**MNYES PSP**

*Uncertainties informing summary questions*

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| ID of indicative questions | Uncertainty | Original Uncertainty Key- id number of original submission given at the start of each original uncertainty, HP = Healthcare professional, P = Patient, C= Carer, O=Other, | Evidence | Source of UncertaintyKey- HP = Healthcare professional, P = Patient, C= Carer, O=Other, |
| 1 | Do childhood, recent or ongoing adverse events trigger or maintain MNYES? | 637.3 HP Underlying pathophysiology between stress/trauma + physical symptoms e.g. chronic low grade inflammation; 301.1 P I am a Survivor of Childhood Sexual Abuse and Exploitation - is my illness connected to traumas; 299.1P I am interested in the relationship between MNYES and trauma (specifically early psychological trauma, ongoing traumatic circumstances, C-PTSD, fight, flight, freeze responses etc. 108.1HP Is there a Relationship with trauma? 431.1 HP what is the link with trauma, adversity and abuse, in particular dissociation; 594.1 HP the link between trauma and MNYES; 429.5 HP How significant are Attachment issues? 429.4 HP Impact of previous adverse life events/trauma? 643.7 O What are the links between MYNES and developmental trauma? (including 'trauma's' of absence, such as 'neglect')? 417.4 HP Are there any trends around how patient with MNYES experience stress/ negative life events (e.g. emotional/ physiological differences compared to a control population); 299.1 P I am interested in the relationship between MNYES and trauma (specifically early psychological trauma, ongoing traumatic circumstances, C-PTSD, fight, flight, freeze responses etc. | Varinen et al., 2017 | HP=7, P=3, O=1, Total=11 |
| 2 | Which conditions/factors influence the development or onset of MNYES (such as age, gender, ethnicity, social factors, lifestyle, diet, infections, genetics)? | 610.1 HP What are the social and societal drivers of development of these conditions? 250.1 P Why are some people more vulnerable to developing FND than others? 362.1 P Could female hormones be causing symptoms; 587.1 P Origins and risk factors? 253.7 P Is this all affected by what we eat and our behaviours before this occurred? 253.1 P why is this happening to me? 135.1 P What causes it? 364.1 P What the cause is. A significant number of people with hypothyroidism are not ‘well’ despite tests and doctors saying all is fine; 350.1 P Causes of painful periods throughout whole cycle? 539.8 P Epidemiology of MNYES - to see if subsets/ predisposing factors can be identified; 13.1 HP MNYES in older adults; 109.1 HP Are there clear histories that lead to certain symptoms? 198.1 P I believe that my symptoms are caused by emotional upset - is it possible to confirm this? 427.1 HP Can we specify what types of life difficulties/adversities\* are associated with onset and persistence of MNYES? \* Terminology here is not standardised: my question includes exploration of all sorts of interpersonal or social stressors, either early in life or just before onset; 429.1 HP Underlying personality traits? 595.1 O Who is more likely to have these difficulties? 598.1 HP what life events and experiences are more prevalent in people with MNYES? 106.8 HP Research regarding any development of MUS/MNYETs in post COVID patients? 125.3 P How do various digestive issues affect menstruation? I.e. are they a cause of irregular menstruation or are the two completely unrelated? 165.4 HP Role of attention and fear in MNYES; 236.5 P My son became addicted to 'Monster' power drinks aged 14 (I learned years later he was drinking about 10 cans a day or more). Could this have caused his Crohn's (he already had JIA); 429.6 HP Impact of family/social dynamics? 472.4 P Could all the information about MNYES and data around each patient including lifestyle, environment, other diagnoses etc. be gathered together and compared to see if there are any common factors etc?? 552.3 P Does the menopause increase the occurrence of MNYES? 597.8 HP What is the sociological profile of patients with this disorder?; 598.2 HP Does attachment style have an impact on MNYES; 630.3 HP What are the prominent demographic characteristics that present with these symptom clusters? 636.4 HP Which segments of the population, if any, are particularly likely to develop these problems? What impact does culture have? 351.4 P Family history other immediate family diagnosed; 742.3 P Can an underactive thyroid re occur in families; 224.1 P What genetic differences can contribute to unusual presentations or test results for known conditions? 498.1 C If it is a hereditary form how come it occurs at different ages? 711.1 HP Prevalence of neurological/FND diagnoses in the families of patients? 106.6 HP Do MUS/MYNETs run in families and if so is this a learned behaviour or something biological or both? 62.1 C What is role of functional b12 deficiency (does not show up in blood tests, yet recognized by nhs in their b12 pages online) in relation to these symptoms? 665.1 P I have several diagnoses that share similar symptoms (b12 deficiency, fibromyalgia, epilepsy) and I'd like to see more research into the effects of long term undiagnosed B12 deficiency on central nerve function that might connect illnesses such as MS, ME, CFS, FMS, and even epilepsy; 4.1HP I want to know the impact if ViT b12; 281.3 P Why are chronic infections not more routinely diagnosed, understood and treated as the basic cause of a lot of so-called MUS? 575.1 P Are any of these studies going to look at tick borne or infectious cause? 426.2 O Which infections are related to it; 388.1 P Why have I now got stomach/bowel problems since my thyroidectomy? Why do I get breathless which my GP keeps telling me is anxiety when I know it is not? Why does my face not feel right and gets worse when I talk? 624.1 HP Causes of MNYES; 634.2 O Why is it that 'stress' is an acceptable trigger for bodily symptoms while anxiety, fear, depression - even excitement - are dismissed as trivial or shameful experiences? 634.3 O This is a problem in the minds not only of doctors (of whom I am one) but of the population as a whole; 634.4 O The probable answer to the 'stress' question is that being stressed is an honourable state (= working hard, for example) while the others are not; 634.1 O the main problem is that mental and physical are seen by almost everyone as quite separate causes for symptoms; 655.1 P Why when your TSH levels are within the normal range do you continue to experience symptoms such as painful aching legs? 272.1 P Something about the Importance of the Recognition of the interrelationship between body and mind; 274.1 P How does the gut biome work for your body's advantage / disadvantage? 274.2 P What affects its composition? 274.3 P What do changes in the biome do? 274.4 P What role does the combination of sugars and yeasts play in gas production? 212.1 P Why can’t dr find out why I feel ill everyday why the give up and just give painkillers or antidepressants; 221.1 P Why do I have bilateral proximal weakness in all 4 extremities? Slight elevated CK levels and the dr just tells me to ride a bike? I walk 3 miles a day but at worse can’t do stairs , get up from floor or get dressed like a normal person? Anti inflammatory diet and tart cherry juice daily has been my saving grace. I am on warfarin. APS dx. I am not a quitter; 281.2 P Why is the default option that it is a problem with the patient, their personality or some previous trauma - even when no such difficulties commonly exist? 68.1 P How is it possible? Surely there has to be a reason why. Could it be the correct tests have not been performed? 123.1 P Why pain after eating and unable to turn food into calories; 177.1 P Causes/triggers of severe pain so they could be avoided and treatment for the pain; 297.1 P What causes ibs? 472.1 P Are they really medically unexplained? 153.1 P What is causing my symptoms? 348.1 P Why do I feel so bad when I am told my TSH is normal; 121.1 P Why do I have a reaction to certain foods, especially gluten, yet despite endoscopy and biopsy, I am not classed as coeliac but my sister is?? 121.2 P Why am I so incapable of moving (so much more than feeling tired) when I eat gluten? 121.3 P Why do I bloat and feel very uncomfortable and breathing becomes slightly more difficult and pulse races when I eat gluten? 283.1 P What causes Sphincter of Oddi Dysfunction? 277.1 P What triggers brain-body disconnect? 253.4 P How Is it possible to get New symptoms regularly? 58.1 P Answers for my symptoms, 296.1 P What could be wrong with me? 396.1 P Why do I have full body muscle fasciculations? 645.1 P External factors that influence (and/or induce) symptoms of cognitive dysfunction that therefore further expanding triggers to include measures such as bio-impedance. 247.1 P Pain in lower left abdominal area. Why. 116.1 P What brings them on so suddenly; 340.1 P What is the reason for the symptoms if all tests are normal; 28.1 P biomedical research to uncover the pathological causes NO more biopsychosocial research, they've been getting too much of the funding for way too long and still haven't worked out how to conduct quality trials (replication crisis anyone?) let alone come up with anything remotely helpful to patients - though admittedly some of their finding helped clinicians feel better about themselves; 55.1 P Is there usually a specific cause for these symptoms; 88.1 P What causes this? It’s definitely not stress or a traumatic event; 233.2 P I have been on Warfarin for 24 years for recurrent DVT and PE. 3 years ago I started bleeding heavily from my mouth every morning. It developed to every night and morning and now it’s a lot of the time. 3 weeks ago I started bleeding heavily through urine as well. Had enough tests to keep an army going. Had Cystoscopy this week. No cancer. Nobody has answers as to why I both bleed and clot a lot. Been tested once for Hughes/APS. Still no answer but I would like one. 366.1 P What causes these symptoms? 380.2 P Why have I never got any get up and go? 380.3 P Why does everything hurt? 439.1 P Why have I got so many under active thyroid symptoms but I’m told I’m within the normal range? 373.1 P Why do I still feel tired and dizzy even though my medication for hypothyroidism is apparently optimal? 373.2 P What causes hypothyroidism and it’s side effects? 100.1 P What are the causes of unexplained fatigue? 401.1 P Re thyroid after being in control with medication have i had a big blip and felt very unwell ? Another new symptom , bad pains in lower legs cramp type pains but stop me in my tracks my doctor does not know; 668.1 P What causes the symptoms and should I be worried. 478.1 P why the medical profession is happy to call something unexplained without actually taking much effort to seek explanation; 641.1 P Urethral/bladder pain with no infection. Possibly linked to some foods? 672.1 P Why do I collapse? If it's all in my head why does cross contamination I didn't know about make me collapse? Are there other people like me? 60.1 P What is causing this? 264.3 P why do these symptoms start randomly? 400.1 P I have severe fatigue, gradually worsening over several years, and many hypothyroid symptoms (and a family history of hypothyroidism) but my thyroxine and TSH are in the "normal" range, though both low. My very high thyroglobulin antibodies (4 x top of normal range) are being ignored. GP's diagnosis: CFS so only help is rather ineffectual "counselling". Refusal to prescribe small trial dose of thyroxine. It seems to be general opinion that thyroid problems are seriously underdiagnosed. Please can research be done in this area. I will gladly take part. New NICE guidelines aren't helping and don't address problems such as population range not being appropriate for every individual or very abnormal thyroid antibodies. 479.1 P I have had s persistent cough that is quite hoopy, yet even after a chest x-ray I have yet to be given answers about what it could be. 568.1 P Is it because of my thyroid? Surely there should be a reason for persistent symptoms like this? 410.1 P a cause of the symptoms: 318.1 P Why is it every time I eat gluten food I’m in agony? Why is it reach a certain time of the day and I’m exhausted I’ve had periods of low blood sugar 2.5 mmols ; 415.1 P Just answers and reasons for symptoms really; 386.1 P Why does my stomach feel as though it’s like a washing machine, always on the go? 282.1 P What are the possible causes of the symptoms, how likely are they to reoccur, are the symptoms indicative of future health problems? 628.1 O causes? 15.1 P Can it be triggered by a flu virus? 49.1 P why do i have pots ; 157.1 HP What perturbations of human perceptual computations lead to functional problems such as Persistent Postural-Perceptual Dizziness? 