

NGC Epilepsies Guideline Committee Interests Register

Publication Date: March 2022

Name	Role with NICE	Type of interest	Description of interest	Interest arose	Interest declared	Interest ceased	Comments
Anderson: Lauren	Lay member	Direct Non-financial	Informal voluntary support group for parents and carers of children and young people with epilepsy.		On application	Ongoing	Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct non-financial	International League Against Epilepsy: UK Branch Committee member	2014	On application	Ongoing	Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct non-financial	Chair of neuropsychology task force, ILAE	2012	On application	Ongoing	Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct Non-financial	Editorial Board Membership: Epilepsy & Behaviour Epilepsy & Behaviour Case Reports Epilepsia Open Neuropsychological Review	2010 2015 2008 2015	On application	Ongoing	Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct non-financial	Advisory Panel for Eisai. Presentation given on neuropsychology for patients with epilepsy.: Honorarium donated to the ILAE	2018	On application	2018	Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct non-financial	Named investigator on a grant from Epilepsy Research UK for a study on post-operative outcomes from epilepsy surgery	2019	On application	2021	Declare and participate
Baxendale: Sallie	GC member	Direct financial	Pre and postoperative assessment on the surgical program is my primary activity in my NHS job. I would estimate that I see 40-50		On application	Ongoing	Private practice mirrors NHS

	Clinical neuropsychologist (adult)		surgical patients a year . I estimate on average I would provide assessments for 3 surgical patients per year on a purely private basis. I provide a pre surgical investigation once a patient has been accepted onto the surgical pathway. I conduct preoperative neuropsychological assessments. If surgery is offered, I counsel people about the likely impact any proposed surgery will have on their neuropsychological function. I conduct postoperative assessment to monitor outcome and provide rehabilitation where necessary. The information from my assessment will be considered together with results from all of the other investigations when deciding if surgery is a viable option for someone. The role is identical to that provided in the NHS.				work. Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct Financial	External examiner fees. Payment received from external universities and health authorities acting as an external examiner/assessor	2019	2019	Ongoing	Declare and participate.
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct Financial	Medicolegal work	2019	2019	2020	Declare and participate.
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct non-financial	Elected to the board of the International Neuropsychological Society. in November 2020. Position starts in February 2021. Focussed on building up international services in resource poor countries.	Dec 2020	9/12/20	ongoing	Declare and participate
Baxendale: Sallie	GC member Clinical neuropsychologist (adult)	Direct financial	Presentation at the ILAE UK Meeting – Laterality effects on the impact of mood on Neuropsychological test performance in Epilepsy' financial prize awarded by the ILAE	October 2020	9/12/20	October 2020	Declare and participate

Baxendale: Sallie	GC member Clinical neuropsycholog ist (adult)	Direct non- financial	Online presentation entitled 'Neuropsychology and Epilepsy: What every clinician treating epilepsy should know in 2021' as part of an educational webinar sponsored by UCB. Honorarium directed to charity and no monies received personally.	11/12/20	14/12/20	11/12/20	declare and participate
Desurkar: Archana	GC member – neurologist (paediatric)	Direct Financial	Contract with Young Epilepsy: for ad-hoc EEG reporting, paid per EEG basis. YE contracted by NHS to carry out EEGs.		On applicatio n	Ongoing	Mirrors NHS work. Declare and participate
Desurkar: Archana	GC member – neurologist (paediatric)	Direct Financial	I see occasional private patients (approx. 12 per year and would very rarely be patients with epilepsy).		On applicatio n	Ongoing	Private practice rarely includes management of epilepsy patients.
Desurkar: Archana	GC member – neurologist (paediatric)	Direct Non-financial	Secretary to British Paediatric Epilepsy Group (BPEG), a subchapter of BPNA- This entails setting up BPEG meetings, agenda items, communication with BPEG group circulation of minutes, important information updates etc. No commercial interest.	2016	On applicatio n	Ongoing	Declare and participate- keep under review
Desurkar: Archana	GC member – neurologist (paediatric)	Direct non-financial	Medical Board pf Matthew's Friends: a charity -involves preparing syllabus for ketocollege, present at meetings on behalf of MF, participate in meeting regarding directions for future travel and projects.		On applicatio n	ongoing	Exclusion for ketogenic diet review
Desurkar: Archana	GC member – neurologist (paediatric)	Direct non-financial	Medical Board of Ring 20 chromosome foundation UK-newly acquired role with this charity, will involve roles similar to above.		On applicatio n	ongoing	Not within scope Declare and participate
Desurkar: Archana	GC member – neurologist (paediatric)	Direct non-financial	Private Investigator on KIWE trial (Ketogenic Diet in Infants with Epilepsy), I am also on Trial Steering Committee.		On applicatio n	Ongoing	Exclusion for ketogenic review
Desurkar: Archana	GC member – neurologist (paediatric)	Direct financial	Ongoing appointment: Member of Medical Advisory Board, Eisai meeting discussed Perampanel 26/11/20	26/11/22 0	26/1/21	ongoing	A non-specific interest as the drug has not been considered

