

Stakeholder Organisation	Evidence Submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Published / Unpublished material	How the evidence can be obtained (For published material, please include full reference details; author, date of publication, full title of paper/report and where can a copy be obtained from)
25% ME GROUP	ME ICC ICC 2011 for ME only. In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term 'Myalgic Encephalomyelitis' (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization's International Classification of Diseases (ICD G93.3). This is the only Criteria that can diagnose Mild to Very Severe within weeks so that Patients can begin to learn how to cope with this disease.	Published	https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x Carruthers, B. M., van de Sande, M. I., De Meirleir, K. L., Klimas, N. G., Broderick, G. , Mitchell, T. , Staines, D. , Powles, A. C., Speight, N. , Vallings, R. , Bateman, L. , Baumgarten-Austrheim, B. , Bell, D. S., Carlo-Stella, N. , Chia, J. , Darragh, A. , Jo, D. , Lewis, D. , Light, A. R., Marshall-Gradisbik, S. , Mena, I. , Mikovits, J. A., Miwa, K. , Murovska, M. , Pall, M. L. and Stevens, S. (2011), Myalgic encephalomyelitis: International Consensus Criteria. Journal of Internal Medicine, 270: 327-338. doi: 10.1111/j.1365-2796.2011.02428.x
25% ME GROUP	IC Primer for ME - The IC Primer was written to provide clinicians a one-stop, user-friendly reference for ME ICC-2011. It includes a concise summary of current pathophysiological findings upon which the ICC are based. A comprehensive clinical assessment and diagnostic worksheet enables clear and consistent diagnosis of adult and paediatric patients world-wide. The treatment and management guidelines offer a blueprint for a personalized, holistic approach to patient care, and include nonpharmaceutical and pharmaceutical suggestions. Patient self-help strategies provide recommendations for energy conservation, diet, and more. Educational considerations for children are included.	Published	http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20Consensus%20Primer%20-2012-11-26.pdf MYALGIC ENCEPHALOMYELITIS – Adult & Paediatric: International Consensus Primer for Medical Practitioners Authors – International Consensus Panel: Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T, Staines D, Powles ACP, Speight N, Vallings R, Bateman L, Bell DS, Carlo-Stella N, Chia J, Darragh A, Gerken A, Jo D, Lewis D, Light AR, Light K, MarshallGradisnik S, McLaren-Howard J, Mena I, Miwa K, Murovska M, Steven S ISBN 978-0-9739335-3-6 Publishers: Carruthers & van de Sande

25% ME GROUP	<p>ME/CFS CCC - Canadian Consensus Criteria 2003 for ME/CFS</p> <p>2003 the CCC is a clinical working case definition to assist physicians and other clinicians in making a diagnosis of ME/CFS. Because fatigue can be present in many other illnesses, the CCC requires for a diagnosis of ME/CFS the presence of four cardinal symptoms—fatigue, PEM, sleep dysfunction, and pain—as well as minor symptoms grouped by region of pathogenesis.</p>	Published	<p>https://www.researchgate.net/scientific-contributions/200115702_Bruce_M_Carrutherscontributions/2001157072_Bruce_M_Carruthers</p> <p>Carruthers, Bruce & Jain, Anil & Meirleir, Kenny & Peterson, Daniel & Klimas, Nancy & Lerner, A. & Bested, Alison & Flor-Henry, Pierre & Joshi, Pradip & Powles, Peter & Sherkey, Jeffrey & Sande, Marjorie. (2011). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome. 11. Dec. 2011</p>
25% ME GROUP	<p>Australia 2018/19 - Established the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Advisory Committee under section 39 of the National Health and Medical Research Council Act 1992 to advise the NHMRC Chief Executive Officer on the current needs for research and clinical guidance on ME/CFS. The Committee finalised its report in late April 2019. The Australian Bar of Standard for both Diagnostics & Research is the Canadian Consensus Criteria (CCC 2003) for ME/CFS and the International Consensus Criteria (ICC 2011) for ME.</p>	Published	<p>NHMRC 2019</p> <p>NHMRC established the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Advisory Committee under section 39 of the National Health and Medical Research Council Act 1992 to advise the NHMRC Chief Executive Officer in late April 2019.</p> <p>https://www.nhmrc.gov.au/health-advice/all-topics/myalgic-encephalomyelitis-and-chronic-fatigue-syndrome</p>
25% ME GROUP	<p>Nursing Care – A very in-depth guide for understanding the high quality nursing care moderate to severe to very severe patients. This particular group of patients are not seen in the majority of Medical clinics as they cannot be easily moved or approached This study aims to raise nurses' awareness of Myalgic Encephalomyelitis (ME). Key symptoms are presented along with possible service responses and treatment options. It emphasises that this condition is often misunderstood but that it can be</p>	Published	<p>https://pdfs.semanticscholar.org/29b6/1d250063c5d5e779b4a786092d9ae292a6a9.pdf?_ga=2.67828689.1317247922.1567683271-1321782229.1567683271&fbclid=IwAR31cnowocFnB9cmVfNKrTPIBbK7IAAd2ArrpipahcxqHaxir2svN9M_WYs</p> <p>Crowhurst G (2005) Supporting people with severe myalgic encephalomyelitis. Nursing Standard. 19, 21, 38-43. Date of acceptance: September 28 2004.</p> <p>February 2/ vol. 19 / no. 21 / 2005 Nursing Standard</p>