244.5 P I suffered an acute pancreatic attack 22 years ago due to trauma. I had two whipped op’s to drain the pseudo cysts . I take Pancrease HL with food, daily. Low carb diet .I eat little and often and have had six to eight more pancreatic attacks since 1998. Usually after a virus. I don’t drink alcohol or caffeine . I recently had another attack after feeling bloated for four weeks, and have been referred to my local gastric doctor. On three occasions I’ve seen him the answer is I don’t know . He’s very thorough and a really good person. I’ve seen your website and wondered if you could help me please? 383.1 P I have been told I may have lupus . But from the age of 11 was told I have idiopathic juvenile arthritis. I have had a son 4 yrs ago . Can this have triggered lupus as still not been tested as yet for lupus . As I now have developed a severe purplish rash on the bottom of my leg , which started as a few spots and now half way up leg .. sorry I know a lot but my pain is more severe than ever the last 12 months. 391.1 P Why do i have debilitating tiredness. Digestive and bowel problems; 483.1 P In the last 3 years I have suffered with bad hissing noises all around my head bad Pressure headaches fuzzy heads pain in neck and back of head muscle and joint pain tiredness fatigue no sex drive I am feeling hot one minute then cold the next weight gain my emotions are up and down hair coming out I have gallstones and a leaky aortic heart valve and my thyroid is border line What’s wrong with me I am feeling so down; 591.1 HP What are the psychological and interpersonal factors that contribute to onset, course, and response to treatment? 656.1 HP Is it a psychological problem, physical or both; 673.1 P Why does my whole body get covered in a rash since FND came into the picture; 704.2 HP What are the main risk factors for MNYES; 717.1 HP If there's a causative agent; 106.7 HP Do MUS/MNEYTs chronic pain patients have differences in inflammatory/immune responses. 119.5 P Why am I suffering; 122.2 P Why I have normal stool in the evening but it is like slop the next morning. 122.3 P Why I have chronic bloating and then diarrhoea. 122.4 P Why the diarrhoea just starts for no reason. 222.2 P Why do I get mouth sores, swollen lymph glands , fatigue and feel run over when “ flared” yet have normal blood work? 224.2 P When do comorbidities and genetic difference increase the risk that a known condition was "ruled out" erroneously? 231.4 P Why is there lots of mucus in my stools sometimes. 236.4 P I have many light headed turns, mostly when I stand up...could this be related to my digestive system...could it be a sign that I'm deficient in something? Or could it be a sign that I have digestive system problems? 250.2 P Why is there not more research being done to understand the causes of FND; 261.2 P Have a better understanding of treatments and causes. 386.2 P Why do I have palpitations and feel agitated even though my blood test results show normal? 386.4 P Some days I can tremble/ shake, why? 486.2 HP Is there any measurable evidence of central nervous system or autonomic nervous system involvement in symptom causation? 597.3 HP What are the cognitive underpinnings of this disorder? 617.2 HP Biological correlates of specific disorders; 633.2 HP What role does the mind play in generating such symptoms. 196.1 HP [1] My experience [as a GP] is that once people get referred, e.g. to a pain clinic, no further diagnostic work is done. It's just how to manage the condition. How can GPs and patients be confident that they are not missing any treatable conditions? In General Practice, too often we assume that 'common things are common' and we don't look for [and don't know about] the many less common or even rare diseases that could cause certain MUS. For instance, histamine intolerance - one patient's brother told me "I could be in A&E every week". Had this patient not brought his brother, who told me all about histamine intolerance, I would have had no clue about what was wrong with him. Diagnosis too often relies on conditions the doctor can think of, rather than an evidence-based logical work-up. This is a great pity. I suspect many more patients could be diagnosed if there was such a work-up. My own expertise is in vitamin B12 deficiency [B12d]. We know that B12d often produces diffuse symptoms, in a large number of body systems, but particularly neurological. Symptoms vary widely between patients. And the blood tests for B12d are so imperfect, they leave at least 2/3 of patients undiagnosed [Ward, 2015]. These patients then go into the books as 'MUS'. The patient often suspects it is not psychological, but their doctor may give the impression that it is. This can lead to increasing frustration in both patient and doctor, and a dysfunctional patient-doctor relationship. Sometimes even a breakdown of trust. Many patients remain undiagnosed for many years, I've even heard 20 years [Hooper, 2014]. During that time, in their desperation, GPs often refer to a dozen or more specialists, try a handful of medication, while the patient continues to deteriorate. I would love to see / collaborate with research on prevalence and diagnosis of B12 deficiency in MUS [please contact me, rietsema@doctors.org.uk]. Prevalence of B12d in the general population is 5% in young people, 22% in people over 65, and 32% in people over 80. I suspect in patient groups with MUS, prevalence is substantially higher. All of the symptoms mentioned at the beginning of this survey can, and often are, symptoms of B12 deficiency. This to my mind is an urgent research need. There are better tests than total serum B12 - serum homocysteine and methylmalonic acid. However, these are expensive and not widely available. So most patients do not have access to them. Research could elucidate: \* The prevalence of B12d in MUS, when tested with total serum B12, holotranscobalamin [this is the B12 available for uptake into the cell], homocysteine and methylmalonic acid [the latter two are metabolites, levels of which rise when B12 is low]. \* In the absence of more sensitive tests for B12d, how can a trial of treatment with vitamin B12 aid in the diagnosis? How can response to treatment be 'measured' and monitored? I think this is an urgent research need, because [1] MUS are common, and lead to high burden on the patient's quality of life, on health care and on GPs [2] B12d is common, and very commonly missed [3] The longer B12d is undiagnosed, the higher the risk of irreversible neurological damage [4] B12d can be easily and effectively treated, with complete symptom resolution if done well. How do GPs differentiate between somatic and 'functional' disorders? And what makes them more or less successful in this? I know there is often a lot of discordance between patient and GP, and between GPs, of what is functional and what is a true somatic disorder. What educational needs do GPs have in this area? Hooper et al., 2014. Patient journeys: Diagnosis and treatment of pernicious anaemia. Brit J Nurs, vol 23, no. 7, pp. 16-21. Ward, M. et al., 2013. P148 Screening with holotranscobalamin is superior to serum B12 in identifying vitamin B12 deficiency in patients with Crohn's disease. Journal of Crohn's and Colitis, 7(S1), p.S68. 626.1 HP What is the long term impact on patients, carers and on the economy(employment, use of healthcare services) of MNYES; 630.5 HP What can we predict about the mortality/ morbidity/ direct and indirect economic costs associated with these conditions from a health and social care perspective? 709.2 HP Demographic correlation to sustained improvement of FND symptoms following treatment. 724.5 HP Does the family’s degree of belief in the relevance of psychological factors improve prognosis? 12.1 HP Relation between symptoms, psychosocial factors and interventions and prognosis. What are helpful factors and which indicate a poor prognosis? 695.2 HP Does an earlier diagnosis of FND help with prognosis for FND patients? 109.7 HP What factors affect prognosis? 639.3 HP What factors predict outcomes /prognosis? 109.6 HP Different prognosis for different symptoms? 592.4 HP Are there any good ways to work out likely prognosis? 268.1 P Is there a cure? If not is there anything that can prevent onset of symptoms? 618.1 HP Which patients will respond to intervention; 711.6 HP Impact of beliefs about diagnosis on treatment outcome; 639.4 HP What actors predict which patients respond best to different therapies? |  | HP=41, P=96, C=2, O=7Total = 146 |
| 3 | What is the relationship over time between MNYES and known medical conditions and does that suggest some shared pathological process? | 552.2 P How many people have underactive or overactive thyroid and MNYES? 441.1 O It is not unreasonable to suggest that non epileptic events are more common in people with epilepsy because of a brain based vulnerability so are they due to the same pathological process? 579.1 P I would like research to show whether certain symptoms can arise following successfully treated Graves disease, and therefore help acknowledge them. Especially: - apparently accelerated digestion - metallic taste in mouth (metallic is best description, but not entirely exact) - cognitive changes - eg: having to relearn things like times tables that seem to have been forgotten as a result of being ill and possibly less effective ability to recognise faces and remember things like who has which pigeon hole (where they are not allocated in alphabetical order) when before Graves these things were quite easy and automatic; 274.5 P How does nerve damage, such as cauda equina syndrome, impact digestion? 407.1 P I feel there could be more of a connection between illnesses/ conditions. One person can seem to be so unlucky and when putting things to doctor other symptoms are just dismissed as IBS or just arthritis or just menopause with out explanation; 295.1 P Relationship of h.pylori to flatulence, stomach pain and constipation; 587.3 P Interactions/co-morbidities? 351.2 P If you have auto immune condition; 351.3 P Any inflammatory disorders; 296.2 P Could there be More than 1 thing wrong? 313.1 P Does Hashimoto’s Disease have symptoms of it's own, with or without the presence of Hypothyroidism? 129.1 O Please look at Mast cell activation syndrome with all of the symptoms you list; 38.1 P Causes and treatment. Related illnesses and understanding patients with multiple diagnoses; 484.1 P I have suffered from fatigue, joint pain, muscle weakness and mood swings for 6years and was diagnosed with fm. During an ultrasound due to an allergic reaction, a thyroid cancer that had metastasized to my lymph nodes was discovered. I received a radical neck dissection to remove thyroid, parathyroid and nodules and 2 cycles of Rai. Though my cancer was later classified as a dedifferentiated thyroid carcinoma, the fatigue, joint pain and muscle weakness disappeared once my thyroxine, vitamin d and calcium were stable. My bloodwork was normal before my thyroid was removed and both my doctors and literature says thyroid cancer should not give symptoms other than palpable nodules which would be detected by a gp, yet my symptoms greatly improved once my cancer was removed and this is very confusing for me ... could you tell me if my symptoms were related to the cancer or not? And if they were not related why did they improve once the cancer was removed? 99.1 P Links between POTS other conditions. I was diagnosed with POTS in 2005 and yet it took until 2012 to establish that I have HEDS. There have been a number of medically unexplained issues along the way like potential mast cell activation, malabsorption, cracked tooth syndrome, ? CSF leak along with symptoms such as sleep problems, fatigue, heat intolerance, brain fog, headaches, chest spasms, mottled limbs; 409.1 O Is Mnyes connected to thyroid problems? I had thyroidoctomy 2010, I had lot of tummy problems for few years now my tummy improved as I use oat milk and I think my thyroid levels better more levelled. I have most recently been reduced to 75 as my Tsh levels normal but other level 23 to 24 so going on to high level I asked doctor to reduce, I was getting depressed with debilitating fatigue my doctor not interested she said only cause I said 23 high level that she agreed to reduce levotheroxine to 75mg, I think my fatigue was linked; 331.1 P Which symptoms could be linked to hypothyroidism/hashimotos. - bowel problems, pain, fatigue etc; 522.1 P Are there any links between Reynauds Syndrome and Endometriosis? 