							as part of any review or discussed by the committee. Declare and participate
Desurkar: Archana	GC member – neurologist (paediatric)	Direct financial	Member of Medical Advisory Board meeting on Brivaracetam, UCB 9/11/20. This meeting was a single event.	9/11/20	26/1/21	10/11/20	A non-specific interest as the drug has not been considered as part of any review or discussed by the committee. Declare and participate
Desurkar: Archana	GC member – neurologist (paediatric)	Indirect financial	Private Investigator on Zogenix Fenfluramine Trial- funds into research department	2017	26/1/21	2019	Declare and participate
Dickson: Jon Mark	GC member - GP	Indirect Financial	Educational Grant paid to The University of Sheffield (Jon Dickson as Chief Investigator) for research into emergency admissions to hospital. UCB had no control over the conduct of the study.	2012	On application	2018	Declare and participate
Dickson: Jon Mark	GC member - GP	Direct Non-financial	Member of the ILAE.	2012	On application	Ongoing	Declare and participate
Dickson: Jon Mark	GC member - GP	Direct Non-financial	Member of the ILA GP Society.	2012	On application	Ongoing	Declare and participate
Dickson: Jon Mark	GC member - GP	Direct Non-financial	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	2012	On application	Ongoing	Declare and participate

			any substantial pieces of advisory work in this capacity.				
Dickson: Jon Mark	GC member - GP	Direct Non-financial	Epilepsy Action, member of medical advisory board.	2016	On applicatio n	Ongoing	Declare and participate
Dickson: Jon Mark	GC member - GP	Indirect Financial	Senior Clinical Lecturer at the University of Sheffield. Involved with research into epilepsy	2012	On applicatio n	Ongoing	Declare and participate
Dickson: Jon Mark	GC member - GP	Indirect Financial	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.	2018	On applicatio n	Ongoing (due to be published 8/7/2019)	The specialist epilepsy nurse review is not being considered by this committee. Declare and participate-tbc
Dickson: Jon Mark	GC member - GP	Direct Non-financial	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 have a mix of academic and commercial sponsors. Commercial sponsors include: GSK and Novonordisk.	2012	On applicatio n	Ongoing	Research activities do not include areas considered by this guideline. Declare and participate.
Dickson: Jon Mark	GC member - GP	Direct Non-financial	Chair for the revision of the national paramedic handbook. Guideline on emergency management of seizures published May 2019.	2019	22/05/19	May 2019	Declare and participate
Gomersall: Sally	Lay member	n/a	None		On applicatio n		No action needed
O'Brien: Lisa	GC member – nurse (paediatric)	Direct Financial	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.	11/04/20 19	On applicatio n	11/4/201 9	Declare and participate for discussion of protocol. Declarati on made more

							than 12 months ago. .
O'Brien: Lisa	GC member – nurse (paediatric)	Direct financial	Travel and accommodation costs to attend a conference in Belgium ran by LivaNova about VNS therapy.	13/06/2019	On application	14/6/2019	Declare and participate
O'Brien: Lisa	GC member – nurse (paediatric)	Direct Non-financial	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.		On application	Ongoing	Declare and participate
O'Brien: Lisa	GC member – nurse (paediatric)	Indirect Financial	Support by drug representatives to sponsor an Epilepsy Nurse Specialist group I attend on a monthly basis.		On application	Ongoing	Declare and participate
O'Brien: Lisa	GC member – nurse (paediatric)	Direct Non-financial	On the medical board of Matthew's Friends-Ketogenic Diet Support Group. My role is to provide general epilepsy advice and support to parents/families/colleagues and other professionals. This includes supporting on training days including Keto College (Sept 2021) where I will be presenting a nurses workshop	09/2020	23/02/2021	Ongoing	Withdraw from committee discussions on Ketogenic Diet.
Petropoulos : Maria-Christina	GC member-paediatrician		None		On application		No action needed
Pullen: Angie	Lay member (joined in January 2021)	Indirect Financial	Attended a patient advisory group exploring lived experience of epilepsy and epilepsy care. Arranged for people with focal epilepsy to attend and share experiences. This was conducted on behalf of Arvelle therapeutics. A fee was paid to Epilepsy Action my employer not to me personally.	01/2021	19/01/2021	01/2021	Declare and participate.
Pullen: Angie	Lay member (joined in January 2021)	Direct - Financial	Payment received by Epilepsy Action from marketing authorisation holders and/or manufacturers of antiepileptic drugs	Jan 2018	Jan 2019	Ongoing	Declare and participate.

