

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 1

Date: 06/02/2019

Location: Diploma Suite, Holiday Inn London Bloomsbury

Minutes: Confirmed

Committee members present:	
Peter Barry (Chair)	(Present for notes 1 – 6)
Ilora Finlay (Vice-Chair)	(Present for notes 1 – 6)
Theo Anbu	(Present for notes 1 – 6)
Michael Beadsworth	(Present for notes 1 – 6)
Joanne Bond-Kendall	(Present for notes 1 – 6)
Saran Bonser	(Present for notes 1 – 6)
Sally Burch	(Present for notes 1 – 6)
Chris Burton	(Present for notes 1 – 6)
Tony Crouch	(Present for notes 1 – 6)
Jo Daniels	(Present for notes 1 – 6)
Dorinda Jack	(Present for notes 1 – 6)
Nicola Kidby	(Present for notes 1 – 6)

Caroline Kingdon	(Present for notes 1 – 6)
Adam Lowe	(Present for notes 1 – 6)
Jennifer McIntosh	(Present for notes 1 – 6)
Gabrielle Murphy	(Present for notes 1 – 6)
Luis Nacul	(Present for notes 1 – 6)
Alan Stanton	(Present for notes 1 – 6)
Susan Watson	(Present for notes 1 – 6)
William Weir	(Present for notes 1 – 6)

In attendance:		
Agnes Cuyas	NGC Information Specialist	(Present for notes 1 – 6)
Kate Kelley	NGC Guideline Lead	(Present for notes 1 – 6)
Mark Perry	NGC Senior Research Fellow	(Present for notes 1 – 6)
Maria Smyth	NGC Senior Research Fellow	(Present for notes 1 – 6)
Melina Vasileiou	NGC Research Fellow	(Present for notes 1 – 6)
David Wonderling	NGC Head of Health Economics	(Present for notes 1 – 6)
Giulia Zuodar	NGC Project Manager	(Present for notes 1 – 6)
Rupert Franklin	NICE Senior Guideline Commissioning Manager	(Present for notes 1 – 6)
Simran Chawla	NICE Patient and Public Involvement Adviser	(Present for notes 1 – 6)
Phil Ranson	NICE Digital Media Manager – Press	(Present for notes 1 – 6)
Helen Finn	NICE Enquiry Handling team	(Present for notes 1 – 6)

Observers:	
None.	

Interests Register							
ME/CFS Guideline committee				Publication Date: 14/10/2020			
Name	Role with NICE	Type of interest	Description of interest	Relevant dates			Comments
				Interest arose	Interest declared	Interest ceased	
Peter Barry	Committee chair		No interests to declare.				
Ilora Finlay	Committee vice chair		No interests to declare.				
Theo Anbu	Committee member	Direct Non-financial professional and personal ⁱ	Lead for the paediatric CFS/ME service at Alder Hey Children's NHS Foundation Trust. 2 sessions a week delivering the CFS service in Alder Hey.	2008	On application		No action other than the process of open declaration.
		Direct Non-financial	Member of the British Association for CFS/ME (BACME).	2012	On application		No action other than the process of open declaration.
		Direct Non-financial	Bell S, Anbu AT, Lydon C, McCaughrean. Evaluating Chronic Fatigue Syndrome service at Alder Hey Children's NHS Foundation Trust. Presented at the British Association for CFS/ME conference, October 2013.	2013	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Anbu AT, Vance Y, McCaughrean J, Lydon C, Cleary G. Patient and parent survey in a specialist paediatric CFS/ME service in Alder Hey Children's NHS Foundation trust. Presentation at the International Association for Chronic Fatigue Syndrome (IACFS), conference, Ottawa, Canada, September 2011.	2011	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Anbu AT. Chronic Fatigue Syndrome in Children. Audit of care in a UK based Paediatric CFS/ME specialist centre. Poster at the International Association for Chronic Fatigue Syndrome (IACFS) conference, Ottawa, Canada September 2011.	2011	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Anbu AT, Cleary G. Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in children. Paediatrics and Child Health 2009;19(2):84-89.	2009	On application		Included on the register for information ⁱⁱ .

Michael Beadsworth	Committee member	Direct Non-financial	Clinical Lead, Infectious Diseases, Clinical Pharmacology, Tropical Medicine and Sexual Health. RLUH.	2016	On application		Non-specific. No action other than the process of open declaration.
		Direct Non-financial	Clinical Lead for Chronic Fatigue Syndrome/ME Regional Services.	2014	On application		No action other than the process of open declaration.
		Direct Non-financial	Consultant Infectious Diseases/Tropical Medicine/General Internal Medicine (GIM), RLUH.	2007	On application		Non-specific. No action other than the process of open declaration.
		Direct Non-financial	Executive committee member of the British association CFS/ME (BACME).	2017	On application		Based on the need for the committee member's expertise and a balanced committee, and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open declaration will be required in participation.
		Direct Non-financial	Dye L, Close GL, Fraser WD, McArdle A, Beadsworth MBJ. Vitamin D status in chronic fatigue syndrome/myalgic encephalomyelitis: a cohort study from the North-West of England. <i>BMJ Open</i> . 2017;7(11):e015296.	2017	On application		Non-specific. No action other than the process of open declaration.
		Direct	McArdle, Gusnanto, Ealr, Sakellariou, Lawton, Owens, Close, Beadsworth	2017	On		Non- specific.

		Non-financial	and Dye. The role of IP-10 in Chronic Fatigue Syndrome. The FASEB journal published online 1 April 2017.		application		No action other than the process of open declaration.
		Direct Non-financial	Earl K., Sakellariou G., Owens D., Sinclair M., Fenech M., Close. G, Lawton C., Dye L., Beadsworth M., McArdle A The Role of Cytokines in Muscle Fatigue in Patients with Chronic Fatigue Syndrome (CFS). The FASEB journal Published Online:1 Apr 2015Abstract Number:1055.34	2015	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Non-financial and Indirect Non-financial	Co-investigator, Evaluation of aberrant mitochondrial function and cytokine production in skeletal muscle of patients with Chronic Fatigue Syndrome. (FATIGUE STUDY: MRC (MR/J002895/1, £250,000) Funding to RLUH. A MRC grant application to extend this study to be submitted in April 2019.	2015	On application	2017	Non- specific. No action other than the process of open declaration.
Joanne Bond-Kendall	Committee member	Direct Non-financial	Children's pain: we can make it better? Frontline, vol,6, March 2018 https://www.csp.org.uk/frontline/article/childrens-pain-we-can-make-it-better	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	A Brigden, M Loades, A Abbott, J Bond-Kendall, and E Crawley Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood Arch Dis Child. 2017 Oct; 102(10): 981–986.	2017	On application		No action other than the process of open Declaration.
		Direct Non-financial	FITNET trial. Role as part of the clinical team implementing the research and delivering both arms of the trial. Recruitment ongoing until May 2020.	2016	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	MAGENTA trial (Managed Activity Graded Exercise in Teenagers and Pre-Adolescents). Role to review aspects of the physiotherapy assessment process for MAGENTA participants and part of the clinical team implementing the research and delivering both arms of the trial. Recruitment closed March 2018.	2015	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of

							interest relating to this specific area and consider the actions needed.
Chris Burton	Committee member	Direct Non-financial	Clinical academic working includes management of people with persistent “medically unexplained” physical symptoms.	2017	On application		Non- specific. No action other than the process of open declaration.
		Direct Non-financial	Member of the European somatic symptoms research network (EuroNet Soma).	2015	On application		Non- specific. No action other than the process of open declaration.
		Direct Non-financial	Member of European Association for Psychosomatic Medicine.	2012	On application		Non- specific. No action other than the process of open declaration.
		Direct Financial	Invited lecture European Association for Psychosomatic Medicine conference in July 2019 in relation to primary care.		On application		Non- specific. No action other than the process of open declaration.
		Direct Financial	Invited lecture for German Association for Psychosomatic Medicine “Translating psychosomatic medicine into mainstream medicine”.	2018	On application		Non- specific. No action other than the process of open declaration.
		Direct Non-financial	Rosendal M, Olde Hartman TC, Aamland A, van der Horst H, Lucassen P, Budtz-Lilly A, et al. "Medically unexplained" symptoms and symptom disorders in primary care:prognosis-based recognition and classification. BMC Fam Pract. 2017;18(1):18.	2017	On application		Non- specific. No action other than the process of open declaration.