573.1 P DEPRESSION anxiety, aversion to cold, lethargy, little patience, sleep issues, constipation, hair loss, memory loss, inability to focus. WHY ARE ALL THESE SYMPTOMS automatically directed to depression and therefore directed to anti depressant medication! Preexisting history of hypothyroidism; 193.1 P Links between diagnoses of IBS and other health conditions that may/should be checked, such as thyroid issues, endometriosis. As these don't seem to be well understood but are not usually life threatening, there are too many 'Don't really know' diagnoses for many people, who cope but who actually want to do more than that; 628.3 O parallels with other conditions e.g. FND; 258.2 P Why do so many people with these symptoms have symptomatic hypermobility; 155.1 HP What is/are the link(s) between POTS, hyper mobile EDS and Mast cell activation syndrome - triggers, predisposition, underlying mechanisms, novel therapies; 435.1 C in 2018 my wife suffered swelling of the lymph nodes in her neck. She had scans and CAT scan and eventually had the lump removed. Pathology said it was not cancer. again in January 2020 she had further swellings and again had them surgically removed. They have now come back a third time and pathology again says they are non-malignant but her Consultant cannot say why they keep swelling and enlarging. Today he is attending a multi disciplinary meeting to see if there are any suggestions from his colleagues. 1. Can you offer any suggestions as she cannot go on having surgery in the same place. 2. She is currently taking Thyroxin75mg. for thyroid deficiency, can that medication be causing the problems? 3. Could any other medication be causing the problem? 521.1 P Can I have mnyes due to my overactive thyroid? As I'm suffering all above mentioned and more? 137.4 HP How does it relate to conversion- dissociative disorders; 155.3 HP Is there a role of autism and perception of symptoms in MNYES; 236.2 P Could recurrent mouth ulcers be a sign of gastric problems (I suffered terribly as a child with multiple mouth ulcers and stomache aches); 236.3 P Could tonsil removal lead to Crohn's and/or Arthritis or could recurrent tonsillitis be a sign of these; 283.3 P Is it related to Bile Reflux, Haemorrhagic Gastritis, Erosive Duodenitis and NASH? 345.2 P Links & causes to ITP; 366.3 P Are these symptoms related to Graves’ disease? 472.5 P Are MNYES linked with chronic stress? 595.2 O How do such difficulties relate to other physical and mental health problems (though I hate that division)? 650.1 HP Explore links between neurodiversity and MNYES; 502.1 P Is there anything I can do to prevent more autoimmune problems occurring like arthritis? 120.1 P Are there long term effects e.g. increased likelihood of stomach or bowel cancer as a result of IBS? |  | HP=4, P=27, C=1, O=5Total = 37 |
| 4 | Could different presentations of MNYES be explained by different mechanisms or causes? | 629.1 O understanding of the heterogeneity; 603.1 HP Currently these symptoms are lumped together just on the basis of having similar presentation. I will like to see them differentiated according to either pathophysiology or aetiology; 441.1 O There is a real problem of classification that requires critical review. Some Pain conditions fall between labels and are seen differently by differing disciplines. Patients prefer labels that imply organic causes and doctors vary in their view; 730.2 HP What conditions would be incorporated in MNYES, is this the same as FND? 605.6 HP Is this a homogenous group of patients, or should we be looking for subgroups for targeting our interventions; 649.3 HP Are there natural groups of patients? |  | HP=4, O=2Total =6 |
| 5 | How many people are affected by MNYES? | 552.1 P How many people have MNYES? 419.1 HP How many people are affected by it in the UK? 619.1 HP How many patients does it affect? | Hilderink et al., 2013 | HP=2, P=1Total = 3 |
| 6 | What are the mechanisms of MNYES and can we identify biomarkers for them? | 381.1 P What is IBS really; 631.1 O Aetiological factors; 358.1 P I’d like the answers as to why it can’t be explained. Is there help on the way?! 587.2 P Mechanisms of development? 277.2 P What body chemistry is altered in instances of FND? 263.1 P How, whatever in my brain went wrong, and which part of my brain? 253.6 P I always feel like I have a cold or unwell, how does the nervous system affect our immune system and can this be the link to having worsing or more symptoms? 253.2 P Is this happened due to a chemical imbalance in my Brain? 188.1 P What the exact mechanisms are behind IBS; 241.1 P Why is the cardiolipin IgG antibody more significant than the IgM and what is the difference between the two? 19.1 P To carry out research to identify the root cause of the illness so that it is no longer medically unexplained; 25.1 P I would like to see more biomedical research into the cause of syndromes such as ME/CFS, fibromyalgia etc; 141.1 HP Brain basis of MNYES, eg psycho-physical, behavioural, imaging, phyiological correlates of MNYES; 418.1 HP More research into what happens in the brain when symptoms occur, in order to give better understanding to patients; 532.1 HP Is it correct to assume a single mechanism (stress, somatisation, etc) for all these disorders which fall together because we don't yet have adequate mechanistic models or biomarkers, rather than pursue specific lines of enquiry according to the symptom? 563.1 P Is there a realisation that we don’t know what we don’t know in relation to MNYES? 607.1 HP What is the role of the Autonomic Nervous System in this disorder; 609.1 HP Aetiology; 686.1 HP More in depth look at the role of the autonomic nervous system in pts with FND and the different effects this can have - eg gastroparesis, CRPS etc; 689.1 HP Further research into pathophysiology behind MNYES particularly in functional movement disorders; 426.3 O Why cellular effects are caused leading to these problems; 429.9 HP Good evidence base for brain activity associated with MNYES to justify incorporating into routine clinical investigations? 592.2 HP is there a unifying mechanism behind the whole spectrum of MUS (e.g. bowel, pain, weakness, seizures)? 605.3 HP Are there different mechanisms for different symptoms/systems of dysfunction; 643.8 O Do psychotherapy models that draw on neuroscience/interpersonal neurobiology (& body-based/ 'right-brained' therapies) have something extra to offer this population? (and in what ways might they be more/less beneficial than the currently used 'left-brained' or 'insight-oriented' modalities )? |  | HP=10, P=12, O=3Total =25 |
| 7 | What is the relationship between mental health problems and MNYES? | 631.2 O Psychiatric and other co-morbidity; 637.1 HP Prevalence of co-morbid psychiatric illness - untreated and treated; 266.1 O I would like to see more information about the link between psychology and neurology; 244.1 P Are they psychosomatic? 425.1 HP Comorbidity with personality difficulties; 614.1 HP Psychological influences of somatic symptoms especially in trauma; 703.2 HP Link between the mind, chronic stress, psychodynamic theory and MNYES; 429.2 HP Underlying anxiety disorders not diagnosed? 429.3 HP Relationship with other MH diagnoses? | Kohlmann et al., 2016 | HP=6, P=1, O=2Total = 9 |
| 8 | What symptoms are commonly reported by people with MNYES and what links them? | 365.1 P Low metabolism issues Tremors; 692.1 HP Functional Neurological Disorder, Chronic Fatigue Syndrome, Chronic Pain, Persistent Postural Perceptual Dizziness; 46.1 P Sleep disturbances especially falling asleep; 397.1 P Unexplained sudden fatigue; 675.1 P Fatigue, depression, muscle aches and pains, feeling of weakness; 262.1 P What physical changes I.e mri changes can be seen in patients? 463.1 P Why I still have fatigue and bone pain; 230.1 P Gut discomfort on waking . It involves gut from throat to rectum .No trouble in the night .Any suggestions; 190.1 P Joint pain, scalp psoriasis, bloating, food intolerances, constipation and Stomach pain; 298.1 P Constant stomach cramps and wind; 217.1 P Joint pain; 319.1 P Numbness in hands, Severe joint pain, Legs not working properly, Stiffness in feet; 338.1 P Why feel so tired but muscles suffer most when try to do exercises every day and feel heart beats in my head all day? 338.2 P Why feel heartbeats in my eyes? 338.3 P Why my skin is always dry even use hydrating cream? 338.4 P Why my stomach hurts everyday and I can eat as usual do even eat vegetables and fruit the most? 222.1 P Why do some people remain seronegative to certain blood tests that would indicate a specific disease yet have all the symptoms of the disease? If a person fails blood tests yet has symptoms and there is a large number of patients all experiencing a similar pattern, surely this must be proof that there is a physical issue and not a psychological one; 363.3 P Fatigue, persistent sore throat, tingling burning aching pain over body; 203.1 P Feet burning, stomachs swelling seeking help from go to no avail in constant ,pain; 329.1 P Issues with bowels, and bladder urgency, dizzy spells, fatigue and headaches; 372.1 P bowel and gastric problems relating to graves disease. fatigue and joint pains. never feeling well, when blood tests are returned as satisfactory or within normal range; 541.1 P How many people suffer with Skeletal pain? 279.2 P The loss of speech after seizures; 377.1 P Pain in upper right quadrant under breast not when eating, sometimes when drinking liquids definately when doing any activity including shopping, cleaning, walking, This only goes away when lying down. pain on right side only over appendix. \*not appendicitis Feeling of not emptying bowels. Constant loose stools or diarrhea; 698.1 P I find although medically treated for my thyroid I still suffer from awful pain in muscles and also stomach problems; 101.1 P what are common signs/symptoms experienced by individuals 462.1 P Fatigue is a huge problem for myself and I see it over and over again in thyroid Cancer forums online. Consultants tell you your bloods are within range so it can't be due to thyroid issues...; 113.1 P I have been told by a consultant at Sheffield that I have Sphincter of Oddi Dysfunction. I have also had it suggested by my GP that I may have IBS and Vestibular migraine. I have a wide variety of symptoms, some of which the doctors say they cannot attribute to any of these conditions. I have daily abdominal pain - which moves. Sometimes on my right side sometimes my left, sometimes in the centre at the top of my stomach, and frequently accompanied by centre back pain between my shoulder blades and around my rib cage. At times I feel I cannot get a breath. I feel as though I'm in a permanent brain fog. I struggle to know what to eat as I live in fear of the symptoms. I have daily headaches and also feel very dizzy and disorientated, and on occasions feel as though I could faint or lose consciousness. I swing from not going to the toilet for several days to going a couple of times a day, yet my diet does not vary. I eat the same meals every day. I experience a feeling of movement at the top of my stomach, centre chest area. This is not painful but extremely alarming. I have had heart tests that showed no problem. My quality of life hhas deteriorated. Though 64, I would like to be able to work or do voluntary work but cannot, as never know from one day to the next how I will be. My SOD consultant says not all my symptoms fit with SOD and so I go back to my GP. I've had many many tests but still have all these symptoms. Not a lot of research has been done into SOD as a condition - iindeed some octors even say they aren't convinced it exists. Yet others are performing procedures suchxas cutting the Sphincter, injecting botox, inserting stents - in the belief that these may ease people's symptoms. I belong to several SOD Facebook groups both in the UK and the USA. Thousands of people are suffering with what they've been told might be SOD but there is no clear way forward for them. A common scenario is that the problems come on after gall bladder removal but there are cases of people who still have their gall bladders. Drug therapy suggested is basically trying a range of drugs that were developed for other conditions in the hope that they might help. We live our lives as best we can, young people do their best to hold down jobs and look after their families. But there is despair amongst these people who are desperate for some kind of solution, or at least improvement. I long for some answers, a way of improving my quality of life. It would be so wonderful if some research could be done into this area that might help and give hope to so many people who are suffering and have nowhere to turn; 239.1 P Feelings of food stuck in throat; 239.2 P Feeling bloated with constant belching; 239.3 P Burning throat; 735.1 P fleeting arthralgia; 680.1 P Paraesthesia in both feet; 468.1 P a feeling of stress /alertness.in the chest. Low testosterone.no concentration.no motivation. Unable to hear a person talking if someone else speaking nearby; 738.1 P Brain fog, Sudden changes in body temperature, especially cannot tolerate cold 🥶, Tiredness, Always feel less energy, Changes in mood; 553.1 P I am having a lot of gastro problems. Stomach pain, acid reflux, sore throat, chest pains. I am also prone to fainting and feeling dizzy and shaky. My doctors brush it off and don’t seem to take it seriously; 404.1 P The muscle fatigue & pain can b very frustrating, along with a brain fog; 169.1 HP Dizziness and fatigue; 368.1 P Digestive problems .numbness in leg and top of foot .muscle leg cramp spasms. Fatigue. Heart palpitations. Fall asleep no warning can wake up hours later were I was sat one minute .tingling burning sensation in feet hands; 382.1 HP I just feel tired all the time I also have like heart flutters not often but there; 385.1 P I am fatigued at times, sweating day and night also have dizzy spells at times, also have bowel problems had this for over 10 years now been under a specialist, I have put all these symptoms down to going through change; 392.1 P Right eye, top right there is always an aura when I look to the right and when it’s bright, been there for over a year. Eye test was ok. Above right eye, just above forehead it feels tingly this sometime goes down into my face. If I rub this area it is always tender; 712.1 HP Cognitive issues, Focus and Attention, Visual loss; 217.2 P Digestive issues; 217.3 P Abdomen pain; 217.4 P Blood in urine; 630.2 HP What are the most common expressions of these clusters of symptoms, and what proportion of them have a diagnosable psychiatric illness? 