			(branded or generic) plus LivaNova (formerly Cyberonics, device manufacturer of VNS, a treatment for epilepsy) for advice and information sessions.				Agreed by GL and NICE CA at recruitment Rationale: despite this being a specific interest, the balance of risks is such that there is no need to withdraw as the member did not personally benefit financially.
Pullen: Angie	Lay member (joined in January 2021)	Direct - Financial	Epilepsy Action sells advertising in its magazines Epilepsy Professional and Epilepsy Today, through its trading company, BEA Trading Ltd, to a number of pharmaceutical and device manufacturers.	Jan 2018	Jan 2019	Ongoing	
Pullen: Angie	Lay member (joined in January 2021)	Direct – Non-financial	The National Institute for Health Research-Health Technology Assessment programme funded Antiepileptic drug management in pregnancy: A double blind randomised trial on effectiveness and acceptability of monitoring strategies (EMPIRE study) Trial registration: 01253916 The trial was conducted across fifty obstetric and/or epilepsy clinics in secondary and tertiary care units in the UK from June 2011 to May 2015.	June 2011	July 2019	May 2018	Withdraw from presentation and discussion of the evidence. The study was included in the review question 4.9 drug monitoring in women and girls

			<p>The health technology assessment was published by NHR in May 2018 VOLUME 22 ISSUE 23 ISSN 1366-5278</p> <p>I was a member of the steering group and advised on patient information lay summary and dissemination.</p>				who are able to get pregnant.
Pullen: Angie	Lay member (joined in January 2021)	Direct – Financial professional/personal interest	Arvelle therapeutics have asked Epilepsy Action my employer to attend a patient advisory board on 16 th December and to find 2 people who have lived experience of focal seizures to contribute. They are paying a fee to Epilepsy Action. The Arvelle drug Cenobamate is currently going through NICE HTA as add on treatment for focal seizures	December 2020	December 2020	December 2020	<p>Declare and participate</p> <p>Agreed by GL</p> <p>Rationale: despite this being a specific interest, the balance of risks is such that there is no need to withdraw</p>
Pullen: Angie	Lay member (joined in January 2021)	Indirect Financial	<p>Presented at a webinar (Making Waves in Epilepsy- Optimising the Management of Epilepsy in Patients with Intellectual Disability)</p> <p>on experience of people with epilepsy and learning disabilities and epilepsy and their families. Contributed to a panel for a question-and-answer session for health professionals from NHS services at the end of the webinar. The webinar was sponsored by Eisai. A fee was paid to Epilepsy Action my employer not to me personally. May 2021</p>	29/4/21	18/05/21	29/4/21	Declare and participate

Rands: Gabriella	GC member- paediatric Clinical Psychologist	n/a	None		On applicatio n		No action needed
Rands: Gabriella	GC member- paediatric Clinical Psychologist	Indirect Financial	Ongoing ketogenic diet study within the department where I work. I have no involvement with the study.	2019	22/05/19		Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	Grant monies awarded by UCB Pharma for immune modulation study,		On applicatio n	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	Grant monies awarded by Eisai Europe for project investigating perampanel anti-epileptic medication post VNS insertion/surgery (project complete)		On applicatio n	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	Grant monies awarded by Bial for project investigating anti-epileptic medication in older people with epilepsy		On applicatio n	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	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		On applicatio n	17.11.18	All honoraria paid to university and trust Declare and participate
Sen: Arjune	Topic advisor	Direct Non-financial	Author of publication: Galvanic Skin Response (GSR)/Electrodermal/Skin Conductance Biofeedback on Epilepsy: A Systematic Review and Meta-Analysis. Nagai Y, Jones CI, Sen A. Front Neurol. 2019.	April 2019	02/07/20 19	2019	Declare and participate

Sen: Arjune	Topic advisor	Indirect Financial	UK investigator for Padsevonil Trial (UCB Pharma): no monies to be personally received throughout.	June 2019	June 2019	December 2020	Declare and participate
Sen: Arjune	Topic advisor	Indirect financial	UK investigator for CORE VNS outcomes registry in people with epilepsy treated with VNS (Livanova): no monies to be personally received throughout.	June 2019	June 2019	Ongoing	Declare and participate
Sen: Arjune	Topic advisor	Direct Non-financial	Author of publication: Perampanel for the treatment of epilepsy; Longitudinal actuarial analysis and dose responses based on monthly outcomes. Stavropoulos I, Louden W, Queally C, Adcock J, Tristram M, Neale M, Moran N, Flores L L, Nashef L, Richardson MP, Bell C, Slaght S, Aram J, Rayner N, Powell R, Mead A, Sen A, Elwes R. Seizure. 2019.	July 2019	02/07/2019	2019	Declare and participate
Sen: Arjune	Topic advisor	Direct Non-financial	Member of the ILAE council.	2017	02/07/2019	Ongoing	Declare and participate
Sen: Arjune	Topic advisor	Direct Non-financial	Member of the Medical Advisory Board for Ring Chromosome 20 foundation UK.	July 2019	02/07/2019	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	Grant monies awarded by European Union for trial investigating EEG (SEIZE IT) To start in 2020.	July 2019	02/07/2019	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	UCB Pharma supported Research study: Assessment of immunophenotyping in people with epilepsy.	02/07/2019	02/07/2019	Ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial	Bial supported: study of eslicarbazepine in older people with epilepsy (no clinical trial of eslicarbazepine; only people who are to have eslicarbazepine anyway are invited.)	02/07/2019	02/07/2019	Ongoing	Declare and participate
Sen: Arjune	Topic advisor	Direct Non-financial	Contributed to publishing the following https://www.nice.org.uk/about/what-we-do/our-programmes/evidence-standards-framework-for-digital-health-technologies	2019	22/10/2019	2019	Declare and participate
Sen: Arjune	Topic advisor	Indirect financial	We have initiated a global study on epilepsy during COVID-19. This is work being done in	June 2020	30/6/2020	ongoing	Declare and participate