	Direct Non-financial	Rief W, Burton C, Frosthholm L, Henningsen P, Kleinstauber M, Kop WJ, et al. Core Outcome Domains for Clinical Trials on Somatic Symptom Disorder, Bodily Distress Disorder, and Functional Somatic Syndromes: European Network on Somatic Symptom Disorders Recommendations. <i>Psychosom Med.</i> 2017;79(9):1008-15.	2017	On application		Non- specific. No action other than the process of open declaration.
	Direct Non-financial	Morton L, Elliott A, Cleland J, Deary V, Burton C. A taxonomy of explanations in a general practitioner clinic for patients with persistent "medically unexplained" physical symptoms. <i>Patient Educ Couns.</i> 2017;100(2):224-30.	2017	On application		Non- specific. No action other than the process of open declaration.
	Direct Non-financial	den Boeft M, Huisman D, Morton L, Lucassen P, van der Wouden JC, Westerman MJ, et al. Negotiating explanations: doctor–patient communication with patients with medically unexplained symptoms—a qualitative analysis. <i>Family Practice.</i> 2017;34(1):107-13.	2017	On application		Non- specific. No action other than the process of open declaration.
	Direct Non-financial	Chowdhury S, Burton C. Associations of treatment effects between follow-up times and between outcome domains in interventions for somatoform disorders: Review of three Cochrane reviews. <i>J Psychosom Res.</i> 2017;98:10-8.	2017	On application		Non- specific. No action other than the process of open declaration.
	Direct Non-financial	Morton L, Elliott A, Thomas R, Deary V, Cleland J, Burton C. Developmental study of treatment fidelity, safety and acceptability of a Symptoms Clinic intervention delivered by General Practitioners to patients with multiple medically unexplained symptoms. <i>J Psychosom Res</i> 2016;84:37-43	2016	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial	Burton C, Lucassen P, Aamland A, Olde Hartman T. Explaining symptoms after negative tests: towards a rational explanation. <i>J R Soc Med</i> 2015;108:84-8	2015	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial	Burton C. Can we explain medically unexplained symptoms? <i>Family Practice</i> 2014; 31: 623-624.	2014	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial	van Gils A, Burton C, Bos EH, Janssens KAM, Schoevers RA, Rosmalen JGM. Individual variation in temporal relationships between stress and	2014	On application		Non- specific.

			functional somatic symptoms. <i>J Psychosom Res.</i> 2014; 77, 34-39.				Included on the register for information ⁱⁱ .
	Direct Non-financial		Rosendal M, Blankenstein A, Morriss R, Fink P, Sharpe M, Burton C. Enhanced care by generalists for functional somatic symptoms and disorders in primary care. <i>Cochrane Database of Systematic Reviews</i> 2013; 18/10/2013;10:CD008142.	2013	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		Burton C, Weller D, Worth A, Marsden W, Sharpe M. A primary care symptoms clinic for patients with medically unexplained symptoms: pilot randomised trial. <i>BMJOpen</i> 2012;2:e000513.	2012	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		Burton C, McGorm K, Richardson G, Weller D, Sharpe M. Health care costs incurred by patients repeatedly referred to secondary care with medically unexplained symptoms: a case control study. <i>J Psychosom.Res.</i> 2012;72:242-7.	2012	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		Burton C, McGorm K, Weller D, Sharpe M. Depression and anxiety in patients repeatedly referred to secondary care with medically unexplained symptoms: a casecontrol study. <i>Psychol Med</i> 2011; 41(3):555-563.	2011	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		Burton C, McGorm K, Weller D, Sharpe M. The interpretation of low mood and worry by patients with medically unexplained symptoms. <i>BMC Fam Pract</i> 2011;12:107	2011	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		McGorm K, Burton C, Weller D, Murray G, Sharpe M. Patients repeatedly referred to secondary care with symptoms unexplained by organic disease: prevalence, characteristics and referral pattern. <i>Fam Pract</i> 2010; 27(5):479-48	2010	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		Burton C, Heath R, Weller D, Sharpe M. Evidence of Reduced Complexity in Selfreport Data from Patients with Medically Unexplained Symptoms. <i>Nonlinear Dynamics in Psychology and the Life Sciences</i> 2010;14:15-25.	2010	On application		Non- specific. Included on the register for information ⁱⁱ .
	Direct Non-financial		Burton, C; Knoop, H; Popovic, N; Sharpe, M; Bleijenberg, G (2009). "Reduced complexity of activity patterns in patients with Chronic Fatigue Syndrome: a case control study". <i>BioPsychoSocial Medicine.</i> 3 (1): 7.	2009	On application		Included on the register for information ⁱⁱ .

			doi:10.1186/1751-0759-3-7. ISSN 1751-0759. PMC 2697171 PMID 19490619.				
		Direct Non-financial	Smith BJ, McGorm KJ, Weller D, Burton C, Sharpe M. The identification in primary care of patients who have been repeatedly referred to hospital for medically unexplained symptoms: a pilot study. <i>J Psychosom Res.</i> 2009;67:207-11.	2009	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Non-financial	Burton C, Weller D, Sharpe M. Are Electronic Diaries useful for Symptoms Research: A systematic review. <i>J Psychosom.Res.</i> 2007;62:553-61.	2007	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Non-financial	Burton C. Beyond Somatisation: a review of the understanding and management of medically unexplained physical symptoms (MUPS). <i>Br.J Gen.Pract.</i> 2003;53:233-41.	2003	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Non-financial	Burton CD. Hyperventilation in patients with recurrent functional symptoms. <i>Br.J Gen.Pract.</i> 1993;43:422-5.	1993	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Financial	Burton C. The ABC of Medically Unexplained Symptoms 2013; Wiley, London	2013	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Financial	Fink P, Burton C, deBie J, Sollner W, Fritzsche K. Current state of management and organisation of care. In: Creed F, Henningsen P, Fink P, editors. <i>Medically Unexplained Symptoms, Somatisation and Bodily Distress: developing better clinical services.</i> Cambridge: Cambridge University Press, 2011	2011	On application		Non- specific. Included on the register for information ⁱⁱ .
		Direct Non-financial and Indirect Non-financial	Burton C, Deary DV, Rowlands GR, Waheed W, Greco M, Nielson A, Cooper C, Dawson J, White D, Thomas R. Thomas S. Multiple Symptoms Study 3: pragmatic trial of a community based clinic for patients with persistent (medically unexplained)physical symptoms) NIHR HS&DR £1,194,291; Funding to the University of Sheffield.	2018	On application		Non- specific. No action other than the process of open declaration.
Saran Bonser	Committee member		No interests to declare.				
Sally Burch	Committee	Direct	Member of Hope 4 ME & Fibro Northern Ireland.	2012	On		No action other than