71.1 P When I open my bowels, I get very nauseous and/or vomit. I have been to several gastroenterologists and even a neurogastroenterologist who have not been able to answer why at London hospitals including St Barts, UCLH and the National Hospital for Neurology and Neurosurgery. No one can tell me why this is. It’s not a syncope thing as I don’t strain, it happens whatever type my stools are. What is the connection between opening my bowels and such sickness? This happens every single time I open my bowels for the last 12+ years; 337.1 P Is loss of libido associated with bowel problems? 255.1 P Why in some people does it affect certain parts of thd body. For example with me it is right leg weakness; 346.1 P Is under active thyroid linked to black outs with experiencing pain? 295.3 P Is difficulty losing weight related to digestive symptoms; 354.1 P I would like to know why symptoms are not viewed as pieces of a puzzle. In my experience medications are prescribed to alleviate a symptom but the symptoms are not viewed as part of a wider picture; 315.1 P I have a lot of symptoms similar to chronic fatigue syndrome, fibromyalgia and ibs. Are these related conditions or symptoms of hypothyroidism? 188.3 P If IBS is one distinct condition or should be divided into several conditions; 188.4 P If commonly co-occurring symptoms (pain, fatigue, bowel disturbances, headaches) can be linked into a distinct condition; 279.1 P Non epileptic seizures and links with functional neurological disorder; 314.1 P Are my symptoms linked to my thyroid? 416.1 P How does overactive thyroid affect muscle weakness, specifically: having to work harder than 'normal' people to maintain muscle strength? Is there a link between unexplained long-term genital itching and overactive thyroid? 133.1 P is there a direct link between stomach pain to cause sweating and blackouts? 592.3 HP What is the best way to integrate emotional/psychiatric difficulties with the mechanism of the physical symptoms? | Kroenke, 2014 | HP=6, P=55Total = 61 |
| 9 | Why do symptoms of MNYES fluctuate? | 231.1 P Why do I have really bad pain days and very little pain days; 122.1 P Why I can eat something one day with no problem but the next time I get chronic diarrhoea; 253.3 P why do I suddenly feel myself one day and then the next I am weak or have a new symptom? 114.1 P what causes irritable bowel syndrome and how can it be so different at different times? 235.1 P Why do I occasionally get Idiopathic Acute Pancreatitis? 183.1 P Why certain foods can be ‘safe’ one day and cause diarrhoea the next(IBS); 199.1 P I have a longstanding (over 60 years) bowel disorder which I think originated from travel as a student in the Middle East. The symptoms are varied but fortunately only include minimal pain, and appear sporadically without any apparent cause. I adhere to a healthy diet; 711.2 HP The degree of variability of symptoms that can be experienced by patients; 231.2 P Why do I have either diarrhoea or am constipated; 231.3 P Why do I feel pain in different regions of my abdomen on different days; 386.3 P My blood test results go up and down like a yo-yo, why, when I am told you are ok? Although I feel far from it; 386.5 P Mood swings and feel hot one minute and cold the next, I am post menopause? 253.8 P Is there chances that this will be a constant thing and we will continue to get relapses and will now need to monitor the way we live? |  | HP=1, P=12Total = 13 |
| 10 | How do patients/carers/healthcare professionals understand the symptoms of MNYES? | 643.1 O How do you make sense of your MYNES? 711.3 HP Beliefs about the mechanisms of FND amongst patients; 649.2 HP What are the explanatory models used by patients? 651.3 HP Patient and carer understanding of diagnosis; 711.11 HP Terminology - perceptions amongst patients, families, healthcare professionals of terms such as MNYES, FND, Conversion, Psychosomatic; 132.1 HP What terminology do patients prefer in relation to these symptoms and how does the terminology relate to the outcome? 711.11 HP Terminology - perceptions amongst patients, families, healthcare professionals of terms such as MNYES, FND, Conversion, Psychosomatic; 605.2 HP What does the name MNYES mean to patients and how does this impact on management and interaction with available NHS services? |  | HP=7, O= 1Total = 8  |
| 11 | What strategies are effective at promoting awareness and up to date clinical knowledge about MNYES amongst healthcare professionals? | 256.4 P How can clinicians be best kept up to date with the latest research findings in their field of expertise? 233.4 P Why are Consultants not always up to date with Research? Do they think they know everything? 514.1 C Why it takes a patients research to lead clinicians to find answers and treatment, and why clinicians don’t have the same drive to find those answers; 610.3 HP Why do clinicians continue to think that patients will be offended by a psychological formulation? 105.1 HP How can we "normalise" "symptoms" and develop a way of accepting some uncertainty; 105.3 HP Can health professionals influence societal expectations of "cure" and ensure that society learns to accept that medicine does not hold the answer to every problem of the human condition; 281.1 P Why do clinicians fail to understand the complexity of chronic problems? Especially in medical circles. the lack of basic training and knowledge is exasperating. A lot is known about these conditions - but not in routine practice; 21.1 P Why so many medical professionals seem unable to sit with uncertainty, resorting to psychosomatic explanations to explain away conditions that they can't otherwise diagnose; 254.2 P When you have a diagnosis like FND and your providers haven’t even heard of the condition, how can you build the trust that you are getting or going to get the care you should be receiving? 256.3 P Can clinicians receive further training in dealing with patients with MNYES? 669.1 P How are all Drs going to be educated about this because I've had severe chronic pain for over 20yrs and have never heard of this; 81.1 P How can conditions like EDS become more widely known so they are quicker to diagnose; 69.1 P Why are doctors not taught to keep an open mind? Why do they automatically jump to a psychological diagnosis? 744.1 P Health professionals to look at me as a whole person that may not fit neatly in to a symptom box; 275.1 P Why does my go not give me much help; 539.19 P How to teach medical students how to treat MNYES with respect; 539.5 P How to train all clinicians (in the whole multidisciplinary team) to diagnose and treat with respect; 1.1 HP How to get medical information about the diagnostic process properly; 23.1 C Why do those who promulgate MUS or this new version 'MNYES' not realise that they're selling a pup? What you're really saying is that you as medics haven't a clue what the correct biomedical diagnosis might be and are too lazy or too drenched in dogma that you're unable to see the fallacious nature of your construct. And that by adhering to this nonsensical construct, which creates a clinical & testing cul-de-sac for patients, individuals might wait years and multiple decades or have to access expensive private testing and care to get to the diagnosis from which they really suffer. Why do those who promulgate this notion not realise that they are causing suffering by adhering to it and not admitting that the misdiagnosis rate for MUS (or its synonyms) is very high and therefore they are doing a disservice to patients? First do no harm; 119.1 P Why does no one seem interested; 719.3 HP How can we get medical professionals to recognise them and refer them appropriately / to Psychology; 743.5 HP What are the most effective methods for educating medical and health professionals on understanding, diagnosing and treating MNYES? 137.6 HP How can we improve the training in MUS for NHS staff, including GPs; 177.3 P More knowledge for staff to be able to understand the impact of not having answers not just the physical problems but how it affects us mentally; 302.2 HP How can those health professionals who cling on to MUS or MNYES be persuaded that we actually do know a lot about the biology, causes and diagnosis of these disorders, certainly more or less the same as what we know about migraine, MS, Parkinsons where we also are only at the beginning of trying to 'explain' them? 496.2 HP How to establish therapeutic and healing relationships bearing in mind the understanding and experience of both patients and professionals (including across professional/specialty groups), as a common hindrance to recovery is the different framing of these syndromes/disorders; 630.6 HP What is the consensus on the language/ communication to be used that explains these conditions both to patients and their carers as well as to healthcare providers that is productive, effective, meaningful and helpful in managing these conditions and the anxieties of the sufferers? 267.1 P What sort of educational information/knowledge can be given to health care professionals to help those who suffer with MNYES not feel like we are making it all up? 696.8 HP Effectiveness of educational sessions/material for first contact practitioners. |  | HP=11, P=16, C=2Total =29 |
| 12 | What are the most effective methods for training clinicians to diagnose and treat their patients with MNYES with compassion, empathy and respect? | 161.1 P Don’t make people feel like there is nothing wrong just because they don’t know the answer; 259.2 P Why are there only a few doctors that will listen and take us seriously? 539.6 P How to train GPs to diagnose and treat with respect; 539.7 P How to train neurologists to diagnose and treat with respect; 588.1 HP How to reassure people about their worries. | Heijmans et al., 2011Weiland et al., 2015 | HP=1, P=4Total =5 |
| 13 | What is the impact of MNYES on healthcare utilisation? | 11.1 HP Impact of MNYES on healthcare utilisation for non-specific symptoms | Nunez-Wallace et al., 2015 | HP=1,Total = 1 |
| 14 | How can employers support people with MNYES? | 539.12 P How to support employers of people with MNYES; 539.13 P What accommodations are needed for people with MNYES in order to ensure they can remain in employment |  | P=2Total =2 |
| 15 | What is the best practice to offer optimal care for patients with MNYES? | 293.3 P How many GPs and Consultants have a process to follow up on those patients who have these issues and over what period time do the continue to follow up? 233.6 P When one has been frequently badly treated by a medic, to whom can one go, not just to complain but for them to do their job and work on finding answers instead of discharging you when you don’t fit their narrow categories. I could spend hours mentioning questions that come to mind because of the way I have been treated and the incompetence of some medical staff. I am 70 years old with a Ph.D in Health Psychology. My brain and body have now deteriorated so badly that I can no longer concentrate sufficiently. I want to see change but in what way, is my conundrum; 412.3 P My swallowing has deteriorated; 412.2 P Why was I discharged the day after the operation when clearly my wound was inflamed and indeed I had to be readmitted 3 days later as it was badly infected; 473.1 P Pots symptoms. Criteria met through tilt table test. Told by cardiologist that he's unsure and considers hyperventilation syndrome. Was referred to respiratory and tested for asthma which was negative. Not had any further correspondence from anyone. | Van der Feltz-Cornelis et al., 2012Roenneberg et al., 2019 | P= 5Total =5 |