			collaboration between University of Oxford and the charity SUDEP Action. 30/06/2020				
Sen: Arjune	Topic advisor	Direct Non-financial	Invited by LivaNova to chair a symposium December 2020 and an ILAE UK meeting at the American Epilepsy Society. These events will focus on epilepsy pathways, specifically how people progress towards getting Vagus Nerve Stimulator (VNS) Implants.	Dec 2020	25/8/20	Dec 2020	Declare and participate
Sen: Arjune	Topic advisor	Indirect financial	Future partnership planned with UNPEG looking at ultra long monitoring of electroencephalograms (EEGs) using subcutaneous device. Work is currently on hold for this project. Though related to the topic, this procedure is not covered by NICE guidance, and is also not commissioned by the NHS.	25/8/20	25/8/20	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Direct non-financial	Invited to give a talk at Eisai-organised educational virtual meeting - Epilepsy in Older People. No monies received	15/12/20	24/11/20	15/12/20	Declare and participate
Sen: Arjune	Topic advisor	Direct non-financial	Speaking at Bial organised webinar Epilepsy in older people– no monies received. Takes place in March 2021	18/3/21	22/1/21	18/3/21	Declare and participate
Sen: Arjune	Topic advisor	Direct non-financial	Talk for ILAE International Epilepsy Day COVID and its effects on epilepsy care? Meeting was supported by UCB Pharma. No payment received and no input from UCB on the presentation.	8/2/21	8/2/21	8/2/21	Declare and participate
Sen: Arjune	Topic advisor	Direct non-financial	Film to be recorded on Epilepsies/ COVID 19. Supported by UCB. No personal funding provided for this series	26/01/21	26/01/21	26/01/21	Declare and participate
Sen: Arjune	Topic advisor	Direct Non-Financial Interest	Author on 3 studies included in the diagnostic accuracy review: 1.Distinguishing psychogenic nonepileptic, mixed, and epileptic seizures using systemic		23/03/21	23/3/21	Declare and participate

			<p>measurers and reported experiences. Epilepsy & behaviour, 116, 2021</p> <p>2. Stertorous breathing is a reliably identified sign that helps in the differentiation of epileptic from psychogenic non-epileptic convulsions: An audit. Epilepsy Research (2007) 77, 62—64</p> <p>3. Clinical features which predict neuronal surface autoantibodies in new-onset focal epilepsy: implications for immunotherapies. J Neurol Neurosurg Psychiatry 2021;92:291–294.</p>				
Sen: Arjune	Topic advisor	Indirect Financial Interest	Epilepsy Monitoring Unit Study of Mortality focusing on SUDEP. This is a project in the U.S. We have been asked to be a lead UK site and I am PI. Analysis of data will be carried out in U.S. The Ethics Approval is in process so the study is not open yet. Funded by the FACES Charity - non-commercial entity based in NY		23/03/21	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial Interest	The VARIED study - this is looking at health utilisation behaviour related to VNS. This is at protocol stage. The project is supported by LivaNova, There is no reimbursement attached to the work. This will not report during the development of the guideline..		23/03/21	ongoing	Declare and participate
Sen: Arjune	Topic advisor	Indirect Financial Interest	Epilepsy Monitoring Unit Study of Mortality - this is the large-scale project from New York capturing retrospective data on people who have had telemetry. We are the lead UK site. Ethics Approval granted April 2021. TMA awaited. Funded by the FACES Charity - non-commercial entity based in NY. No personal monies will be received at any time related to this study. Jan 2021		23/03/21		Declare and participate