	member	Non-financial			application		the process of open declaration.
		Direct Non-financial	Trustee of Hope 4 ME & Fibro Northern Ireland.	2014	On application	2017	No action other than the process of open declaration.
		Direct Non-financial	Member of Patient & Client Council Northern Ireland: ME Working Group (representative for the charity Hope 4 ME & Fibro NI) Member of the subgroup for the employment of a ME clinical lead in Northern Ireland.	2016	On application	2018	No action other than the process of open declaration.
		Direct Non-financial	"Just ME" www.sallyjustme.blogspot.co.uk Blog hibernated October 2018.	2013	On application	2018	No action other than the process of open declaration.
		Direct Non-financial	Comments on the ME/CFS Patient forums listed below: <ul style="list-style-type: none"> • Chronic Fatigue Syndrome support • Phoenix Rising • Science 4 ME 	2012	On application	Lowered profile on ME forums since October 2018	No action other than the process of open declaration.
		Direct Non-financial	Brief talk. The #InvisibleME conference ,Belfast, organised by the Patient & Client Council.	2015	On application		Included on the register for information ⁱⁱ
		Direct Non-financial	Spoken at Hope 4 ME & Fibro NI events: <ul style="list-style-type: none"> • The James Coyne event • Chasing Competent Care Conference • Millions Missing Demonstration • Seeking Solutions Conference • NVTV interview on ME care in Northern Ireland 	2015-2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Talk at ePatient conference . Queens University Belfast	2017			No action other than the process of open declaration.

Tony Crouch	Committee member	Direct Non-financial	Social Work Advisor to 25% ME Group. Represents 25% ME Group at Forward ME.	2015	On application		No action other than the process of open declaration.
		Direct Non-financial	Social Work Advisor to The Young ME Sufferers (TYMES) Trust.	2002	On application		No action other than the process of open declaration.
		Direct Non-financial	Committee member on Chief Medical Officer's working group for ME (children).	2000	On application	2002	Included on the register for information ⁱⁱ
		Direct Non-financial	Invited by chief social worker for children and families to talk about ME and safe guarding and addressed a meeting of her Principal Social Workers Network.	2017	On application		No action other than the process of open declaration.
Jo Daniels	Committee member	Direct Non-financial	Honorary contract with NHS trust supervising clinical psychologists in the region working in medical settings and practicing cognitive behavioural therapy.	2009	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct financial	Private practice supervision of therapist in CBT funded by NHS.	2016	On application		Non-specific. The supervision does not involve a therapist working with people with ME/CFS. No action other than the process of open declaration.
		Direct Non-financial	Caswell & Daniels (2018) Anxiety and depression in chronic fatigue syndrome, prevalence and effects on treatment: A systematic review and metaregression British Association of Behavioural and Cognitive Psychotherapies .Conference presentation	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of

							interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Daniels (2018) The prevalence and treatment of health anxiety in Chronic Fatigue Syndrome (CFS) British Association of Behavioural and Cognitive Psychotherapy.Conference presentation.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	ActionforME. Presented at Bath screening of unrest on 14 th November 2017 https://www.actionforme.org.uk/news/unrest-screening-plus-q-and-a-in-bath-on-14-november/	2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Daniels, J. (2016) Therapeutic Alliance in Chronic Fatigue syndrome: invited speaker, skills workshop for British Association for CFS/ME National Conference, Milton Keynes, UK.	2016	On application		Included on the register for information ⁱⁱ
		Direct financial	Daniels, J (2013) Mental health screening in CFS/ME: Invited speaker, St Bartholomew Hospital CFS/ME Training day, Wolfson Institute of Preventative Medicine, London, UK. Honorarium estimated £200.	2013	On application		Included on the register for information ⁱⁱ
		Direct Non-financial	Daniels, J. (2012) The art of Engagement, Invited speaker, St Bartholomew Hospital CFS/ME Training day, Wolfson Institute of Preventative Medicine, London, UK.	2012	On application		Included on the register for information ⁱⁱ
		Direct Non-financial	Daniels, J. (2012) Socialization to the treatment model: developing clinical skills, skills workshop for 6th British Association for CFS/ME National Conference, Milton Keynes, UK.	2012	On application		Included on the register for information ⁱⁱ
		Direct Non-financial	Daniels, J. & Wearden, A. (2010) Illness cognitions and socialization to the treatment model: predictors of outcome in a randomised controlled trial for the treatment of CFS/ME, paper presented at the 38th Annual	2010	On application		At each meeting the chair will review this interest to determine

			Behavioural and Cognitive Psychotherapy Conference, Manchester, UK.				whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Roos, J. & Wearden A., (2010) Socialization to the treatment model and change in illness beliefs during Pragmatic Rehabilitation (PR) for Chronic Fatigue Syndrome, paper presented at the 6th World Congress of Behavioural and Cognitive Therapies, Boston, USA.	2010	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Roos, J. & Wearden, A. (2009) Socialization to the treatment model and outcome in pragmatic rehabilitation for Chronic Fatigue Syndrome: preliminary findings, poster presentation session at the 37th Annual Behavioural and Cognitive Psychotherapy Conference, Exeter, UK.	2009	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Daniels, Jo; Wearden, Alison J. (Mar 2011). "Socialization to the Model: The Active Component in the Therapeutic Alliance? A Preliminary Study". Behavioural and Cognitive Psychotherapy. 39 (2): 221–227. doi:10.1017/S1352465810000792. ISSN 1469-1833.	2011	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Daniels, J., Brigden, A, & Kurocova, A. (2017) Examining mood and anxiety in CFS/ME, Psychology and Psychotherapy, Research and Practice.	2017	On application		No action other than the process of open declaration.

		Direct Non-financial	Daniels J, Brigden A, Kacorova A (2017) Anxiety and depression in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): Examining the incidence of health anxiety in CFS/ME. Psychol Psychother. Sep;90(3):502-509. doi: 10.1111/papt.12118. Epub 2017 Feb 28.	2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Daniels, J. & Loades, M.E. (2016) A novel approach to treating CFS/ME and health anxiety: a case study, Clinical Psychology and Psychotherapy, 24 (3) 727-736.	2016	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Daniels, J., & O'Dowd, H., (2011) 'Chronic Fatigue Syndrome/Myalgic Encephalopathy' in Brook, P., Pickering, T., & Connell, J. (Ed.) 'Oxford Handbook of Pain Management', Oxford University Press: Oxford.	2011	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Daniels J, Wearden AJ. Socialization to the model: The active component in the therapeutic alliance? A preliminary study. Behavioural and cognitive psychotherapy. 2011 Mar;39(2):221-7.	2011	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Roos J, Wearden A. What do we mean by "socialization to the model"? A Delphi Study. Behavioural and cognitive psychotherapy. 2009 May;37(3):341-5.	2009	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Doctoral thesis. Illness Cognitions and Socialization to the treatment model in pragmatic rehabilitation for CFS/ME.	2009	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this

							specific area and consider the actions needed.
		Direct Non-financial and Indirect financial	North Bristol NHS Trust Springboard Fund .Lead applicant .Study extension: Developing an adapted treatment package for anxiety in Chronic Fatigue Syndrome/ME: a case series” £4,329. Funding to University of Bath.	2016	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial and Indirect financial	North Bristol NHS Trust Springboard Fund Lead applicant “Developing an adapted treatment package for anxiety in Chronic Fatigue Syndrome/ME: a pilot case series” £19,975. Funding to University of Bath.	2013	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial and Indirect financial	Supervision of doctoral students projects 1. Safety-seeking behaviours in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis: a pilot experimental investigation of typology and function. Submitted as part of a DClinPsy doctoral thesis and is currently being written up for publication. 2. Prevalence and effects of anxiety and depression on Chronic Fatigue Syndrome/ME treatment outcomes: a systematic review and meta-regression. Submitted as part of a DClinPsy doctoral thesis and is currently being written up for publication. 3. An evaluation of the current use of the Short health anxiety inventory in a specialist CFS/ME service. This was a small service evaluation project, Submitted as part of a DClinPsy doctoral thesis and is currently being written up for publication.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
Dorinda Jack	Committee member	Direct Non-financial	Member of ME North East, Carers Northumberland.	2008	On application		No action other than the process of open declaration.
		Direct Non-financial	Trustee of Carers Northumberland Trustee Board (voluntary).	2010	On application		Non-specific. No action other than the process of open declaration.
		Direct Non-financial	Chair of Carers Northumberland Trustee Board (voluntary)	2015	On application		Non-specific.