	serious and more research is needed to promote better understanding of the physical symptoms.		
25% ME GROUP	Brain Scans, SPECT & Qeeg can show inflammation of brain and how the brain is functioning. Griffith University: Autonomic correlations with MRI are abnormal in the brainstem vasomotor centre in Chronic Fatigue Syndrome using the CCC 2003. Abnormal regressions were detected in nuclei of the brainstem vasomotor centre, midbrain reticular formation and hypothalamus, but also in limbic nuclei involved in stress responses and in prefrontal white matter. Group comparisons of CFS and NC did not find MRI differences in these locations. We propose therefore that these regulatory nuclei are functioning correctly, but that two-way communication between them is impaired in CFS and this affects signalling to/from peripheral effectors/sensors, culminating in inverted or magnified correlations.	Published	https://www.ncbi.nlm.nih.gov/pubmed/27114901 Neuroimage Clin. 2016 Mar 31;11:530-537. doi: 10.1016/j.nicl.2016.03.017. eCollection 2016. Autonomic correlations with MRI are abnormal in the brainstem vasomotor centre in Chronic Fatigue Syndrome. Barnden LR , Kwiatek R , Crouch B , Burnet R , Del Fante Neuroimage Clin. 2016 Mar 31;11:530-537. doi: 10.1016/j.nicl.2016.03.017. eCollection 2016
25% ME GROUP	Encephalitis is an inflammation of the brain, Encephalomyelitis Brain/Spine caused by a viral infection leading to permanent brain damage. Different viruses cause inflammation. The inflammation is caused either by an infection invading the brain (infectious encephalitis) or through the Cortex to Brain Stem. ME is currently listed in the WHO ICD @ G93.3 as a Neurological Post Viral disease. Disease management must treat both Myalgia & the Encephalomyelitis together as the immune system is attacking the brain in error (post-infectious or autoimmune encephalitis). Viruses are the most frequently identified cause of infectious encephalitis (e.g. herpes viruses, enteroviruses, West Nile, Japanese encephalitis, Dengue Fever, La Crosse, St.	Published	What is Encephalitis? Encephalitis Society website @ https://www.encephalitis.info/what-is-encephalitis Various downloadable .pdfs available on the web page More about encephalitis Encephalitis Society website @ https://www.encephalitis.info/