Sen: Arjune	Topic advisor	Direct Non-Financial Interest	Appointed to the World Health Organisation Topic Expert Group on Epilepsy (as part of the WHO intersectoral plan). No monies to be received.		18/05/21	ongoing	Declare and participate
Sen: Arjune	Clinical advisor	Non-financial Direct	Talk at European Medical Journal Meeting on 16.6.21, discussions will focus on pathways for people with drug resistant epilepsy and how we can improve the links between secondary and tertiary care.			08/06/2021	Declare and participate.
Shankar: Rohit	GC member-Learning disabilities psychiatrist	Indirect Financial	A Register for New Anti-Epileptic Drugs In ID/PDD populations 10 years ethics approval Adopted by UK NIHR 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. 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.	2014	On application	Ongoing	Declare and participate
Shankar: Rohit	GC member-Learning disabilities psychiatrist	Indirect Financial	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.	2015	On application	Ongoing	Declare and participate
Shankar: Rohit	GC member-Learning disabilities psychiatrist	Direct Financial	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. 1. Eisai- European advisory board - the effectiveness and safety of adjunctive	2018	On application	12/8/2018	Partial exclusion for pharmacological questions-tbc Any future honorariums will be paid to Trust research funds

			<p>perampanel in the routine clinical care of patients with myoclonic seizures in Idiopathic Generalised Epilepsy 29/8/18</p> <ol style="list-style-type: none"> 2. Eisai - European Epilepsy Conference symposium – talk on risk management of people with ID and epilepsy 29/8/18 3. Desitin – Training on communication skills 10/10/18 4. UCB – talk on SUDEP in Cardiff LD meeting 16/10/18 5. UCB – Focus on Epilepsy conference – talk on challenges of management of epilepsy and ID. 6/11/18 				
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct Non-financial	<p>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>	2011	On application	Ongoing	Partial exclusion for the new technologies question.
Shankar: Rohit	GC member- Learning	Direct Non-financial	<p>Academic secretary for the intellectual disability faculty of the Royal College of Psychiatrists</p>	2019	22/05/2019	Ongoing to be complete	Declare and participate

	disabilities psychiatrist					d in June 2020.	
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct Non-financial	Attending advisor for the NHS England pathway on epilepsy.	2019	22/05/20 19	2019	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	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.	2019	22/10/20 19	2019	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct non -financial	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	2019	22/10/20 19	2019	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct Non-financial	02.10.2019 Invited keynote ILAE British Chapter – SUDEP communication – No payment	2019	22/10/20 19	2019	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	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)	2019	1/7/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect -Financial	Grant received Grant from UCB for research on Brivaracetam using the ID AED Register (NIHR study number: 31484) Chief Investigator. (12/2019)	12/19	1/7/20	ongong	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect -Financial	Grant received /- Grant from Eisai for research on Perampanel influence on Autism using the ID AED Register (NIHR study number: 31484) Chief Investigator. (03/2020)	03/20	1/7/20	ongoing	Declare and participate

Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	Grant received - GW Pharma – to extend the Ep-ID register from adults to children with Epidyolex as a pilot molecule. (06/2020)	06/20	1/7/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	Pharmaco-resistant epilepsy treatment options & Quality of Life – funded by LivaNova accepted onto NIHR portfolio IRAS 272686, CPMS 45575 Chief Investigator	07/20	1/7/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	Shortlisted for grants waiting results– NIHR Phase 2 AI (co-applicant) - Computational Decision Support in Epilepsy using retrospective EEG Small Business Research Initiative (SBRI) stage 2 (chief investigator) – Brain in Hand.	07/20	1/7/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct Non- Financial	Publications 1. 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. Seizure - European Journal of Epilepsy https://doi.org/10.1016/j.seizure.2020.05.004 2. Allard, J, Henley W, Snoeijen-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 Acta Neurologica Scandinavica https://doi.org/10.1111/ane.13261 3. Watkins L, Dyer OM, Lawthom C,	2020	1/7/20	2020	Declare and participate Item 10: partial exclusion from discussion for Q8.1 a,b risk factors for SUDEP reviews

			<p>McGuire M, Thomas R, Shankar R The evidence for switching dibenzazepines in people with epilepsy" Acta Neurologica Scandinavica https://doi.org/10.1111/ane.13248</p> <p>4. 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? Seizure https://doi.org/10.1016/j.seizure.2020.02.013</p> <p>5. Angus- Leppan H, Moghim M, Cock H, Kinton L, Wells M, Shankar R Valproate risk form - surveying 215 clinicians involving 4775 encounters Acta Neurologica Scandinavica doi: 10.1111/ANE.13231</p> <p>6. Sawhney I, Zia A, Yazdi B, Shankar R Awareness of bone health risks in people with epilepsy and Intellectual Disability British Journal of Learning Disabilities DOI:10.1111/bld.12321</p> <p>7. Smart C, Page G, Shankar R et al. Keep Safe: The when, why and how of epilepsy risk communication Seizure Feb 2020</p> <p>8. Burrows L, Lennard S, Hudson S, McLean B, Jadav M, Henley W, Sander JW, Shankar R Interventions reducing unnecessary emergency department attendances for seizures:</p>				
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			<p>a scoping review Seizure https://doi.org/10.1016/j.seizure.2020.01.012</p> <p>9. 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>10. 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>11. 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>				
Shankar: Rohit	GC member-Learning disabilities psychiatrist	Direct Non-Financial	Expert advisory meetings attended – Epilepsy Foundation SUDEP summit monthly virtual meeting (02/2020).	02/220	1/7/20	02/2020	Declare and participate
Shankar: Rohit	GC member-Learning	Direct non-financial	Epilepsy Foundation SUDEP international workshop (virtually) (25/06/2020)	06/2020	1/7/20	06/2020	Declare and participate