							No action other than the process of open declaration.
Nicola Kidby	Committee member	Direct Non-financial	Membership of Association of Young People with ME (AYME). This association now part of Action for ME.	2012	On application		No action other than the process of open declaration.
		Direct Non-financial	Volunteer with Healthwatch Central Bedfordshire	2014	On application		Non-specific. No action other than the process of open declaration.
Caroline Kingdon	Committee member	Direct Non-financial	UK ME/CFS Biobank, London School of Hygiene and Tropical Medicine Research Nurse.	2013	On application		No action other than the process of open declaration.
		Direct Non-financial	Nacul Luis Carlos, Mudie Kathleen, Kingdon Caroline C., Clark Taane G., Lacerda Eliana Mattos Hand Grip Strength as a Clinical Biomarker for ME/CFS and Disease Severity <i>Frontiers in Neurology</i> ,9,2018.	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	Lacerda Eliana M., Mudie Kathleen, Kingdon Caroline C., Butterworth Jack D., O'Boyle Shennae, Nacul Luis The UK ME/CFS Biobank: A Disease-Specific Biobank for Advancing Clinical Research Into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome <i>Frontiers in Neurology</i> 9, 2018.	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	Kingdon, CC; Bowman, EW; Curran, H; Nacul, L; Lacerda, EM; (2018) Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls. <i>Pharmacoeconomics</i> open. ISSN 2509-4262 DOI: 10.1007/s41669-018-0071-6.	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	Nacul, L; Lacerda, EM; Kingdon, CC; Curran, H; Bowman, EW; (2017) How have selection bias and disease misclassification undermined the validity of myalgic encephalomyelitis/chronic fatigue syndrome studies? <i>Journal of health psychology</i> . p. 1359105317695803. ISSN 1359-1053 DOI: 10.1177/1359105317695803.	2017	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this

							specific area and consider the actions needed.
		Direct Non-financial	Luis Nacul, Caroline C. Kingdon, Erinna W. Bowman, Hayley Curran & Eliana M. Lacerda (2017): Differing case definitions point to the need for an accurate diagnosis of myalgic encephalomyelitis/chronic fatigue syndrome, <i>Fatigue: Biomedicine, Health & Behavior</i> , DOI: 10.1080/21641846.2017.1273863.	2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Jain, V; Arunkumar, A; Kingdon, C; Lacerda, E; Nacul, L; (2017) Prevalence of and risk factors for severe cognitive and sleep symptoms in ME/CFS and MS. <i>BMC Neurol</i> , 17 (1). p. 117. ISSN 1471-2377 DOI: 10.1186/s12883-017-0896-0.	2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Lacerda, EM; Bowman, EW; Cliff, JM; Kingdon, CC; King, EC; Lee, JS; Clark, TG; Dockrell, HM; Riley, EM; Curran, H. (2017) The UK ME/CFS Biobank for biomedical research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and Multiple Sclerosis. <i>Open J Bioresour</i> , 4. ISSN 2056-5542 DOI: 10.5334/ojb.28.	2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Lacerda, EM; Kingdon, CC; Bowman, EW; Nacul, L; (2017) Using a participatory approach to develop and implement the UK ME/CFS Biobank. <i>Fatigue</i> , 6 (1). pp. 1-4. ISSN 2164-1846 DOI: https://doi.org/10.1080/21641846.2018.1396021 .	2017	On application		No action other than the process of open declaration.
Adam Lowe	Committee member	Direct Non-financial	Member of ME Association and TYMES Trust.	2016	On application		No action other than the process of open declaration.
		Direct Non-financial	Founder of Respect for ME Website not to be updated during guideline development.	2017	On application		No action other than the process of open declaration.
		Direct	I have volunteered with a number of charities and patient groups for ME.	2017	On		No action other than

		Non-financial			application		the process of open declaration.
		Direct Non-financial	Participation in online social media groups for: <ul style="list-style-type: none"> • #MEAction UK • Science 4 ME • Salford & Trafford ME Group Facebook group. 	2017	On application		No action other than the process of open declaration.
		Direct Non-financial	Online media presence various comments and responses: <p>https://www.nationalelfservice.net/other-health-conditions/chronic-fatigue-syndrome/a-pace-gate-or-an-editorial-without-perspectives/</p> <p>https://vadamagazine.com/lifestyle/health/no-confidence-charities-reject-nice-no-update-proposal-mecfs-guideline</p> <p>https://vadamagazine.com/entertainment/film/review-unrest-dir-jennifer-brea-2017</p>	2017	On application		No action other than the process of open declaration.
Jennifer McIntosh	Committee member	Direct financial	Manual of Dietetics (2014) Edited by Joan Gandy Chapter, CFS/ME and Diet. £70 completion of each chapter (£140 in total).	2014	On application		Included on the register for information ii
		Direct financial	Manual of Dietetics (2014) Edited by Joan Gandy Chapter, CFS/ME and Diet. 6th edition pending publication 2019.		On application		This interest will not be considered as an evidence publication to the committee. There is no action other than the process of open declaration.
		Direct Non-financial	Published chapter, Diet and CFS/ME Fighting for Fatigue, Sue Pemberton and Catherine Berry (2009) Hammersmith Press, London, UK.	2009	On application		Included on the register for information ii.
Gabrielle Murphy	Committee member	Direct Non-financial	Clinical Lead, Fatigue Service Directorate Infection and Immunity, The Royal Free London NHS Foundation Trust.	2003	On application		No action other than the process of open declaration.
		Direct	Chair of British Association for CFS/ME (BACME) 2004-2005 and 2006-	2004	On	2018	Based on the need for