	<p>Louis, Western equine, Eastern equine viruses and tick-borne viruses). Any virus has the potential to produce encephalitis, but not everybody who is infected with these viruses will develop encephalitis. Viral or Bacterial Infectious Meningitis spread by Sepsis can contribute to permanent Brain Damage.</p>		
25% ME GROUP	<p>NICE question 2, request for Evidence on the experience of people who have had interventions for ME/CFS</p> <p>Information presented relates to the Questionnaire Survey which was distributed in December 2000; analysis completed in August 2001, entitled M.E. Family/Household Members Survey Questionnaire Results. the relevant questions for NICE request: If health of other members in your family/household has improved or returned to normal. Is this attributed to any intervention/remedy? This question explored and evaluates experiences of interventions of people who have severe and very severe ME. An important survey as so little data is available about and by people who have severe ME.</p>	<p>"Not published in a journal, book, or video, but "published" on 25% ME Group website"</p>	<p>M.E. Family/Household Members Survey Questionnaire Results, Questionnaire Survey was distributed in December 2000; analysis completed in August 2001 available as .pdf on the website of the 25% M. E. Group via the link below: https://25megroup.org/download/1819/?v=1830</p>
25%ME GROUP	<p>NICE question 2, request for Evidence on the experience of people who have had interventions for ME/CFS</p> <p>Information presented relates to a Questionnaire distributed in March 2000; this analysis completed in July 2000, undertaken by 25% ME Group charity and completed by M.E. sufferers who are or have been Housebound / Bedbound for 2+ years. This is an important survey as so little is published about and by people who have severe and/or very severe ME.</p>	<p>"Not published in a journal, book, or video, but "published" on 25% ME Group website"</p>	<p>M.E. Questionnaire Results: The questionnaire was completed by M.E. sufferers who are or have been Housebound / Bedbound for 2+ years Questionnaire distributed in March 2000; this analysis completed in July 2000 available as .pdf on the website of the 25% M. E. Group via the link below: https://25megroup.org/download/1819/?v=1828</p>

<p>25% ME GROUP</p>	<p>For NICE convenience, the relevant questions are itemised here, together with the link to the whole survey is posted at the bottom Question 7. How long after onset of diagnosis did you receive appropriate advice treatment, if at all? Question 8. Of the following professionals (or disciplines) who offered treatment/advice to you, which of them do you feel have been most helpful? Question 10, Do you attribute your chronic severe state to anything specific? Many of the responses attributed their chronic severe state to the interventions they had for ME/CFS, including, inter alia, Graded exercise, lack of information/overactivity Question 11. In what setting have you received therapy? This question also looked at whether this therapy was perceived as helpful or unhelpful. Question 12 relates to treatment received within hospitals Question 13 asks those whose health showed improvement, what they attribute that improvement to. The responses include therapies.</p>	<p>“Not published in a journal, book, or video, but “published” on 25% ME Group website”</p>	<p>Severely Affected ME (MYALGIC ENCEPHALOMYELITIS) Analysis Report on Questionnaire issued January 2004 Analysis Report (March 1st 2004) by 25% ME Group available as .pdf on the website of the 25% M. E. Group via the link below: https://25megroup.org/download/1819/?v=1827</p>
<p>25% ME GROUP</p>	<p>M.E. Generic Members Survey undertaken by 25% ME Group charity Questionnaire was distributed in October 2001, analysis completed in March 2002. Questionnaire Results. The questionnaire was completed by M.E. Sufferers who are or have been Housebound / Bedbound for 2+ years</p>	<p>“Not published in a journal, book, or video, but “published” on 25% ME Group website”</p>	<p>M.E. Generic Members Survey Questionnaire Results The questionnaire was completed by M.E. Sufferers who are or have been Housebound / Bedbound for 2+ years Questionnaire was distributed in October 2001, analysis completed in March 2002 available as .pdf on the website of the 25% M. E. Group via the link below: https://25megroup.org/download/1819/?v=1826</p>
<p>25% ME GROUP</p>	<p>Question 2. Evidence on the experience of people who have had interventions for ME/CFS.</p>	<p>PUBLISHED</p>	<p>Quarterly, Newsletter of the 25% ME Group. 25% ME Group membership statistics When a person joins the 25% ME Group we ask if they have tried</p>