	disabilities psychiatrist						
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct Non- Financial	Epilepsy Action systematic review committee for epilepsy in older adults - 3 meetings (25/06/2020)	06/2020	1/7/20	06/2020	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct Non- Financial	Roles commenced – Royal Society of Medicine – ID chapter council member conducting work on ID in epilepsy (05/2020)	05/2020	1/7/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect -Financial	NIHR AI grant to test Bio-Ep – co-applicant and clinical lead - this is a new bio marker for EEGs to predict seizures. Grant paid to Trust	August 2020	22/9/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	Grant paid to Trust from NeuroEvent labs - https://neuroeventlabs.com/ (develop AI seizure monitoring) for CFT/AHSN to run an implementation study in people with ID. Grant applicant and lead investigator.	Septemb er 2020	22/9/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect -Financial	Grant paid to Trust from GW pharma to set up a children's arm to our NIHR adopted Ep- ID 10 year research register. Grant applicant and lead investigator	June 2020	22/9/20	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct non- financial	Author of published paper McCabe J, McLean B, Henley W, Harris C, Cheatle K, Ashby S, Shankar R Sudden Unexpected Death in Epilepsy (SUDEP) and seizure safety: modifiable and non-modifiable risk factors differences between primary and secondary care Epilepsy & Behaviour doi: 10.1016/j.yebeh.2020.107637	Dec 2020	26/1/21	Dec 2020	partial exclusion during discussion of 8.1 risk factors for epilepsy related mortality
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	British Paediatric Neurologist annual conference - Chair of session and speaker talk on "Epilepsy in people with Developmental disability" - GW pharma		26/1/21		Declare and participate

			sponsored. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust				
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Speaker at RCGP – Intellectual Disability special interest group - ID and epilepsy. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust		26/1/21		Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Speaker at London Intellectual Disability Faculty - Personalised medicine in epilepsy and I D. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust		26/1/21		Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Royal Society of Medicine - organiser and speaker for "Step Together" launch - event sponsored by GW pharma. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust	17/11/21	26/1/21	17/11/21	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Gave talk on Sudden Unexpected Death in Epilepsy - podcast - Averelle sponsored. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust		26/1/21		Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Oxford Intellectual Disability epilepsy talk - Quality Improvement in the management of people with epilepsy (PWE) & ID – an evidence based approach – Eisai. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust		26/1/21		Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect -financial	Speaker at conference - Lacosamide in the general population and in people with intellectual disability: Similar responses? - UCB sponsored. Honorarium payment made to research budget Cornwall Partnership NHS Foundation Trust		26/1/21		Declare and participate

Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct financial	I was sponsored for the American Epilepsy Society 4-8 December 2020 virtual conference fees in December by Eisai to present 2 posters on Perampanel looking at mental health safety in children. Usual attendance expenses only.	4/12/20	26/1/21	8/12/20	Usual expenses only. Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Direct non- financial	Leading a Cochrane update into pharmaceutical interventions in people with Learning disability and epilepsy.	Jan 2021	26/1/21	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	Grant from: EPIC (European funding), for data set analysis related to Epilepsies EpSMon App.		27/04/20 21	ongoing	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist		Member of the National Confidential Inquiry group for epilepsy		20/5/21	ongoing	
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	Review of epilepsy apps –a talk given on behalf of the International Medical Press on the different epilepsy apps which are available. Sponsored by UCB - honorarium paid to Trust		20/5/21	23/2/21	partial exclusion during discussion of 8.1 risk factors for epilepsy related mortality
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect Financial	ABN podcast - on complexity of managing epilepsy in people with ID for playing at the ABN meeting. Sponsored by Averelle - honorarium paid to the Trust		20/5/21	05/21	Declare and participate
Shankar: Rohit	GC member- Learning disabilities psychiatrist		Chaired RSM online meeting on Intellectual disability and epilepsy - sponsorship from GW pharma.		20/5/21	17/11/20	Declare and participate

Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Review of epilepsy Apps - A talk on the different epilepsy apps which are available their strengths, weakness 23rd February For the International Medical Press sponsored by UCB honorarium paid to Trust			08/06/20 21	Asked to withdraw from meeting for risk factors for SUDEP reviews
Shankar: Rohit	GC member- Learning disabilities psychiatrist	Indirect financial	Provided a podcast on complexity of managing epilepsy in people with ID for Averielle to play at the Association of British Neurologists meeting May 2021. Honorarium paid to Trust			08/06/20 21	Declare and participate.
Smith: Philip	GC member- neurologist (adults)	Indirect financial	Research grant and author of SANAD II.		On applicatio n		SANAD is not being considered by this committee. Partial exclusion may be required during joint committee discussions on pharmacological treatments.
Smith: Philip	GC member- neurologist (adults)	Direct Non-financial	President of Joint Neurosciences Council.	2018	On applicatio n	2020	Declare and participate
Smith: Philip	GC member- neurologist (adults)	Direct Non-financial	Chair Epilepsy Action Advisory Council for Wales.	2016	On applicatio n	2019	Has stood down early from this role. Declare and participate
Smith: Philip	GC member- neurologist (adults)	Direct Non-financial	MHRA Expert Panel on Sodium Valproate.	2015	On applicatio n	2018	Declare and participate

Smith: Philip	GC member- neurologist (adults)	Direct financial	Co-editor of Practical Neurology. Honorarium received from BMJ.		09/07/2019		Declare and participate
Smith: Philip	GC member- neurologist (adults)	Direct Non- Financial	Editorial on Status epilepticus has been published in the New England Journal of Medicine.	2019	22/10/2019	2019	Partial exclusion may be required during joint committee discussions on pharmacological treatments.
Smith: Philip	GC member- neurologist (adults)	Direct Non- Financial	Invited to talk at symposium at the Association of British Neurologists (ABN), hosted by Arvelle Therapeutics – on resistant epilepsy.		25/8/20		Declare and participate
Smith: Philip	GC member- neurologist (adults)	Direct Non- Financial	Invited to write a review on 'Initial Management of Seizure' for the New England Journal of Medicine	26/1/21	26/1/21		Declare and participate
Thomas: Trudy	GC member- pharmacist (adult)	Direct Non-financial	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.		On application	2019	Does not include anything on UCB products and this arrangement has now ended Declare and participate
Ward: Stephen	Chair	N/A	None		On application		No action needed
Winterbottom: Janine	GC member- nurse (adults)	Direct Non-financial	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.		On application	Ongoing	Declare and participate
Winterbottom: Janine	GC member- nurse (adults)	Indirect Financial	Presented a talk about my epilepsy nurse service the south of England epilepsy nurses, this was sponsored by UCB	2019	22/05/2019		Declare and participate

			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				
Winterbottom: Janine	GC member-nurse (adults)	Indirect financial	Speaker fee from UCB pharma paid to the Walton Centre neuroscience fund for epilepsy nurse training.	2019	22/05/2019	2019	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Indirect Financial	Research grant application. NIHR RfPB application of research proposal concerning preconception care of women with epilepsy.		22/05/2019	Ongoing	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Indirect Financial	Update on earlier declaration. NIHR grant application on pre-conception counselling for women with epilepsy moved to stage 2 in the application process.	2019	09/07/2019	Ongoing	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Direct Non-financial	Attendance at UCB Pharma sponsored teaching session inviting Dr Marcus Reuber Consultant Neurologist from Sheffield to present patient audit on Eslicarbazepine		10.09.2019		Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Direct Non-financial	Cochrane Systematic review protocol Preconception counselling for women with epilepsy a mixed methods review Submitted for publication 20/06/2020	June 2020	1/7/20	06/20	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Indirect financial	NIHR RfPB grant Developing a preconception care pathway for women with epilepsy in UK 23/03/2020. Funding made to research department	March 2020	1/7/20	ongoing	Decalre and participate
Winterbottom: Janine	GC member-nurse (adults)	Direct non-financial	Cochrane Systematic review protocol Preconception counselling for women with ep published on 11/12/2020 in the Cochrane Library.	June 2020	15/12/20	12/20	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Direct non-financial	Work with Epilepsy Action on content for patient information concerning women with epilepsy, requested to make an information video on preconception counselling for women with epilepsy, it will focus on my experience as nurse, what preconception		23/03/21	03/21	Declare and participate

			counselling is, what might be covered and how women might benefit for them and their future pregnancy. 02 03 2021				
Winterbottom: Janine	GC member-nurse (adults)	Direct non-financial	Article submission to Epilepsy Today and Epilepsy Professional member journals of Epilepsy Action, to report results of our PPI work to development my NIHR preconception study, update of research, and advertisement for participant recruitment patient and professional submission date for article 05 04 2021.		23/03/21	04/21	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Direct non-financial	Attendance at the All-Party Parliamentary group meeting 22nd March. Topics for discussion MBRRACE report and MHRA report of evidence of anti-seizure medications taken in pregnancy. Discussion of presentations and potential implications for my NIHR preconception study. 22 03 2021		23/03/21	22/3/21	Declare and participate
Winterbottom: Janine	GC member-nurse (adults)	Direct non-financial	Invited member of International Bureau of Epilepsy to work on their epilepsy and pregnancy awareness raising campaign. This is an advisory role. Member and support organization working toward improving epilepsy services worldwide and advancing the treatment of people with epilepsy and raising the awareness of related issues. April 2021		27/04/21	04/21	Declare and participate