		Non-financial	2018. Executive member 2005-2006.		application		the committee member's expertise and a balanced committee, and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open declaration will be required in participation.
		Direct Non-financial	Member of the MRC Collaborative 2016-2018 as chair of BACME.	2016	On application	2018	Based on the need for the committee member's expertise and a balanced committee, and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open declaration will be required in participation.
		Direct Non-financial	Member of the MRC Collaborative. Member of the Omics and Big Data working group.	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	International Collaboration on Fatigue Following Infection (COFFI) Lead of the organising committee for the international Collaboration on	2015	On application		No action other than the process of open

		and Indirect financial	Fatigue Following Infection (COFFI) which held its first meeting in London in 2015 and in its intention and ethic contributed to the protocol of the Mega Study. One of the aims was to link the ME/CFS biobanks across the globe. Funding from Sue Estermann Fund, donor approved and managed by the London Community Foundation who transfer funds into the Royal Free Charity account for the Fatigue Service.				declaration.
		Direct Non-financial	ME society. Medical Advisor to Sussex and Kent ME Society, 2007-2018.	2007	On application	2018	No action other than the process of open declaration.
		Direct Non-financial	Patron to Sussex and Kent ME Society.	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	Member of the subcommittee of the MRC collaborative for the James Lind Alliance for a Priority Setting Partnership (PSP) for ME/CFS.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Financial	International Conference on Fatigue Syndromes organised by the Departments N Copernicus University in Torun L Rydygier Collegium Medicum in Bydgoszcz Department of Hygiene, Epidemiology and Ergonomics Division of Ergonomics and Exercise Physiology. Talk titled Diagnosis and treatment of ME/CFS in the United Kingdom. Travel and accommodation costs.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non -Financial	Keynote speaker: The physical and the philosophical of CFS/ME: a review in the light of the new commissioning protocols. BACME Conference.	2018	On application		No action other than the process of open

							declaration.
	Direct Non-financial	Simon Collin, Gabrielle Murphy, Rona Moss-Morris, Vegard Bruun Wyller, Knut-Arne Wensaas, Jeannine Hautvast, Chantal Bleeker-Rovers, Ben Z Katz, Ute Vollmer-Conna Dedra Buchwald, Renée Taylor, Paul Little, Esther Crawley, Andrew Lloyd, Peter White on behalf of the COFFI Study Group. Cohort Profile: The Collaborative on Fatigue Following Infection (COFFI). Presented at the UK CFS/ME Collaborative Conference, 13-14 October 2015, Newcastle, UK.	2015	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Presenter: Workshop on Sleep and Fatigue Syndromes BACME Conference.	2010	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Russell, A. Heggul, N. Nikkheslat, N. Borsini, A. Zajkowska, Z. Moll, N. Forton, D. Agarwal, K. Chalder, T. Mondelli, V. Hotopf, M. Cleare, A. Murphy, G. Foster, G. Wong, T. Schütze, G.A. Schwarz, M.J. Harrison, N. Zunszain, P.A. Pariente, C.M. Persistent fatigue induced by interferon-alpha: a novel, inflammation-based, proxy model of Chronic Fatigue Syndrome <i>Psychoneuroendocrinology</i> (in press).		On application			At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
	Direct Non-financial	Ben Z Katz, Simon M Collin, Gabrielle Murphy, Rona Moss-Morris, Vegard Bruun Wyller, Knut-Arne Wensaas, Jeannine L.A. Hautvast, Chantal P Bleeker-Rovers, Ute Vollmer-Conna, Dedra Buchwald, Renée Taylor, Paul Little, Esther Crawley, Peter D White & Andrew Lloyd (2018) The international collaborative on fatigue following infection (COFFI), <i>Fatigue: Biomedicine, Health & Behavior</i> , 6:2, 106-121, DOI: 10.1080/21641846.2018.1426086.	2018	On application			At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
	Direct Non-financial	Clark LV, Buckland M, Murphy G, et al. <i>Cytokine responses to exercise and activity in patients with chronic fatigue syndrome: case-control study</i> . <i>Clinical and Experimental Immunology</i> , 2017 190:360-371, 10.1111/cei130123.	2017	On application			No action other than the process of open declaration.
	Direct Non-	White,PD, Chalder T, Sharpe M, Angus BJ, Baber HL, Bavinton J, Burgess	2018	On			At each meeting the

		financial	M, Clark LV, Cox DL, DeCesare JC, Goldsmith KA, Johnson AL, McCrone P, Murphy G, Murphy M, O'Dowd H, Potts L, Walwyn R, Wilks D Response to the editorial by Dr Geraghty. J Health Psychol. 2017 Aug;22(9):1113-1117. doi: 10.1177/1359105316688953. Epub 2017 Jan 24.		application		chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Fernie BA, Murphy G, Wells A, Nikčević AV, Spada MM Treatment Outcome and Metacognitive Change in CBT and GET for Chronic Fatigue Syndrome. Behav Cogn Psychother. 2016 Jul;44(4):397-409. doi: 10.1017/S135246581500017X. Epub 2015 Apr 21.	2016	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Fernie BA, Maher-Edwards L, Murphy Gabrielle, et al. <i>The Metacognitions about Symptoms Control Scale: Development and Concurrent Validity</i> Clin.Psychol.Psychother 2014 DOI: 10.1002/cpp.1906.	2014	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Lorraine Maher-Edwards, Bruce A. Fernie, Gabrielle Murphy, Marcantonio M. Spada. Metacognitive Factors in Chronic Fatigue Syndrome Clinical Psychology & Psychotherapy (2012).	2012	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	P D White, K A Goldsmith, A L Johnson, L Potts, R Walwyn, J C DeCesare, H L Baber, M Burgess, L V Clark, D L Cox, J Bavinton, B J Angus, G Murphy, M Murphy, H O'Dowd, D Wilks, P McCrone, T Chalder*, M Sharpe*, on behalf of the PACE trial management group†. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. Lancet 2011; 377: 823–36.	2011	On application		Declare and withdraw from drafting recommendations on the non-pharmacological management of ME/CFS. The committee member may be asked to respond to specific questions from the committee regarding this paper.

		Direct Non-financial	Lorraine Maher-Edwards, Bruce A. Fernie, Gabrielle Murphy, Adrian Wells, Marcantonio M. Spada. Metacognitions and negative emotions as predictors of symptom severity in chronic fatigue syndrome. J Psychosom Res 2011; 70: 311–317.	2011	On application		Included on the register for information ⁱⁱ .
		Direct financial	Fernie, B and Murphy, G Coping Better with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, Karnac 2009. Royalties used for an E-book conversion and no royalties have been received.	2009	On application		Included on the register for information ⁱⁱ .
		Direct Non-financial	Member of trial management group for PACE trial 2007-2010.	2007	On application	2010	Declare and withdraw from drafting recommendations on the non-pharmacological management of ME/CFS .The committee member may be asked to respond to specific questions from the committee regarding this paper.
		Direct Non-financial	Cosignatory of a letter in national newspapers including the TIMES and Independent supporting PACE https://www.independent.co.uk/voices/letters/ios-letters-emails-online-postings-2-december-2012-8373777.html .	2012	On application		Declare and withdraw from drafting recommendations on the non-pharmacological management of ME/CFS .The committee member may be asked to respond to specific questions from the committee regarding this paper.
		Direct Non-financial and Indirect	Lead investigator: Eye Movement Desensitisation and Reprocessing (EMDR): case series pilot Funding by the Susan Estermann Fund to The Royal Free Charity Due to start in May 2019		On application		No action other than the process of open declaration.