			<p>graded exercise and cognitive behavioural therapy, and if so, with what effect. These are the statistics for 234 members who had tried GE and 191 who had tried CBT:</p> <p>Were you made worse by GE? Yes 203 = 86% No 10 = 4% No change 25 = 12%</p> <p>Were you made worse by CBT? Yes 79 = 41% No 29 =15% No change 83 = 43% Accessed via the following link: https://25megroup.org/download/1796/?v=3065</p>
<p>25% ME GROUP</p>	<p>NICE question 2, request for Evidence on the experience of people who have had interventions for ME/CFS</p> <p>RESULTS OF THE FORWARD-ME SURVEY FOR CBT AND GET</p> <p>Due to the vital information contained in this report we suggest the entire report is studied in depth</p> <p>“The survey was designed to gather evidence from people who have been offered CBT and/or GET based on the current NICE Guidelines since 2007. Much of the evidence received echoes what we already know from previous surveys and feedback received by charities over a number of years.”</p> <p>“Due to the short timescales involved, the survey was only available online and it was not possible to allow paper responses. Please note, this will mean that a number of people with ME, particularly those who are severely affected, will not have been able to have their experiences considered. 13.8% of respondents had severe ME.”</p>	<p>PUBLISHED</p>	<p>Executive Summary for Forward ME of survey conducted by Prof. Helen Dawes, Oxford Brookes University, Jan 2019, accessed via the ME Research UK website (http://www.mereseach.org.uk/ and available via the link below: http://www.mereseach.org.uk/wp-content/uploads/2019/04/Amended-Final-Consolidated-Report.pdf</p>

	“We asked people “what severity is their condition both before and after treatment?”. The percentage of people describing their condition as severe before treatment was 12.6% and this increased to 26.6% after treatment.”		
25% ME GROUP	NICE question 2. Equality. describes many of the problems with the PACE research and explores its impact in relation to its impact in relation to debates about welfare reform.	PUBLISHED	Faulkner, George. "In the Expectation of Recovery". Centre for Welfare Reform. Retrieved Dec 2, 2018.
25% ME GROUP	NICE Question 1 Activity level Exercise performance measure Physical function	PUBLISHED	Stevens, Staci R; Davenport, Todd E (2010), "Functional Outcomes of Anaerobic Rehabilitation in a Patient with Chronic Fatigue Syndrome: case report with 1-year follow- up" (PDF), Bulletin of the IACFS/ME, 2010;18 (3):93-98
25% ME GROUP	NICE question 1. Fatigue CPET testing	PUBLISHED	Davenport, Todd E.; Stevens, Staci R.; Baroni,K; Vanness, J. Mark; Snell, Christopher R. (2011), "Reliability and validity of Short Form 36 Version 2 to measure health perceptions in a sub-group of individuals with fatigue", Disabil Rehabil, 33
25% ME GROUP	NICE Question 1 Mood Sex differences	PUBLISHED	Wallis, Amy; Butt, Henry L; Ball, Michelle; Lewis, Donald P; Bruck, Dorothy (Jan 13, 2016), "Support for the Microgenderome: Associations in a Human Clinical Population", Scientific Reports, volume 6; article
25% ME GROUP	NICE Question 1 Treatment adverse effects	PUBLISHED	Vink, Mark (2017). "Assessment of Individual PACE Trial Data in Myalgic Encephalomyelitis/ChronicFatigue Syndrome,Cognitive Behavioural

			Therapy and Graded Exercise Therapy are Ineffective, Do Not Lead to Actual Recovery and Negative Outcomes may be Higher than Reported". J Neuro Neurobiol. 3 (1).
25% ME GROUP	Question 1 Fatigue Natural recovery without treatment	PUBLISHED	Ghatineh, Simin; Vink, Mark (Aug 11, 2017). "FITNET's Internet-Based Cognitive Behavioural Therapy Is Ineffective and May Impede Natural Recovery in Adolescents with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. A Review". Behavioural Sciences. 7 (3): 52
25% ME GROUP	Question 1 Quality of life Exercise performance measure Fatigue Physical function Activity level Recovery	PUBLISHED	Twisk, Frank N. M. (Nov 2014). "A Question 1 Quality of life Return to work Fatigue Physical function Activity Recovery definition of recovery in myalgic encephalomyelitis and chronic fatigue syndrome should be based upon objective measures". Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation. 23 (9):
25% ME GROUP	Question 1 Quality of life Return to work Fatigue Physical function Activity Recovery	PUBLISHED	Adamowicz, Jenna L.; Caikauskaite, Indre; Friedberg, Fred (Nov 2014). "Defining recovery in chronic fatigue syndrome: a critical review". Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation.
25% ME GROUP	Question 1 Psychological status Return to work	PUBLISHED	Tiersky, Lana A.; DeLuca, J.; Hill, Nancy; Dhar, S. K.; Johnson, S. K.; Lange, Gudrun; Rappolt, G.; Natelson, Benjamin H. (2001). "Longitudinal assessment of neuropsychological functioning, psychiatric status, functional disability and employment status in chronic fatigue syndrome". Applied
25% ME GROUP	Question 2. Therapies	PUBLISHED	Research on Chronic Diseases