| 16 | What is the current provision of services providing care and treatment for patients with MNYES? | 695.1 HP How many FND patients come through the Hyper Acute Stroke Units? 711.12 HP Audit of numbers of patients across non-specific FND services Eg mental health, memory services, neurorehab, ICT etc; 711.9 HP Mapping services across UK that provide treatment to FND patients; 593.2 HP How many patients can access holistic care particularly for chronic symptoms (including pain syndromes) - e.g. have access to OT/physio/psychological therapy in addition to medical and nursing review; 630.4 HP Which faculties/ disciplines (outside of mental health) encounter these sufferers and what training need do they have in effectively managing these patients? | Stone et al., 2010 | HP=5Total =5 |
| 17 | What are current clinical attitudes and levels of knowledge about MNYES? | 312.1 P Is this recognised by medical professionals? 153.2 P Why do doctors seem reluctant to help? 652.1 P What are doctors attitudes toward people with MMYES? 652.3 P What health practictioner biases exist when consulting with MYNES? 97.1 P Why do doctors instantly jump to putting the cause down to anxiety or outright say you’re faking it if they can’t immediately identify what’s wrong, or your blood test results come back as normal? 293.1 P How many GPs and Consultants are aware and know what MYNES, FND and all other associated interrelated health issues are. 293.5 P How many Consultants and GPs truly understand what MYNES, FND and all other interrelated health issues are and how do their ownpersonal attitudes to these issues impact on the health, care packages and wellbeing of their patients? I am interested in this issue so I am aware many are NOT!!! 293.2 P How many NHS GPs and Consultants follow NHS and NICE guidance on MYNES on a weekly monthly and annual basis; 84.1 P What unconscious biases lead to MNYES being labelled as such; 629.2 O understanding of potential for iatrogenic harm and the dichotomy this may place health professionals in; 564.1 P Are doctors biased with non-explained symptoms, and why aren't they taught that things like H. Pylory were also at some point considered "psychosomatic"? 86.1 P Why does The Medical community often refuse to acknowledge these symptoms as anything other that psychosomatic or similar descriptions even when there are clear symptoms? 357.1 P Is diagnosis of MUS driven by lack of holistic clinicians; 250.3 P Why are some medical professionals not aware of what FND; 569.7 HP There are ethical dimensions of MNYES that research could focus on, for instance how should health professionals handle cases when they suspect that patients are intentionally trying to mislead? Are placebo therapies justified? 650.2 HP Philosophical inquiry into the systems of thinking that make these symptoms so challenging. | Rawlings et al., 2018  | HP=2, P=13, O=1Total = 16 |
| 18 | What are patient experiences of the treatment/support they have received for MNYES? | 652.4 P Are Health practitioners aware of how their biases influence the patient experience? 685.2 HP It would be good to understand the client's experience of AHP treatment received and accessed. It is more usual we hear about how individuals have been able to access the correct diagnosis and the doctors involved with their treatment; 291.5 P What are people with MNYES's experiences of healthcare for MNYES? 417.2 HP Patient experiences of healthcare staff in relation to having MNYES (gp, hospitals, wards, community); 643.2 O What is your experience of health services in relation to your symptoms? 643.3 O In what ways could your healthcare be improved? |  | HP=2, P=2, O=2Total =6 |
| 19 | How can clinicians collaborate effectively to form the most appropriate care pathway and service model to offer assessment and treatment for patients with MNYES? | 295.4 P Should I seek medical help or just learn to live with symptoms; 296.3 P Who can help me & what should I be tested for? 612.2 HP how to combine physical therapy with psychological therapy; 623.1 HP Best management approach, evidence based; 656.4 HP Is treatment more specialist for FND than in general practice short term psychological intervention i.e. is better results , outcomes for patients in certain treatments; 688.1 HP Does combining psychotherapy interventions along side physiotherapy intervention have better outcome than either intervention provided in isolation? In relation to pain fatigue and unexplained movement disorders; 696.1 HP Effectiveness of treatment physio/psych/ot separately or combined; 109.2 HP Is there benefit to having a service that sits between physical and mental health that can review these service users? 110.3 HP What service is most appropriate for management of patients with MNYES - psychological medicine in acute hospitals or CMHTs or Liaison mental health services? 563.5 P Do we need specialist units/ Dr’s with an interest in MNYES? 602.4 HP Service models - why do we have NES services and not services for other common mus; 619.3 HP Can we set up a rapid access clinic? 635.3 HP Is treatment by medics, mental health service or combination most effective? 643.4 O If a new, holistic, service was to be developed (to work with MYNES)what would be the mission/aspiration of that service? And who would be involved in the 'team' and offering what? 352.1 P Identify a cause and a recognised referral pathway for tests to confirm diagnosis. An end to automatic referral for counselling instead of medical screening because GPs believe it is just psychological. 20.1 P How can patients with physical symptoms better access consultant physicians for a full and thorough diagnostic assessment instead of being fobbed off with inappropriate and useless psychological therapies? 351.6 P How many times you have been referred to mental health rather than follow up medical investigations; 94.1 O We would be free to ask any questions, travel etc if it meant it would benefit you & it could help better the quality of care mynes people receive. As so much is not accessible on people depends whether your gp believes you, how much it costs the gp or nhs( repeatedly hear this), who will fund it( repeatedly hear this). We are going into debt trying to find answers ourselves. As After 18 yrs wasted really in a medical system not gear up to look out for or treat mynes properly. My body is in about 13 hospitals some nhs & some private. Nothing links up. Have cried recently watching a mynes documentary serious on net flixs, as I do have some of te conditions but no way of accessing the help here or knowing who it is you turn to. It is all a huge stress to myself & my family as we are sure it is for all mynes families & loved ones . We've got a room full of folders & have been even suggested by some drs to bring them with us to consultations? How? We have 4 arms & mine are pretty useless & my husband needs his arms free to help me. Nothing looks at mynes holistically & its not considered when things malfunction across the body that there is something bigger going on. You have to give the gp symptoms in different appointments. If you go into a gp with a list of symptoms your mad, you couldn't have all those, you see the drs switch off & not help. Rather than think wow thats alot to start to malfunction in a person whom was once healthy. You are left years suffering & reporting the same symptoms, scared to say you now have additional symptoms. You do get additional or worsening symptoms the longer you body tries to struggle on with no help. Thank you. Hi I am considering leaving the country due to this. I have had some v good doctors in London but I don't live in london. I still have not got Answers to everything. WhenI have bad pots symptoms & everything plays up at once its in my head locally. Sadly they won't send me to London. I can't cope any more. It doesn't matter amazing what flyers, books or websites EDS or POTS UK produce I get told by my GP they just don't hv time. If its not in my head I'v been told, to cherry pick my worst symptoms, its best to help more people a little than 1 patient alot? I'v been told to pull up my socks, I'v been told I can't dr shop? When specialist have requested specific drs. Drugs aren't my friend & often they want to give me lots of drugs & for me to go away. I now don't go to the GP unless I absolutely have to & usually by then A&E is the next stop. I am have allergic reactions to everything & its not resolved or being looked into. I am having alot of severe adverse drug reactions. I have begged to have my genetics checked as there are alot of unresolved answers to symptoms. I know there are other sub syndromes from pots & I have quiet a few. However I know there are more. Drs think you want to be ill or are a hypochondriac. I'd like to know the correct diagnoises so that I can manage my condition to best of my ability. Sadly for me & I am sure for most women with pots, if you hadn't been dismissed so quickly & for so long, I wouldn't have deteriorated. I never return to previous health. So prevention were possible would have been amazing. But due to deterioration & deterioration it has lead to other conditions. 18yrs on I'd have hoped it would have been much better for our daughter. As 18yrs ago I was misunderstood & ignored. 1 dr fought to help but he retired now. And I was told, 18yrs ago, the % of woman who are not believed & how long it takes to get help. But 18yrs on I am hearing the same antidote. Our daughter is going through the exact same battle. Me have some diagnoises & knowledge has not help our daughter at all. If its like this in a 1st world country how bad is it for women globally? I get drs in hospital apologising the day I have had appauling treatment. The younger doctors apologise saying they stayed up all night reading about POTS & EDS & couldn't believe they'd never heard of them. They are facinated ask lts of question & say sorry for the treatment they witnessed. It isn't acceptable though that so many people are still living with this treatment as their reality. Having to battle to believed by Drs & support. In London I am treated totally different & you hear all the similar stories from other POTS patience in waiting rooms or at Forums. I can't fathom how nothing is understood or recognised & I am too busy to read that is an acceptable excuse. As if Drs read the short Pdfs it would safe alot of time & tears in the long run. They may actually believe & recognise what our bodies are capable of doing, recognise it & be able to advise better; 293.4 P What is the consistent national NHS pathway for this health issue? 543.1 P Why GPs ignore it? Why it is not being investigated? Why no support or treatment is offered? 233.1 P When one suffers with major diagnoses and co-morbidities, is it possible for one Specialist team to take over, rather than doing the research oneself without adequate medical knowledge and training. I have a tremendous amount of data I have collected from many years of inadequate Diagnoses and treatment by a variety of medics. I don’t know how best to use it? Obtaining such information has been like getting blood out of a stone; 270.1 P Q. Why are you not looked at as whole person but divided into specialist clinics who only look after their part? 236.1 P Why it has taken 30 years and many repeated visits for the GP to get me sent for tests...telling me each visit that I have IBS but not doing anything more. Thirty years! Finally being tested, gall bladder had to be removed and problems with Pancreas (tests on going and put on Creon to compensate for lack of enzymes). Should repeated visits to the GP generate a 'need' for further tests, how many, what criteria etc; 482.1 P I would just like to know why , in this day and age are there still so many of us suffering from mnyes!; 33.1 P Where do we go when no one knows what’s happening; 540.1 P Why don’t GP’s refer you unless they actually know what’s wrong; 303.1 P Number of people who have been passed from debt to debt and then no follow up, so they are now lost in the system; 16.1 P How to get the right support; 357.3 P Is NHS ill equipped for chronic illness so MUS diagnosis becomes dumping ground for difficult cases; 290.1 P I am not sure, I suppose that I would like Dr's not to write one off once the usual avenues of diagnosis have been exhausted, so my question would be 'what now?'; 139.1 HP Why colleagues choose to think these symptoms are MNYES - what thought process and intelligent inquiry went in to the decision - what physical examination was undertaken - what investigations were performed. The majority of the time I find a medically explainable reason, and often my patients have been told, literally from across the clinic room desk with no clear consideration of the history, no examination, and a reliance on normal blood tests, that there is either nothing wrong with them or they have a MNYES - if we don't look then of course to us it unexplained! Worse still in my opinion colleagues go on to explain the symptoms as psychological with no apparent assessment of the psychological state of the individual; 165.1 HP What health care professionals can deliver effective treatments for MNYES; 599.1 HP Is there a role for outpatient clinics for patients with persistent physical symptoms that do not focus on therapy but are mental health nurses working with people on a more social model. E.g. focusing on social contact, activity in day, practical help; 601.1 HP does approaching these as common end-points of common underlying physical, psychological, and behavioural processes allow us to deploy effective treatments? 