		financial					
		Direct Non-financial and Indirect financial	Lead investigator: Joint Hypermobility Syndrome, Postural Orthostatic Tachycardia Syndrome, and the frequency in a busy London Fatigue Clinic – a case series. Funding application made to the Susan Estermann Fund and will go to The Royal Free Charity to manage.		On application		No action other than the process of open declaration.
Luis Nacul	Committee member	Direct Non-financial	Clinical Associate Professor at London School of Hygiene and Tropical Medicine.	2014	On application		No action other than the process of open declaration.
		Direct Non-financial and Indirect Non-financial	Lead on CureME project, this includes the ME biobank. CureMe has ongoing investment from The ME Association Ramsay Research Fund funding to LSHTM.	2011	On application		No action other than the process of open declaration.
		Direct Non-financial	Health and Equity Needs Assessment work in ME/CFS (for 6 CCGs in Suffolk and Norfolk).	2015	On application		No action other than the process of open declaration.
		Direct Non-financial	Member of European network of researchers in ME/CFS.	2015	On application		No action other than the process of open declaration.
		Direct Non-financial	Board Member of the International Association of Chronic Fatigue Syndrome.	2018	On application		Based on the need for the committee member's expertise and a balanced committee, and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open

							declaration will be required in participation.
		Direct Non-financial	International Advisor for the Canadian Collaborative in ME/CFS.	2018	On application		No action other than the process of open declaration.
		Direct Non-financial	Advisor for ME Trust.	2018	On application		Based on the need for the committee member's expertise and a balanced committee, and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open declaration will be required in participation.
		Direct Non-financial	Nacul L. UK ME/CFS Biobank. A resource for international research. ME/CFS Canadian Collaborative Team Conference. Advancing an international research agenda to address ME/CFS research priorities: from basic research to clinical practice. Montreal, Canada, 5-7 May 2018.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Nacul L. Epidemiological and clinical research in ME/CFS: How can they support hypothesis generation and testing? ME/CFS Canadian Collaborative Team Conference. Advancing an international research agenda to address ME/CFS research priorities: from basic research to clinical practice. Montreal, Canada, 5-7 May 2018.	2018	On application		No action other than the process of open declaration.

Direct Non-financial	Nacul L. Research and services needs for ME/CFS. In: Special Session in Epidemiology: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Fact, Fiction, Findings. American Public Health Association 2017 Meeting. Atlanta, GA, US, 4-8 Nov 2017.	2017	On application		No action other than the process of open declaration.	
Direct Non-financial	Lacerda, EM; Kingdon, CC; Bowman, EW; Nacul, L; (2017) Using a participatory approach to develop and implement the UK ME/CFS Biobank. <i>Fatigue</i> , 6 (1). pp. 1-4. ISSN 2164-1846 DOI: https://doi.org/10.1080/21641846.2018.1396021 .	2017	On application		No action other than the process of open declaration.	
Direct Non-financial	Nacul L. The Case for Stratification in ME/CFS: Experience from the UK ME/CFS Biobank (+ 5 poster presentations). 2016 IACFS/ME Conference, Fort Lauderdale, Fla, US, 27-30 Oct 2016.	2017	On application		No action other than the process of open declaration.	
Direct Non-financial	Nacul L. Protocols and Patient Databases for ME/CFS. The Biomedical Research into ME Colloquium 6 (BRMEC6), London, UK, 1, 2 June 2016.	2016	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	Nacul Luis Carlos, Mudie Kathleen, Kingdon Caroline C., Clark Taane G., Lacerda Eliana Mattos Hand Grip Strength as a Clinical Biomarker for ME/CFS and Disease Severity <i>Frontiers in Neurology</i> ,9,2018.	2018	On application		No action other than the process of open declaration.	
Direct Non-financial	Lacerda Eliana M., Mudie Kathleen, Kingdon Caroline C., Butterworth Jack D., O'Boyle Shennae, Nacul Luis The UK ME/CFS Biobank: A Disease-Specific Biobank for Advancing Clinical Research Into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome <i>Frontiers in Neurology</i> 9, 2018.	2018	On application		No action other than the process of open declaration.	
Direct Non-financial	Kingdon, C.C. ; Bowman, E.W. ; Curran, H. ; Nacul, L. ; Lacerda, E.M. ; Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls. <i>Pharmacoecon Open</i> (2018) ; DOI: 10.1007/s41669-018-0071-6; PMID: 29536371 Open Access.	2018	On application		No action other than the process of open declaration.	
Direct Non-financial	Jain, V. ; Arunkumar, A. ; Kingdon, C. ; Lacerda, E. ; Nacul, L. ; Prevalence of and risk factors for severe cognitive and sleep symptoms in ME/CFS and MS. <i>BMC Neurol</i> (2017) 17(1):117; DOI: 10.1186/s12883-017-0896-0; PMID: 28633629 Open Access	2018	On application		No action other than the process of open declaration	
Direct Non-financial	Luis Nacul, Caroline C. Kingdon, Erinna W. Bowman, Hayley Curran & Eliana M. Lacerda (2017): Differing case definitions point to the need for	2017	On application		No action other than the process of open	

			an accurate diagnosis of myalgic encephalomyelitis/chronic fatigue syndrome, <i>Fatigue: Biomedicine, Health & Behavior</i> , DOI: 10.1080/21641846.2017.1273863.				declaration.
	Direct Non-financial		Nacul, L.; Lacerda, E.M.; Kingdon, C.C.; Curran, H.; Bowman, E.W. How have selection bias and disease misclassification undermined the validity of myalgic encephalomyelitis/chronic fatigue syndrome studies? <i>Journal of Health Psychology</i> (2017) :1359105317695803; DOI: 10.1177/1359105317695803 Open Access.	2017	On application		Declare and withdraw from drafting recommendations on the non-pharmacological management of ME/CFS .The committee member may be asked to respond to specific questions from the committee regarding this paper.
	Direct Non-financial and Indirect Non-financial		A longitudinal immunological and virological study for ME CFS biomarker discovery. Role: PI with Prof HM Dockrel 5R01AI103629 (US National Institute Health \$1,588,225)PI: L. Nacul & HM Dockrell.06/13-08/21 Funding to LSHTM.	2013	On application		No action other than the process of open declaration.
	Direct Non-financial and Indirect Non-financial		1R21AI121759-01A1 (NIH) PI: J Cliff 08/16-07/18 Droplet digital PCR for evaluation of associations between human herpesvirus infection and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Role: Co-Investigator. Funding to LSHTM.	2016	On application		No action other than the process of open declaration.
	Direct Non-financial and Indirect Non-financial		ITCRZH3910 (ME Association) "Opening the UK ME/CFS Biobank" 01/16-12/18. Opening the UK Myalgic Encephalopathy/ Chronic Fatigue Syndrome (ME/CFS) Biobank Role: PI with Dr E Lacerda, Funding to LSHTM.	2016	On application		No action other than the process of open declaration.
	Direct Non-financial		Local review of the ME/CFS Specialist Service in the UK.	2015	On application		No action other than the process of open declaration.

Charles Shepherd	Co-optee Committee member	Direct Non-financial	Trustee and Honorary medical adviser to the ME Association.	2003	On application		Based on the need for the committee member's expertise and a balanced committee, and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open declaration will be required in participation.
		Direct Financial	Private practice exclusive to ME/CFS.	2000	On application		Following a review of this interest by NICE, it was agreed that on balance it was appropriate for Dr Shepherd to fully participate in discussions, given the relevance of his experience in this area. No action other than the process of open declaration.
		Direct Non-financial	Chairman of the ME/CFS Biobank Steering Group.	2015	On application		No action other than the process of open declaration.
		Direct Non-financial	Member of the Executive Board of the UK CFS/ME Research Collaborative (CMRC).	2013	On application		Based on the need for the committee member's expertise and a balanced committee,

							and in acknowledgement of the difficulty in finding an individual without potential conflict of interest, in this instance NICE has confirmed that no action other than the process of open declaration will be required in participation.
		Direct Non-financial	Member of the MRC multidisciplinary expert advisory group on ME/CFS research.	2008	On application	2010	Included on the register for information ⁱⁱ .
		Direct Non-financial	Member of the ME/CFS Tissue Archive (post-mortem tissue) Feasibility Study Group.	2010	On application		No action other than the process of open declaration.
		Direct Non-financial	Member and Honorary Treasurer of the Melvin Ramsay Society.	1991	On application		No action other than the process of open declaration.
		Direct Non-financial	Member of the Forward ME Group of charities. A group of ME/CFS patient support and research funding charities that meets under the chairmanship of the Countess of Mar at the House of Lords.	2008	On application		No action other than the process of open declaration.
		Direct Non-financial	Member of the Fluctuating Conditions Group (FCG) set up by the Department of Work and Pensions (DWP).	2009	On application	2015	Included on the register for information ⁱⁱ
		Direct Non-financial	Member of ME Observatory Steering Group. A collaborative epidemiological research programme involving academics from the University of East Anglia, Hull and York Medical School, and the London School of Hygiene and Tropical Medicine.	2006	On application	2011	Included on the register for information ⁱⁱ
		Direct Non-financial	Member of the PRIME Project Steering Group. A research initiative funded by the GUS charitable trust and various ME/CFS charities. This work is now completed.	2003	On application	2004	Included on the register for information ⁱⁱ