			(2017) Volume 1, Issue 2 Studies and surveys implicate potential iatrogenic harm of cognitive behavioural therapy and graded exercise therapy for myalgic encephalomyelitis and chronic fatigue syndrome patients.
25% ME GROUP	Question 1 Fatigue	PUBLISHED	Human Microbiome Journal Volume 13, August 2019, 100061 A retrospective outcome study of 42 patients with Chronic Fatigue Syndrome, 30 of whom had Irritable Bowel Syndrome. Half were treated with oral approaches, and half were treated with Faecal Microbiome Transplantation JN Kenyon, S Coe, H Izadi
25% ME GROUP	Question 1 Fatigue/fatiguability	PUBLISHED	Jacob E. Teitelbaum, Barbara Bird, Robert M. Greenfield, Alan Weiss, Larry Muenz & Laurie Gould (2000) Effective Treatment of Chronic Fatigue Syndrome and Fibromyalgia—A Randomized, Double-Blind, Placebo-Controlled, Intent-To-Treat Study, Journal of Chronic Fatigue Syndrome, 8:2,
25% ME GROUP	Question 1 Fatigue/fatiguability	PUBLISHED	Michael Jenkins MSc FRCP & Margaret Rayman DPhil RPHNutr (2005) Nutrient intake is unrelated to nutrient status in patients with chronic fatigue syndrome, Journal of Nutritional & Environmental Medicine, 15:4, 177-189,
25% ME GROUP	Question 1 Cognitive Function Orthostatic intolerance	PUBLISHED	Ocon AJ, Messer ZR, Medow MS, Stewart JM. Increasing orthostatic stress impairs neurocognitive functioning in chronic fatigue syndrome with postural tachycardia syndrome. Clin Sci (Lond). 2012;122(5):227–238.

25% ME GROUP	Question 1 Psychological status	PUBLISHED	Maes M, Twisk F, N, M, Ringel K: Inflammatory and Cell-Mediated Immune Biomarkers in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Depression: Inflammatory Markers Are Higher in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome than in Depression. Psychother Psychosom 2012;81:286-295.
25% ME GROUP	Question 1 fatigue Physical function	PUBLISHED REVIEW	Davenport, Todd E.; Stevens, Staci R.; VanNess, J. Mark; Stevens, Jared; Snell, Christopher R. (Jul 17, 2018). "Checking our blind spots: current status of research evidence summaries in ME/CFS". Br J Sports Med: bjsports-
25% ME GROUP	Question 2	PUBLISHED	Diagnosics 2019, 9(1), 26; Published Assessment of Post-Exertional Malaise (PEM) in Patients with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS): A Patient-Driven Survey by Carly S. Holtzman , Shaun Bhatia , Joseph Cotler and Leonard A. Jason * Published: 2 March 2019
25% ME GROUP	Question 1 Metabolic Monitoring Activity level Fatigue Sex differences	PUBLISHED	Metabolic features of chronic Naviaux et al PNAS September 13, 2016 113 (37) E5472-E5480; first published August 29, 2016
25% ME GROUP	Question 1. Equality	PUBLISHED	Blaming the victim, all over again: Waddell and Aylward's biopsychosocial model of disability

