B, Shankar R Improving Epilepsy Management with EpSMon: a Templar to highlight the multifaceted challenges of incorporating digital technologies into routine clinical practice Epilepsy & Behavior https://doi.org/10.1016/j.yebeh.2019.106514</p> <p>College Report –</p> <p>17. Shankar R, Haut F, Courtenay K Mental health services for adults with mild intellectual disability (CR226). 01 Mar 2020. Royal College of Psychiatrists (10/2019 – 06/2020)</p>		<p>15 partial exclusion from discussion for Q8.1 a,b risk factors for SUDEP reviews (tbc)</p>
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RS		<p>Expert advisory meetings attended –</p> <ol style="list-style-type: none"> 1. Epilepsy Foundation SUDEP summit monthly virtual meeting (02/2020) 2. Epilepsy Foundation SUDEP international workshop (virtually) (25/06/2020) 3. Epilepsy Action systematic review committee for epilepsy in older adults - 3 meetings (25/06/2020) 	Direct Non-Financial	Declare and participate
RS		<p>Roles commenced –</p> <ol style="list-style-type: none"> 1. Chair – Royal College of Psychiatrists (south-west division) (01/07/2020) 2. Royal Society of Medicine – ID chapter council member (05/2020) 	Direct Non-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. Draft review protocols

Angela Cooper and Mark Perry led the committee in discussions on the following review protocols:

- 4.9 Drug Monitoring: What is the appropriate serial monitoring of drug levels, including timing, in girls or women who are thinking about conceiving, are pregnant or in the post-partum period?
- 6.5 Surgery referral: What are the criteria for referral to epilepsy surgical services?
- 1.1a Risk Factors for Further seizure: What are the most accurate tools for predicting a further seizure, in people who have had a single seizure?
- 1.1b Risk Factors for Further Seizure: What are the risk factors for a further seizure after a first seizure, and what is the magnitude of risk of those factors?
- 8.1a Risk Factors SUDEP: What are the most accurate tools to predicting death, including SUDEP, in people with epilepsy?
- 8.1b Risk Factors SUDEP: What are the risk factors for epilepsy-related

<p>mortality, including SUDEP, and what is the magnitude of risk of the factors?</p> <ul style="list-style-type: none">• 1.3-1.6a Diagnosis: What is the most accurate approach for 1) diagnosis of epilepsy, and 2) differentiation between types of epilepsy• 1.3-1.6b Diagnosis: What is the most clinically and cost-effective approach for diagnosis of epilepsies?
<p>4. Presentations: Methodology</p>
<p>To support discussions on the review protocols listed above, Mark Perry delivered the following two presentations:</p> <ul style="list-style-type: none">• Diagnostic review approaches• Prognostic review approaches
<p>5. Any other business</p>
<p>There being no further business the meeting ended at 1300.</p>

Date of next meeting: 25 August 2020

Location of next meeting: Virtual Meeting: Zoom Platform