	Direct Non-financial	Member of the 'Expert Group' of health professionals that answered questions from the public on all aspects of management of ME/CFS for an on-line health clinic for NHS Choices.	2013	On application		Non-specific. No action other than the process of open declaration.
	Direct Non-financial	Member of a consultative group set up by the Department of Health (2004) to monitor the planning and development of 50 new hospital-based multidisciplinary clinical services in England for people with ME/CFS.	2004	On application		Included on the register for information ⁱⁱ
	Direct Non-financial	Member of the Secretariat that advised the All Party Parliamentary Group on ME. Proposed changes to medical guidelines on ME/CFS for use by decision makers at the Department of Work and Pensions (July 2005) ME/CFS Research to Oral Hearings of the Gibson Inquiry (July 2006) NHS Services to Oral Hearings of Inquiry into NHS Services for people with ME/CFS (July 2009).	2004	On application	2016	Included on the register for information ⁱⁱ
	Direct Non-financial	Member of the Chief Medical Officer's Working Group on ME/CFS which produced the 2002 CMO report on ME/CFS website: http://www.dh.gov.uk (CMO publications section).	2000	On application	2002	Included on the register for information ⁱⁱ
	Direct Non-financial	Member of the former Department of Social Security Expert Group on Chronicity and Prognosis in ME/CFS. A <i>British Medical Journal</i> summary of the report (1996) produced by this group is available at: http://bmj.bmjournals.com/cgi/content/full/313/7061/885/a .	1996	On application	2002	Included on the register for information ⁱⁱ
	Direct Non-financial	Action for ME (AfME). Provision of clinical/medical input to residential courses run by the charity Action for ME. The courses were previously run at the Ammerdown Centre in Somerset.	2003	On application	2005	Included on the register for information ⁱⁱ
	Direct Non-financial	Recent presentations have involved helping to organise and take part in medical panel discussions in relation to the film Unrest during 2017 and 2018. Locations here have included the House of Commons (Speakers State Rooms), Stormont in Northern Ireland, University Medical Schools in	2017	On application		Non-specific No action other than the process of open declaration.

		Cardiff, Sheffield and Lieden (Holland).				
Direct Non-financial	Regular media contributions on the subject of ME/CFS. Numerous interviews for BBC radio and TV programmes - including Radio 4 'Today', BBC Radio 2 (Jeremy Vine) BBC 5 Live news, BBC Breakfast Time, BBC Radio Scotland news, and the BBC health website.	2000	On application		Non-specific. No action other than the process of open declaration.	
Direct Non-financial	ME/CFS/PVFS – An exploration of the key clinical issues. ME Association. May 2018. Lead author with Dr Abhijit Chaudhuri, Consultant Neurologist, Essex Centre for Neurological Sciences, Queens Hospital, Romford, Essex.	2018	On application		Non-specific. No action other than the process of open declaration.	
Direct Non-financial	Numerous medical lectures and training sessions to both health professionals and people with ME/CFS over the past 30 years.	1988	On application		Included on the register for information ⁱⁱ	
Direct Non-financial	PACE trial claims for recovery in myalgic encephalomyelitis/chronic fatigue syndrome – true or false? It's time for an independent review of the methodology and results. Shepherd CB. <i>Journal of Health Psychology</i> , 2018, 22, 1187-1191.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.	
Direct Non-financial	Cosignatory on Forward ME Letter to The Times: Patients with ME/CFS 'are not simply "deconditioned" as claimed by many psychiatrists' 23 March 2018.	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.	
Direct Non-financial	Cosignatory on http://www.virology.ws/2017/03/13/an-open-letter-to-psychological-medicine-about-recovery-and-the-pace-trial/ Criticism of PACE.	2017	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of	

							interest relating to this specific area and consider the actions needed.
	Direct Non-financial	Problems with the PACE trial. Shepherd CB. <i>Psychological Medicine</i> , 2013, 43, 1790 – 1791.	2013	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Chronic fatigue syndrome: severely affected, severely neglected. Shepherd CB <i>British Medical Journal</i> , 2010, 340, 1181.	2010	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Exploring the feasibility of establishing a disease-specific post-mortem tissue bank in the UK: a case study in ME/CFS. Lacerda EM, Nacul L, Pheby D, Shepherd C, Spencer P <i>Journal of Clinical Pathology</i> , 2010, 63, 1032 – 1034.	2010	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	High-profile case highlights issues surround assisted suicide. Shepherd CB <i>British Journal of Neuroscience Nursing</i> , 2010, 6, 58.	2010	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Managing my ME – What people with ME/CFS and their carers want from the UK's health and social services. MEA publication.	2010	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Supported Dr Des Turner MP and the All Party Parliamentary Group on ME in the preparation of their report: Inquiry into NHS Service Provision for People with ME.	2009	On application	2010		Included on the register for information ⁱⁱ .
	Direct Non-financial	Neuropathology of post-infectious chronic fatigue syndrome. Cader S, O'Donovan D.G., Shepherd C., Chaudhuri A. <i>Journal of the Neurological Sciences</i> 2009 (S60-S61).	2009	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	ME: Chronic fatigue syndrome or a distinct clinical entity? Goudsmit E, Shepherd C, Dancey CP & Howes S. <i>Health Psychology Update</i> , 2009, 18, 26 – 33.	2009	On application			Included on the register for information ⁱⁱ .
	Direct Non-financial	Supported Dr Gregor Purdie in the preparation of the <i>Scottish Good Practice Statement</i> on ME/CFS.	2008	On application	2010		Included on the register for information ⁱⁱ .
	Direct Non-financial	ME guideline is unworkable. Shepherd CB. <i>British Medical Journal</i> , 2007, 335, 528.	2007	On application			Included on the register for information ⁱⁱ .