602.1 HP How to manage in a small underfunded service - the value of formulation and joint working where there is no adequate psychological input available. Value of peer support groups/ group interventions; 633.1 HP How long and how wide should the search be for diagnosis.. when does one draw the conslusion that they are non organic; 638.1 HP Optimal models for an integrated care pathway and dedicated service; 657.1 HP How we can provide a consistent approach to Management; 693.2 HP Would the future pathway help non specialist teams (like community teams without access to psychological support) in treating FND patients? 694.2 HP Recommendations for clinical pathways for people with MNYES; 696.7 HP Effectiveness of a specialised pathway from first contact gp or a and e to go straight into a specialist program; 711.10x HP Delphi study to compile draft FND guidelines for identification and management of FND; 714. HP how services investigate and manage the condition; 155.2 HP How do we ensure MNYES patients have access to care as often with multi system disease it's both everybody's problem and nobody's; 222.2 P Trying to pigeon hole patients with broad range of symptoms into labelled boxes serves no one (Fibromyalgia is a case in point). Similarly, putting them in "Functional" boxes when there is an underlying cause that could be treated needs to be stopped. I would like to see patients with obvious symptoms being given the respect that its not "all in their heads" and that proper investigations will be done until the correct diagnosis is reached and appropriate treatment commenced; 244.4 P How best to provide patient-centred and coordinated care to avoid passing people from pillar to post, unnecessary repeat visits and inappropriate referrals; 263.2 P Why was I just left to it with now support? (Quote go at the time you're depressed, that's why you can't walk!); 270.2 P Why does not more GPS, consultants look into this instead of fobbing you off? 455.3 HP Is testing sometimes too much and a barrier to getting better? 472.3 P Would some kind of 'care-pathway' help the patients with MNYES cope better with them? Rather than feeling you're wasting your time and the doctor's time; 472.2 P Can there be standardised tests when presenting with these MNYES to a GP, (as I think a lot of the time you're fobbed off), so the GP has to go through a kind of checklist of tests/questions etc. to try to determine what could be causing the symptoms; 474.2 HP how can the groups above work best with physician / general health service colleagues, to foster empathetic, efficient and patient-centred care pathways for those with MNYES? 496.3 HP Treatment protocols that represent gold-standard and ideal treatment (eg with extensive psychology available), and more real-world approaches where patients are held mainly in primary care, medical clinics, and small liaison psychiatry departments; 563.2 P When should we realistically stop looking for a diagnosis for those with MNYES? 569.2 HP From the perspective of clinicians in secondary care who are not experts on MNYES, but come across a significant number of such cases because GPs want to rule out other diagnoses, I wish to know: -at what point do I stop investigating such patients for "organic" diseases? -would a specific and well defined patient pathway result in better patient outcomes? 576.5 P Why do people with MYNES fall through the cracks and how best can these gaps in medical care be filled?; 576.2 P What difference does it make to outcomes by having a separate medical pathway for people with MNYES? 605.5 HP Who should be involved in treating MNYES? 648.1 HP Best practice treatment pathways; 413.2 P why isn't a team of 'experts' looking at your case? 572.1 P That multiple Health problems are looked at holistically possibly under a MDT to check if they are possibly connected as a result of a specific diagnosis, rather than being treated individually as separate irrelevant ailments. This could help to find a better treatment plan and hopefully improve quality of life based on person centred care approach; 654.1 P Why different clinical disciplines do not work more closely / share expertise with one another. It seems what is blindingly obvious to one specialist, to another is completely unfathomable. To me, developing a cross referencing device (programme) where clinicians could input symptoms / information and get a read-out of possible diagnosis options would be a route to work towards - rather than depending on the experience and / or guesswork of clinicians, and reliance on patience remembering every associated symptom; 474.1 HP how can patients, caregivers and psychological medicine-liaison psychiatry service providers work best together, with aim of improvement in patient quality of life; 308.2 C will there be more joined up care across more than one discipline in the future as my partner's health problems span several specialities. |  | HP=31, P=30, C=1, O=2Total =64 |
| 20 | What aspects of multi-disciplinary treatment programmes are effective for MNYES? | 427.2 HP What are the effective components of multi-disciplinary treatment programmes for severe, chronic or complex MNYES. |  | HP=1Total =1 |
| 21 | What is the impact of receiving and sharing an MNYES diagnosis for both patients and carers? | 107.8 O What other impacts does this category have on patients- for example, on an individual level, creating a medically-sanctioned culture where it is acceptable to deny them medical, social, and/or financial assistance, and on a broader level, to deny research into their symptoms that is not dominated by the 'psychological-origin' school of thought? Thank you for offering this survey and giving patients a chance to share their thoughts. Please, \*please\* listen to what we have to say- don't keep denying us a voice!; 264.2 P what do you tell people about your symptoms; 563.6 P What is the psychological burden for those told they have MNYES? 643.5 O Outside of the healthcare system, what is your experience of others on learning about your MNYES? 744.3 P Discussion about the impact on your life of potential Long Term Conditions; 597.7 HP What is the social impact of this disorder? |  | HP=1, P=3, O=2Total =6 |
| 22 | How should information be shared with patients with MNYES and their carers throughout the diagnostic phase? | 306.1 P Why don’t GPS share test results (qualitative) with their patients? Why is my personal medical information kept from me? I’d like to be able to see and understand my blood test results (for example) more fully, first hand; 674.1 P that we're actually told what is happening to our bodies & why. i guess i've got peripheral neuropathy due to previous pain & now poor sensation, numbness & cold skin. i'd like to know why my spinal or neck pain hasn't been explained. why do i have movement problems, stiffnesss and disorientation. why is it a lifelong condition i'll never know the answer to. born with chronic unexplained diaorrhea, JRA & then well for less than 1- years before adult onset of lupus type symptoms. I now have cognitive troubles, can no longer read for meaning or analyse information so cannot complete my degree. why isn't someone interest enough to unpick what is happening. I was 26 when i first asked that question - i am now nearly 52. my husband barely remembers the original me. I am lucky he still loves the new me; 132.1 HP What terminology do patients prefer in relation to these symptoms and how does the terminology relate to the outcome? 605.2 HP What does the name MNYES mean to patients and how does this impact on management and interaction with available NHS services?503.1 P What should we do when the physician is somewhat indifferent re: the symptoms? is there a diagnostic search tool that you could enter your demographics and health history and symptoms that could steer you in a direction for further investigation; 254.1 P If you have physical symptoms and believe that the doctors have not answered nor eliminated all possible answers, what can you do. |  | HP=2, P=4Total = 6 |
| 23 | What are the information needs for patients with possible MNYES related to diagnostic and treatment decisions, and how should this be provided? | 537.1 P Are there any objective signs - eg blood or bio markers - which might help in pointing to a suggested cause of a particular set of symptoms? 149.1 P Can the symptoms be treated without getting a ‘diagnosis’ of a recognised medical condition? It’s not good enough to send a patient away with ‘its IBS’ when there is a significant change in symptoms. The pain/cramping/bowel habits that have changed must be a) treated as ‘real’ symptoms & b) monitored regularly, especially if unresolved. Finally, c) recognise that the symptoms may require more than just the broad spectrum ‘routine’ tests - specialist staff should be involved in the care & treatment of unexplained symptoms to find better tests/treatments for such symptoms; 413.4 P Why aren't basic health essential like vitamins and mineral levels checked as a norm? Particularly for CFS/Fibromyalgia/ ME patients? 541.2 P What testing and knowledge is available to patients experiencing skeletal pain? 408.1 P I have so many symptoms all over the body I need to know what you tell the doctor or how you prioritise your symptoms for them to come to any sensible conclusions. Do the doctors look at the whole body or just areas? Are there conditions where the whole body is affected; 661.1 P Why isn't more work being done in this field looking at the person as a whole, not just the isolated symptoms and signs. So their environment, their home/ work circumstances. What other symptoms etc have they experienced in their past that were unexplained. What influence does their emotions and mind have on these symptoms. What was going on in their lives when the symptoms first started. Could these symptoms be linked to the minds response to stress and Fight, flight and fight response; 370.1 P Why won’t many GP’s listen to patients symptoms when treating unexplainable illness instead of relying on test results and then dismissing us? 30.1 HP What questions should we ask and what tests should we do to find or exclude organic illness in MNYES? 128.2 P No one takes your medical history when you have unexplained symptoms; 577.1 P Is there any tests that could be conducted to try to link mnyes to other underlying health problems? 413.3 P why aren't you referred for scans / x-rays straight away as in many European countries to rule in or rule out conditions? 413.6 P Why aren't thorough thyroid checks done as a norm? Particularly for CFS/Fibromyalgia/ ME patients? 413.5 P why aren't women reaching or post menopausal or post hysterectomy offered DEXA scans as a norm? 345.1 P Further testing for conditions including enzymes (or lack of) which convert t4; 376.1 P Why GP's seem reluctant to do tests other than a standard blood test; 616.1 HP Diagnostic tools - examination features, biomarkers; 280.1 O fMRI has helped in bringing credibility to those with Fibromyalgia - has this been/could this be explored in MYNES too. |  | HP=2, P=14, O=1Total = 17 |