			Tom Shakespeare, Nicholas Watson, Ola Abu Alghaib, Critical Social Policy 2017, Vol.37(1): 22-41
25% ME GROUP	Question 2	PUBLISHED	Chu, Lily; Valencia, Ian J.; Garvert, Donn W.; Montoya, Jose G. (Jun 1, 2018). "Deconstructing post-exertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: A patient-centered, cross-sectional survey". PLOS One.
25% ME GROUP	Question 1. Fatigue/fatiguability. Exercise performance measure. Activity levels. Physical function	PUBLISHED	Snell, Christopher R; Stevens, Staci R; Davenport, Todd E.; Van Ness, J Mark (2013), "Discriminative Validity of Metabolic and Workload Measurements for Identifying People With Chronic Fatigue Syndrome", Physical Therapy, 93 (11): 1484–1492
25% ME GROUP	Question 1 Fatigue. Physical function. Activity level	PUBLISHED	Vink, Mark; Vink-Niese, Alexandra (Jul 2018). "Multidisciplinary rehabilitation treatment is not effective for myalgic encephalomyelitis/chronic fatigue syndrome: A review of the FatiGo trial". Health Psychology Open. 5
25% ME GROUP	Question 1 Fatigue Physical function Return to work Quality of life Treatment adverse effects	PUBLISHED	Vink, Mark; Vink-Niese, Alexandra (Jul 2018). "Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review". Health Psychology Open. 5 (2):
25%ME GROUP	Question 1 Fatigue /fatiguability	PUBLISHED	Patients with chronic fatigue syndrome performed worse than controls in a controlled repeated exercise study despite a normal oxidative

	Recovery time		phosphorylation capacity, Ruud CW Vermeulen, Ruud M Kurk, Frans C Visser, Wim Sluiter & Hans R Scholte Journal of Translational Medicine Volume 8, Article number: 93 (2010)
25% ME GROUP	Question 1 Exercise performance measure	PUBLISHED	Decreased oxygen extraction during cardiopulmonary exercise test in patients with chronic fatigue syndrome , Ruud CW Vermeulen & Ineke WG Vermeulen van Eck Journal of Translational Medicine volume 12, Article number: 20 (2014)
25% ME GROUP	Question 1 Self reported symptoms	PUBLISHED	Maes, Michael; Mihaylova, Ivana; De Ruyter, Marcel (February 2006), "Lower serum zinc in Chronic Fatigue Syndrome (CFS): relationships to immune dysfunctions and relevance for the oxidative stress status in CFS", Journal of Affective Disorders, 90(2-3): 141–147
25% ME GROUP	Question 1 Fatigue Pain sleep	UNPUBLISHED	https://www.clinicaltrials.gov/ct2/show/NCT02063126?recrs=aef&type=lntr&cond=Cfs&draw=7&rank=5
25% NE GROUP	Question 1 Fatigue Pain sleep	PUBLISHED	Fukuda, S; Nojima, J; Kajimoto, O; Yamaguti, K; Nakatomi, Y; Kuratsune, H; Watanabe, Y (Apr 29, 2016), "Ubiquinol-10 supplementation improves autonomic nervous function and cognitive function in chronic fatigue syndrome", BioFactors (Oxford, England),
25% ME GROUP	Question 2	PUBLISHED LOCAL REPORT	Trafford Tired of Explaining Experiences of Services for ME CFS Patients in Trafford and Greater Manchester Apri Local Healthwatch

			Healthwatch Trafford Date of publication Friday, 17 March, 2017 https://www.healthwatch.co.uk/reports-library/me-cfs-patient-experience-report
25% ME GROUP	Question 2	PUBLISHED LOCAL REPORT	Healthwatch Lancashire ME/CFS report 2017 https://www.healthwatch.co.uk/reports-library/me-cfs-patient-experience-report
25% ME GROUP	Question 1. Sleep	PUBLISHED REVIEW	Jackson, ML; Bruck, D (2012), "Sleep Abnormalities in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Review, Journal of Clinical Sleep Medicine", Journal of Clinical Sleep Medicine, 8 (6): 719-28
25% ME GROUOP	Question 1 Fatigue /fatiguability Pain	PUBLISHED REVIEW	Werbach, MR (April 2000). "Nutritional strategies for treating chronic fatigue syndrome". Alternative medicine review : a journal of clinical therapeutic. 5 (2): 93108. ISSN 1089-5159.
25% ME GROUP	Question 2. Equality. Patient experience	PUBLISHED	Geraghty, K & Blease, C 2018, 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and the Biopsychosocial Model: A Review of Patient Harm and Distress in the Medical Encounter' Disability and Rehabilitation .
25% ME GROUP	Question 1 Fatigue /fatiguability Activity level Physical function	PUBLISHED	Geraghty, K & Adeniji, C 2019, 'The 'Cognitive Behavioural Model' of Chronic Fatigue Syndrome: Critique of a Flawed Model' Health Psychology Open
25% ME GROUP	Question 2 Equality Patient experience	PUBLISHED	Blease, C, Carel, H & Geraghty, K 2016, 'Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome' Journal of Medical Ethics