Direct Non-financial	ME/CFS – A guide to Research, Diagnosis and Management. Shepherd CB. Sussex ME/CFS Society. January 2007 (third edition).	2007	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	The debate: Myalgic encephalomyelitis and chronic fatigue syndrome. Shepherd CB. <i>British Journal of Nursing</i> , 2006, 15, 662 – 669.	2006	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	ME Diagnosis: Delay Harms Health – A Report from the ME Alliance. ME Alliance, April 2005. Available on-line at: http://www.meassociation.org.uk (lead author).	2005	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	'Living with ME' – Vermilion/Random House. ISBN: 0-09-181679-3 (third edition). Organised the re-publication of Dr Melvin Ramsay's historical account of ME/CFS: <i>Myalgic encephalomyelitis and postviral fatigue states. The saga of Royal Free Disease</i> . This was republished in July 2005 by The ME Association. ISBN: 0-09550490-1-6.	2005	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	Patients with chronic fatigue syndrome are being ignored. Shepherd CB <i>British Medical Journal</i> , 2004, 329, 1405.	2004	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	Editorial on CFS was biased, inaccurate and misleading. Shepherd CB. <i>British Medical Journal</i> , 2002, 324, 914.	2002	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	Cognitive behaviour therapy for chronic fatigue syndrome. Shepherd CB <i>Lancet</i> , 2001, 358, 239.	2001	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	Pacing and exercise in chronic fatigue syndrome. <i>Physiotherapy</i> , 2001, 87, 395 – 396.	2001	On application		Included on the register for information ⁱⁱ .	
Direct Non-financial	ME association. I take the lead role in assessing, monitoring and supervising the research portfolio that is funded by The ME Association's Ramsay Research Fund (RRF). Full details of current and past research funded by the MEA RRF can be found on the research section of the MEA website: http://www.meassociation.org.uk/research/ .	2000 to date	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and	

		<p>Some of the key research previously funded by the MEA RRF includes:</p> <p>Professor Derek Pheby et al (University of the West of England) - factors that may be associated with the development of severe ME/CFS.</p> <p>Professor John Gow et al (Institute of Neurological Sciences, University of Glasgow) - gene expression in ME/CFS .</p> <p>Professor Julia Newton et al (University of Newcastle) - abnormalities in muscle energy metabolism in ME/CFS.</p> <p>Current: ME/CFS Biobank at University College London (Royal Free Hospital and LSHTM) – where we fund all the basic running costs amounting to approx. £80,000 per year.</p> <p>Current: Professor Jo Cambridge et al (UCL) and Dr Luis Nacul et al (LSHTM/ME Biobank) - immune system study examining B and T cell status and defects in energy metabolism.</p> <p>Current: Dr Keith Geraghty (University of Manchester) – academic appointment which is examining the theoretical basis of CBT and GET in relation to ME/CFS.</p> <p>Current: Professor Elisa Oltra (University of Valencia, Spain) - Role of microRNAs.</p> <p>Recent: Dr Amolak Bansal et al – exercise physiology and cognitive function (St Helier Hospital, Surrey).</p> <p>Recent: Professor Jason Ellis et al – sleep and sleep management (Northumbria Centre for Sleep Research, University of Northumbria)</p> <p>Recent: Professor Anne McArdle et al – RRF co-funded a muscle mitochondrial function study with the MRC (University of Liverpool).</p> <p>Recent: Professor Jo Nijs et al – post-exertional malaise study (Vrije University Brussels, Belgium and Dr Lorna Paul, University of Glasgow).</p>				consider the actions needed.
	Direct Non-financial	Assistance to the National Horizon Scanning Centre at the University of Birmingham in the production of their assessment for the NHS and NICE of Ampligen (poly1:poluC12U) - a possible new pharmacological treatment for ME/CFS.	2003	On application		No action other than the process of open declaration.
	Direct financial	Medico-legal work in relation to both civil and criminal matters concerning people with ME/CFS. Expert for people with ME/CFS.	2000	On application		No action other than the process of open declaration.

Alan Stanton	Committee member	Direct Non-financial	Member of the RCPCH Guideline development group on the management of CFS/ME 2004.	2004	On application		Included on the register for information ⁱⁱ
		Direct Non-financial	Stanton and Powell (2013) Discharge against medical advice (DAMA) forms- a damaging document? Child Abuse Review, 22(5): 377-380.	2013	On application		Included on the register for information ⁱⁱ .
Susan Watson	Committee member		No interests to declare.				
William Weir	Committee member	Direct Non-financial	Consultant in infectious diseases. Locum consultant usually in acute medicine (full time).		On application		No action other than the process of open declaration.
		Direct Financial	Private practice 2 days a month approximately 8-10 ME patients a month. Medico-legal work in relation to both civil and criminal matters concerning people with ME/CFS.		On application		Following a review of this interest by NICE, it was agreed that on balance it was appropriate for Dr Weir to fully participate in discussions, given the relevance of his experience in this area. No action other than the process of open declaration.
		Direct Non-financial	Press and social media publications. Quoted in Guardian article. https://www.theguardian.com/society/2018/may/06/missing-the-fizz-my-long-battle-to-understand-the-mysteries-of-me ME: bitterest row yet in a long saga independent 2012 I spent £20,000 trying to beat ME with quack cures. And all I really needed to do was slow down. Mail 2008 BBC Radio 4, You and Yours - Transcript 05.11.07 - ME Discussion (Peter White) Dr William Weir on UTV: irrefutable evidence of immunological dysfunction in ME	2018	On application		At each meeting the chair will review this interest to determine whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
		Direct Non-financial	Cosignatory on Forward ME Letter to The Times: Patients with ME/CFS 'are not simply "deconditioned" as claimed by many psychiatrists' 23 March 2018.	2018	On application		At each meeting the chair will review this interest to determine

							whether there are any potential conflicts of interest relating to this specific area and consider the actions needed.
	Direct Non-financial	Cosignatory on http://www.virology.ws/2017/03/13/an-open-letter-to-psychological-medicine-about-recovery-and-the-pace-trial/ Criticism of PACE.	2017	On application			No action other than the process of open declaration.
	Direct Non-financial	Invited talks to Hope for ME Fibro Northern Ireland.	2018	On application			No action other than the process of open declaration.
	Direct Non-financial	Seminars to Medical specialist trainees. Manchester.	2018	On application			No action other than the process of open declaration.
	Direct Non-financial	Member of Chief medical officers working group on ME/CFS.	2000	On application	2002		Included on the register for information ⁱⁱ
	Direct Non-financial	BMJ Response: Tackling fears about exercise is important for ME treatment, analysis indicates 2015	2015	On application			Included on the register for information ⁱⁱ .

Apologies:

Amy Kelsey

NGC Senior Project Manager

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the first meeting of the ME/CFS guideline. The Committee members and attendees introduced themselves.

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

2. Confirmation of matter under discussion, and declarations of interest

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

- Diagnostic criteria
- Diagnostic tests
- Differential diagnoses

The Chair asked everyone to verbally declare any interests.

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

3. Presentations

The Chair introduced Rupert Franklin, NICE Senior Guideline Commissioning Manager, who gave a presentation on the role of the Guideline Commissioning Manager and working with NICE.

The Chair introduced Simran Chawla, NICE Patient and Public Involvement Adviser, who gave a presentation on patient involvement.

The Chair introduced Phil Ranson, NICE Digital Media Manager, and Helen Finn, NICE Enquiry Handling team, who gave a presentation on the role of the NICE Communications team.

The Chair gave a presentation on the scope outline, review questions and timeline of the guideline.

4. Questions and discussion

<p>The Committee discussed the following draft review protocols and were given the opportunity to ask questions.</p> <ul style="list-style-type: none"> • Diagnostic criteria • Diagnostic tests • Differential diagnoses
<p>5. Other issues</p>
<p>Kate Kelley gave a presentation on the information surrounding a call for evidence.</p>
<p>6. Any other business</p>
<p>None.</p>

Date of next meeting: 29/03/2019

Location of next meeting: Diploma Suite, Holiday Inn London Bloomsbury

ⁱ Non-financial professional and personal interests will now referred to as ‘non-financial’ throughout the table

ⁱⁱ [The policy](#) states that for members and the committee chair, the register will include the interests from the date of appointment plus the preceding 12 months. For reference this register includes information and publications that will not be considered as published evidence to the committee and are outside of the preceding 12 months from the date of appointment.