| 24 | How valid and reliable are current diagnostic tools for MNYES and what are the limitations of testing? | 402.1 P Why do patients have to go with the blood test results when they might be just over the guidelines, whatever they maybe? My thyroxine has constantly been reduced over the years but my well being is not taken into account. The doctors always go with the blood test results; 682.1 P How can someone whose average body temperature is 35.4 and spends the majority of the year cold, not have an underlying issue? I would like to be sure that regardless of where a blood test is analysed, the lab results are based on the same measuring criteria. More direct pre blood test advice should be provided, to ensure as accurate reading as possible, e.g. fasting before the test etc. 592.1 HP How can we improve objective diagnosis of symptoms such as pain, sensory disturbance and cognitive "fog"? 288.1 P I have a number of unexplained/ undiagnosed conditions and symptoms on different areas of the body, yet the medical system doesn’t deal with the body as a whole. When will western medicine stop treating the conditions as separate entities and start looking for correlations and relationship between ongoing conditions? 655.2 P Symptoms appear to come and go, is this because levels fluctuate so taking annual blood tests is insufficient to adequately manage unexplained symptoms? 34.1 P Why do GPs tend to overlook the physical presenting symptoms in young patients, focusing on finding a mental health diagnosis instead? 216.1 P Definate diagnosis and treatment; 469.1 P An accurate diagnosis; 188.5 P If IBS truly exists as a distinct condition or is just a catch all term used when GPs are unable or unwilling to pursue further investigations beyond the most common causes of symptoms; 93.1 O I would like GPs & consultants at the hospital so easily dismissing women, that pain & fatigue etc is in your head or you are causing it some how. There must be another route for help. I am still battling with many unexplained symptoms. Me & my family have figured out my diagnoises, shocked from documentaries. Begged & begged to see a specialist. But its only when people witness your symptoms ypur believed. Yet ths is not how the nhs works. I can't have sumptoms pop to my dr & pop on an mri machine. Often tests follow as outpatience months after symptoms have quietened down. This goes to prove its all in your head until they witness an episode & are stunned or panicked. I still suffer with serious allergic reactions & vitamin deficincies & bowel problems. But when you have other complex conditions they literally say 'O your so complex I don't know'. 'Your not dying'.'you don't hv cancer'. I don't have a quality of life & as not fully diagnoised an rotting away at home undiagnoised & untreated. With family struggling greatly. They don't get a consideration. And now are daughter has the same symptoms; 413.1 P why is every symptom looked at individually? 103.1 P Why do doctors end up coming to the conclusion that it's psychosomatic and therefore requires psychological interventions and treatments ONLY? 332.1 P For standard tests there are parameters that are ‘normal’ - can these be more specific for types of people ie based on height, body weight etc? A normal level of something may not be enough for someone very tall or short so things get overlooked or not diagnosed. Can levels be honed? 677.1 P Why after getting all the routine blood test am i still no further on in finding out what is wrong; 32.1 P If there are more tests/ investigations that can be done or a different procedure for dealing with MNYES because at the moment I’m just told by doctors that I’m lying; 550.1 C The adage “when you hear galloping, look for horses, not zebras” is true much of the time, but how can we get doctors to look beyond the “horses” and consider the “zebras” in a timely manner; 130.1 P How many doctors think of extending investigations to include dietician, psychologist or lifestyle analyst once the endoscopes and colonoscopies come back negative? 611.1 P Whether my symptoms really need medical investigations to be explained or can a doctor not tell me based on what I describe may be the cause even if it is psychological or so called “mechanical” in nature. 128.1 P Someone to listen and catalogue the symptoms and see the patterns; 548.1 P What illnesses have imperfect testing, that could account for some of the myriad of MUS related illnesses? 47.1 P Since reaction to iodised contrast, suffered most horrific sezuires that never suffered before, developed pots and other problems. ???? My question is : why most neurologist look at few obvious categories: MS- Parkinson's??? There are so many of us suffering extrymly debilitating autonomic nervous system problems that can bring on sezuires yet so ignored. Everything is labelled as anxiety. Yet far from it.; 115.1 HP What are the minimum investigations that should be done in this group of patients; 743.1 HP What are most effective ways of diagnosing MNYES? 262.3 P How to address diagnostic overshadowing for those with mental health conditions? 262.2 P A standardised process for diagnosis? 431.2 HP have services adequaltey assessed for systemic physical conditions; 623.2 HP Clarify diagnosis; Hypochondriachal vs, somatic symptoms, vs Conversion disorder/ Dissociative/ Functional Neurological Disorder. |  | HP=5, P=20, C=1, O=1Total =27 |
| 25 | Which validated screening tools for emotional wellbeing/ quality of life are most useful for people with MNYES? | 429.10 HP Valid screening tools for emotional well being/quality of life for people with MNYES? |  | HP=1Total =1 |
| 26 | How many people are misdiagnosed with MNYES and what are the consequences? | 22.1 O Why is there so little research into MUS misdiagnosis rates? 74.1 P How many people are given incorrect mental health diagnoses? 79.1 P How many MNYES diagnoses are reached without considering dysautonomia; 724.1 HP What proportion go on to have a reputable diagnosis? 3.1 HP What Percentage of people end up with a medical diagnosis eventually; 357.2 P Is diagnosis of MUS too easily applied; 711.8 HP Number of other diagnoses that have made (number of medical assessments undertaken, length of time to diagnosis) in patients ultimately diagnosed with FND; 417.3 HP No. of patients who have been told they have MNYES who then go on to receive a diagnosis of their symptoms which is physical in nature; 390.1 O What is the rate of patient-reported misdiagnosis of 'medically unexplained symptoms'? 107.7 O An MNYES or MNYES-category diagnosis is often made without thoroughly testing for known diseases, and further medical testing is actually discouraged for patients in this category. This means already-known diseases, some of them progressive in nature, are often missed. How many people have had irreversible damage or even died due to failure to properly investigate symptoms when they first appeared? 18.1 P How many of these patients have undiagnosed rare diseases? 563.3 P How many people diagnosed with MNYES then receive a diagnosis, especially of a rare disease? 2.1 HP Which organic conditions commonly present as MNYES and how best to identify them; 390.2 O What is the average length of time of delayed diagnosis for patient-reported misdiagnosis? | Eikelboom et al., 2016 | HP=5, P=5, O=4Total = 14 |
| 27 | How are MNYES related to disability? | 422.1 P Medical vs social model of disability. Many years ago, I was diagnosed with MS after an illness. Subsequent investigations suggested I do not have MS but “residual neurological damage from a non-specific illness”. I consider myself disabled according to the social model yet medically, whatever caused the damage remains undiagnosed. |  | P=1,Total =1 |
| 28 | How can clinicians identify when a MNYES scenario is beginning to develop and provide information about this? | 163.1 P For me. I have been this way 9 years with no real plan of going forward. Always from gastroenterologist "watch and wait" how much more of my life do I have to surrender to this pain and swelling? 40.1 P Why is it taking years to figure out why I am getting all of these symptoms; 175.1 P Why does it become impossible to give a diagnosis after many years of symptoms and 'wrong' diagnosis; 53.1 P How long it takes people to get answers to their symptoms; 671.1 P Why does it take so long to diagnose the reasons? 265.1 P Why after thirty six years of being diagnosed with IBS have doctors not thought to investigate further than blood tests and this year for the first time a CT scan? 119.2 P I've been left years in pain; 270.3 P 20 years and lots more co morbidities that not one person can explain? 651.1 HP Delays in confirming diagnosis and numbers/types of inappropriate treatments occurring as a result; 196.1 HP [1] My experience [as a GP] is that once people get referred, e.g. to a pain clinic, no further diagnostic work is done. It's just how to manage the condition. How can GPs and patients be confident that they are not missing any treatable conditions? In General Practice, too often we assume that 'common things are common' and we don't look for [and don't know about] the many less common or even rare diseases that could cause certain MUS. For instance, histamine intolerance - one patient's brother told me "I could be in A&E every week". Had this patient not brought his brother, who told me all about histamine intolerance, I would have had no clue about what was wrong with him. Diagnosis too often relies on conditions the doctor can think of, rather than an evidence-based logical work-up. This is a great pity. I suspect many more patients could be diagnosed if there was such a work-up. My own expertise is in vitamin B12 deficiency [B12d]. We know that B12d often produces diffuse symptoms, in a large number of body systems, but particularly neurological. Symptoms vary widely between patients. And the blood tests for B12d are so imperfect, they leave at least 2/3 of patients undiagnosed [Ward, 2015]. These patients then go into the books as 'MUS'. The patient often suspects it is not psychological, but their doctor may give the impression that it is. This can lead to increasing frustration in both patient and doctor, and a dysfunctional patient-doctor relationship. Sometimes even a breakdown of trust. Many patients remain undiagnosed for many years, I've even heard 20 years [Hooper, 2014]. During that time, in their desperation, GPs often refer to a dozen or more specialists, try a handful of medication, while the patient continues to deteriorate. I would love to see / collaborate with research on prevalence and diagnosis of B12 deficiency in MUS [please contact me, rietsema@doctors.org.uk]. Prevalence of B12d in the general population is 5% in young people, 22% in people over 65, and 32% in people over 80. I suspect in patient groups with MUS, prevalence is substantially higher. All of the symptoms mentioned at the beginning of this survey can, and often are, symptoms of B12 deficiency. This to my mind is an urgent research need. There are better tests than total serum B12 - serum homocysteine and methylmalonic acid. However, these are expensive and not widely available. So most patients do not have access to them. Research could elucidate: \* The prevalence of B12d in MUS, when tested with total serum B12, holotranscobalamin [this is the B12 available for uptake into the cell], homocysteine and methylmalonic acid [the latter two are metabolites, levels of which rise when B12 is low]. \* In the absence of more sensitive tests for B12d, how can a trial of treatment with vitamin B12 aid in the diagnosis? How can response to treatment be 'measured' and monitored? I think this is an urgent research need, because [1] MUS are common, and lead to high burden on the patient's quality of life, on health care and on GPs [2] B12d is common, and very commonly missed [3] The longer B12d is undiagnosed, the higher the risk of irreversible neurological damage [4] B12d can be easily and effectively treated, with complete symptom resolution if done well. How do GPs differentiate between somatic and 'functional' disorders? And what makes them more or less successful in this? I know there is often a lot of discordance between patient and GP, and between GPs, of what is functional and what is a true somatic disorder. What educational needs do GPs have in this area? Hooper et al., 2014. Patient journeys: Diagnosis and treatment of pernicious anaemia. Brit J Nurs, vol 23, no. 7, pp. 16-21. Ward, M. et al., 2013. P148 Screening with holotranscobalamin is superior to serum B12 in identifying vitamin B12 deficiency in patients with Crohn's disease. Journal of Crohn's and Colitis, 7(S1), p.S68. | Murray et al., 2016 | HP=2, P=8Total =10 |