COOPTEES

Burn: Sasha	Co-optee GC member Paediatric surgeon	Direct financial	Occasional private medico-legal work		On application	Ongoing	Declare and participate
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Croft: Susan	Emergency medicine consultant	Direct Financial	Prepared a bespoke presentation looking at acute exacerbations in respiratory, diabetes and epilepsy that was delivered on 2 occasions to local meetings of Health Care Professionals. I was paid by Astrazeneca to do this. These were not in any way related to the subject areas covered by these guidelines.	10/12/2017	June 2019	03/05/2018	Declare and participate
Croft: Susan	Emergency medicine consultant	Direct Non-financial	<p>Currently seconded to work at Sheffield University (School of Health and Related Research) for a day per week on:</p> <p>CLAHRC Yorkshire and Humber Theme – Avoidable Attendance and Admissions in Long Term Conditions – this is match-funded by my employer (Sheffield Teaching Hospitals)</p> <p>Connecting Health Cities project – uniting local health data and advanced technology to improve health services for patients across the North of England.</p>	14/07/2014	June 2019	Ongoing	Declare and participate

			The work undertaken in these roles is not related to the subject area covered by these guidelines.				
Liew: Ashley	Co-optee GC member-neuro-psychiatrist (paediatric)	Direct Non-financial	Executive secretary for the Child & Adolescent Intellectual Disability Psychiatry Network whose members see patients with epilepsy.	2015	On application	Ongoing	Declare and participate
Liew: Ashley	Co-optee GC member-neuro-psychiatrist (paediatric)	Direct Non-financial	I am the Neuropsychiatry representative on the Council for the British Paediatric Neurology Association which represents Paediatric Neurologists who see patients with epilepsy relatively frequently.	2017	On application	Ongoing	Declare and participate.
Liew: Ashley	Co-optee GC member-neuro-psychiatrist (paediatric)	Direct Financial	Received speaking and travel honoraria from Flynn Pharma and Shire in relation to psychiatric medication not directly used in the treatment of epilepsy.	2019	22/05/2019	2019	Declare and participate.
Miserocchi: Anna	Co-optee GC member- surgeon (adult)	n/a	None		On application		No action needed
Miserocchi: Anna	Co-optee GC member- surgeon (adult)	Indirect Financial	Awarded grant from Medtronic. This medical manufacturer provides lasers for surgeries. The surgery this equipment is	2019	22/10/2019	2019	Declare and participate

			used for is not currently offered in the UK.				
Payne: Gareth	Co-optee GC member Neurophysiologist	Direct Non-financial	Member & Treasurer of the Council of the British Society for Clinical Neurophysiology	2014	On application	Ongoing	Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Direct non-financial	Curriculum lead for the Specialty Advisory Committee for Clinical Neurophysiology	2016	On application	Ongoing	Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Direct non-financial	Regional Specialty Advisor to Royal College of Physicians	2017	On application	Ongoing	Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Direct financial	I hold shares in Aviva Plc		On application	Ongoing	Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Direct financial	Carries out some private EEG work		On application	2019	Will discontinue during the development of the guideline.

							Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Indirect financial	Wife is National Professional Advisor for urgent primary care at the Care Quality Commission	2018	On application	Ongoing	Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Indirect financial	Wife is a non-Executive Director of Shropshire Doctors (GP out of hours service)	2019	On application	Ongoing	Declare and participate
Payne: Gareth	Co-optee GC member Neurophysiologist	Indirect non-financial	Wife was Wales Chair of RCGP	2016	On application	2018	Declare and participate
Reilly: Colin	Co-optee GC member – educational psychologist	Direct Non-financial	International League Against Epilepsy – Co - Chairperson Paediatric Psychiatric Issues.	2018	On application	ongoing	Declare and participate
Reilly: Colin	Co-optee GC member – educational psychologist	Direct Non-financial	Epilepsy12 Methodology and Dataset Group - RCPCH. Educational Psychologist member.	2019	On application	ongoing	Declare and participate
Reilly: Colin	Co-optee GC member – educational psychologist	Indirect financial	Co-investigator on a NIHR randomised control trial of a psychological intervention for mental health problems in children with epilepsy	2019	25/06/2019	Ongoing	Declare and participate
Trivedi: Ashifa	NGA Committee Contributor	Direct Non-financial	NICE Multiple Obstetric Guidelines Update Committee – pharmacist role	November 2017	On application	Ongoing	Declare and participate

Trivedi: Ashifa	NGA Committee Contributor	Direct Non-financial	NICE Epilepsy – pharmacist role	November 2019	On application	Ongoing	Declare and participate
Trivedi: Ashifa	NGA Committee Contributor	Direct Non-financial	NPPG/RCPCH Medicines Committee – pharmacist role	June 2019	On application	Ongoing	Declare and participate