25% ME GROUP	Question 1 Fatigue Physical function Activity level Treatment adverse effects	PUBLISHED	Geraghty, K & Blease, C 2016, 'Cognitive behavioural therapy in the treatment of chronic fatigue syndrome: A narrative review on efficacy and informed consent' Journal of Health Psychology.
25% ME GROUP	Question 1 Treatment related adverse effects Exertional adverse effects	PUBLISHED	Twisk, F & Geraghty, K 2015, 'Deviant cellular and physiological responses to exercise in Myalgic Encephalomyelitis and chronic fatigue syndrome' Jacobs Journal of Physiology, vol. 1, no. 2.
25% ME GROUP	Question 2. Equality. Patient experience	PUBLISHED	Geraghty, K & Esmail, A 2016, 'Chronic fatigue syndrome: is the biopsychosocial model responsible for patient dissatisfaction and harm?' British Journal of General Practice, vol. 66 , no. 649, pp. 437-438
25% ME GROUP	question 2. Fatigue/fatiguability. Pain	Open-label clinical study. Unpublished	Application of the Yasko Protocol to the Treatment of Chronic Fatigue Syndrome Rich Van Konynenburg, Ph.D. Independent Researcher/Consultant richvank@aol.com Neil Nathan, M.D. Yasko Protocol Conference - Boston July 30-August 1, 2011
25% ME GROUP	Question 1 Fatigue/ fatiguability Exercise performance measures Pain Cognitive function Activity level Treatment adverse effects Quaility of life Psychological status Return to work	PUBLISHED	BMJ best practices chronic fatigue syndrome 2018 , Dr James N. Baraniuk
25% ME GROUP	Question 1. Mortality	PUBLISHED LOCAL REPORT	National Office Statistics Mentions of postviral fatigue syndrome (benign myalgic encephalomyelitis), deaths registered in England and Wales, 2001 to 2016. Release date:18 May 2018

			Reference number:008461. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/008461mentionsofpostviralfatiguesyndromebenignmyalgicencephalomyelitisdeathsregisteredinenglandandwales2001to2016
25% ME GROUP	Question 1 Sleep Pain Fatigue Orthostatic intolerance Adverse treatment effects Care needs	PUBLISHED	Carruthers et al , (Aug 22, 2011). "Myalgic encephalomyelitis: International Consensus Criteria". Journal of Internal Medicine. 270 (4): 327–338
25% ME GROUP	Question 1 Outcome Measure on Fatigue	PUBLISHED	Fisk JD, Ritvo PG, Ross L, Haase DA, Marrie TJ, Schlech WF. Measuring the functional impact of fatigue: initial validation of the fatigue impact scale. Clin Infect Dis. 1994 Jan;18 Suppl 1:S79-83. https://eprovide.mapi-trust.org/instruments/fatigue-impact-scale/abs This instrument provides an assessment of the effects of fatigue in terms of physical, cognitive, and psychosocial functioning. There are 40 items on the scale. It was developed with MS patients. A version of this scale is used as part of the MS quality of Life Inventory package (see next item)
25% ME GROUP	Question 1: Methods of Monitoring and Review	PUBLISHED	Multiple Sclerosis Quality of Life Inventory: A User's Manual Paul G Ritvo et al. 1997 National Multiple Sclerosis Society New York, USA Comprises a battery of instruments to gauge many of the dimensions of quality of life highlighted at Question 1 in this call for evidence - see list in table of contents p4: https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/MSQLI_-A-User-s-Manual.pdf Developed by the Consortium of Multiple Sclerosis Centers Health Services Research Subcommittee