| 29 | Which self-management techniques are effective in MNYES? | 125.1 P Given a flare up of digestive issues what (easily available) herbal remedies will help or hinder? E.g. peppermint tea is often recommended, but there doesn't seem to be much variety on what could soothe me, beyond old wives tales; 696.4 HP Effectiveness of workbooks or self help interventions; 431.3 HP what impact do body based practices have eg yoga, dancing; 632.4 HP Role of self-help in recovery; 42.1 P What can be done to make my everyday life easier? 284.1 P What are the most commonly used effective self help measures for IBS symptoms; 167.1 P how to controle IBS like symptons of constipation followed by frequent bowel movement and debilitation; 470.1 P How can I overcome the tiredness; 470.3 P should I give up gluten; 470.4 P does going gluten free help with joint pain; 253.5 P How do we fight the Tiredness that occurs from doing the simplest of tasks? 195.1 P 1 food plan; 568.2 P How can I manage my symptoms and be able to get on with a healthy life? 410.2 P how to manage the symptoms is there any hope? 501.1 P I’d also like to know how to deal with the symptoms so they don’t affect my work ability; 242.1 P Self help for Helicobacter pylori,(doctors will not listen when you tell them you have the same symptoms as before)so they won't give you medications you need when your guts are telling you that is what it is,especially when you already have a duodenal ulcer from when they did an endoscopy previously.all the doctors do is send you for another endoscopy,you can't do the stool test,for 2 wks prior to test if your on ppi,which is useless when you feel ill,my doctors don't offer the breath test only blood & stool tests,they just tell to use the ppi? 360.1 P I'm on my second round of solumedrol and started taking levothyroxine I'm so tired and and feel alfull can't function what can I do to help this; 551.1 PWhat I can do to minimise or get rid of symptons; 119.3 P How can I make a change; 151.3 P How can I ensure that I can leave the house and not experience sudden diarrhea? I walk 6-10 miles a day and Diarrhea is a constant embarrassment; 366.2 P What can I do to improve my symptoms? 455.2 HP What are the best treatments for symptom recovery? 643.6 O On a day-to-day what are the biggest challenges you face? What supports do you find most helpful (both internal & external sources)? 743.2 HP What are the most effective education strategies in treating MNYES? | Moayyedi et al., 2014Tiequn et al., 2015Searle et al., 2015 | HP=5, P=18, O=1Total = 24 |
| 30 | What can improve treatment engagement for patients with MNYES? | 635.2 HP Factors predicting engageability with treatment. |  | HP=1Total =1 |
| 31 | What are the most effective pharmacological treatments for different MNYES symptoms? | 539.16 P Identify effective medication adherence techniques for MNYES; 63.1 P Is Amantadine a potential treatment for IBS? I have been prescribed it for another reason but have found it has enabled me to reintroduce food to my diet that I have not been able to eat for years; 109.4 HP Is there a role for psychotropic medication and if so, which are most efficacious? 125.2 P Are enzyme tablets effective? Do they have side effects? Should they be easily available? 429.7 HP How useful are psychotropic medications? 106.5 HP Opiates and chronic pain diagnosed as fibromyalgia (if this sits in MUS/MYNET remit). Do opiates have better outcomes in terms of pain management and functional recovery or do they worsen the situation? Might be helpful for GP colleagues; 106.4 HP Similar medication versus non-medication versus combined? 108.2 HP What medication has been helpful? | Derry et al., 2017Kleinstaeuber et al., 2014Walitt et al., 2016Ford et al., 2017 | HP=5, P=3Total = 8 |
| 32 | What are the most effective psychological treatments for different symptoms of MNYES? | 639.1 HP How effective is CBT? 276.1 HP what are effective therapies using mindfulness; 606.1 HP What other psychological approaches apart from cognitive behavioural therapy may be helpful for the management of MNYES symptoms? (e.g. hypnotherapy, interpersonal/ psychodynamic therapies have all shown benefit but more evidence is required.); 617.1 HP Efficacy of psychosocial Interventions; 696.2 HP Effectiveness of group therapy Vs individual; 696.3 HP Compare CBT/act; 711.4 HP Efficacy of psychological interventions with FND/MNYES (ACT, CBT models); 743.3 HP What are the most effective psychological based therapies for MNYES? 106.3 HP Research in terms of what are the best non-medication strategies for MUS/MYNET in light of the above? Mindfulness? Distraction? Acceptance therapy? An adapted form of CBT? Role for a dynamic psychotherapy? I recall some kind of therapy where the patient talks about when pain developed and life/relational issues etc at that time and writing a letter to themselves? 110.2 HP What psychological treatments are most effective in managing MNYES? 132.2 HP What psychological interventions can help patients with MNYES? Are there interventions which can be common to all MNYES? 137.3 HP 3) What forms of therapy help - eg CBT, reattribution therapy? 594.2 HP Impact of psychological therapy on outcomes for patient group; 594.3 HP What psychological therapies are actually useful to the patients and improve outcomes; 597.4 HP Can this disorder be improved with psychodynamic psychotherapy? 602.2 HP Brief psychological interventions -which work? 639.2 HP How effective are other forms of psychotherapy (e.g. psychodynamic interpersonal therapy for dissociative seizures, trauma focussed therapies); 701.2 HP How can mindfulness be beneficial to improving all symptoms of FND? 425.2 HP Effectiveness of psychological therapies; 427.3 HP Is psychological treatment with an interpersonal component (Such as psychodynamic interpersonal therapy, interpersonal therapy, family or couple therapy) effective as a component of management; 429.8 HP Is there a good evidence base for psychoanalytic psychotherapy? 591.2 HP What is the role of psychological (talking) therapies in treatment? 609.2 HP Effectiveness of brief psychodynamic psychotherapy; 617.3 HP Efficacy of psychological intervention for pain; 649.1 HP What is the appropriate behavioral approach to management? 717.2 HP What strategies/therapies are most helpful; 719.1 HP What is the best therapeutic strategy for these symptoms? 720.1 HP early intervention (e.g A&E), therapy inc physio and imaging of FND patients, PPPD (dizziness and early intervention); 729.1 HP What is the most effective/beneficial approach and treatment for treating patients and their family's; 731.2 HP How are they best helped; 569.9 HP Likewise, high priority is investigations into the efficacy of interventions, which (if I understand the literature correctly) are likely to be focused around phychological treatments; 595.3 O What treatments work - which therapies? 616.2 HP Therapy strategies particularly for functional i cognitive impairment. | Anheyer et al., 2017Waterschoot et al., 2014Koelen et al., 2014Van Dessel et al., 2014Ganslev et al., 2020Gutkin et al., 2021Goldstein et al., 2020 | HP=29, O=1Total =30 |
| 33 | Overall, what are the most effective treatment strategies for different symptoms of MNYES? | 619.2 HP What are the key useful treatments? 636.1 HP Most effective treatment strategies? 651.2 HP Evidence based treatments; 717.2 HP What strategies/therapies are most helpful. | Mesa-Jiménez et al., 2015Ainpradub et al., 2016Kamper et al., 2014Zech et al., 2017 | HP=4Total = 4 |
| 34 | What are the most effective physical treatments for different symptoms of MNYES? | 539.1 P What are the best physiotherapy protocols; 539.3 P What are the best occupational therapy protocols; 691.2 HP Best evidence/ Interventions/ strategies to support improvement in function; 701.1 HP What are the most effective treatment strategies for functional sensory symptoms? 705.2 HP Is there different treatment approaches depending on the formulation for the diagnosis for OT/PT? 743.4 HP What are the most effective physical and functional based therapies for MNYES? 597.5 HP What is the role of occupational therapy? 597.6 HP What is the role of physiotherapy? 119.4 P What options do I have; 165.2 HP Whether combined therapies, such as 'psychologically informed' physiotherapy, can improve MNYES; 165.3 HP Effective therapies for chronic dizziness; 195.2 P 2 pain relief; 225.2 P Nerve pain and how to get rid of it; 291.3 P Has the existing evidence for effective interventions for MNYES been reviewed? 305.2 P Standardised treatment. | Furlan et al., 2015Naumann et al., 2014Salazar et al., 2017Müller et al., 2014Martins et al., 2016Lam et al., 2013 | HP=8, P=7Total =15 |
| 35 | Do treatments for co-existing psychiatric conditions impact on the symptoms of MNYES? | 637.2 HP Impact of treating co-morbid psychiatric illness on symptomology; 600.1 HP How can trauma based interventions ie EMDR support recovery from trauma associated with medically unexplained symptoms (both previous trauma and trauma associated with medical intervention); 299.2 P I wonder about the mind body connection and the applicability of recent developments in psychological medicine for trauma recovery to MNYES; 637.3 HP Does stress or trauma processing treatment help improve outcome? |  | HP=3, P=1Total =4 |
| 36 | How do treatments for MNYES work? | 595.4 O How do treatments work? |  | O=1Total = 1 |
| 37 | How can the most appropriate treatment be selected, dependent on different MNYES symptoms, that a person with MNYES is most likely to benefit from? | 207.1 P how is it that surgery can cause more adhesions when its to alleviate the symptoms; 132.3 HP What are the similarities and differences between the experience and management of patients with different manifestations of MNYES? 183.2 P I have a pacemaker to stop my heart going below 75 bts/min for junctional tachycardia and also palpitations. I had 3 failed ablations. Q) Why, if pacemaker batteries are just supposed to switch off and not ‘run down ‘ did I struggle and feel very ill in the last two years, then feel great as soon as the battery has been changed? 612.1 HP how to select the type of therapy a patient is most likely to respond to (interpersonal, CBT, brief dynamic, other); 684.2 HP Is there a particular client group who can benefit from community (at home or out-patient) services, or a group for who need to be prioritised for input from a specialist centre with in-patient services; 719.2 HP Are different strategies suitable for different symptoms? 605.4 HP Is specificity of treatment important? (e.g. does fatigue need different treatment from pain or GI problems); 606.2 HP How can individuals be best matched to treatments that are likely to be of benefit for them. (e.g. the group are often thought of as being homogenous whereas the reality is there is great heterogeneity- for some people there is a strong psychological component, whereas for others there is little evidence of psychological factors being important); 618.2 HP Which intervention to choose/ how to stratify treatment options. |  | HP=7, P=2Total =9 |
| 38 | What are the most effective ways to support patients with MNYES and their carers to live with their symptoms? | 625.1 HP Why do so many patients and families find it very difficult to accept the power of the mind over the body's systems? Is it societally-driven or more related to individual family culture? 610.2 HP Is it dangerous to leave psychiatry and and psychology out of treatment approaches, by encouraging patients to view these problems as entirely "physical"? 105.2 HP How can we as professionals develop a shared way forward with those with lived experience of MUS; 127.1 P I would like to know what is wrong with me and how to treat this to allow me to have a quality of life; 470.5 P how do I get more energy and reduce weight gain; 256.1 P What can medical clinicians do to help patients feel that their symptoms are genuine and being taken seriously?; 256.2 P Can individual symptoms be treated, despite not having a diagnosis for the condition as a whole? 508.1 P No questions, just a more holistic approach to treating patients rather than relying on an inflexible set or criteria. For instance if I hear, 'well you TSH is within range so your extreme intolerance to the cold. dry skin and tiredness can't be related to that' one more time I will scream; 510.1 P what would help (therapies? workplace adaptations?.... just don't come up with lifestyle changes which sacrifice quality of life for economic exploitability!); 54.1 P Can they look at alternatives rather than adding a pill in; 420.1 P I would like to know why there is no care given on the mental health side . I cannot take Levothyroxine properly as it makes me extremely anxious and ups theOCD level, but also cannot do without it. I had radio active iodine 16 years ago, and since then life has been hell with tremors , mental health , seizures , and many other symptoms that all health professionals say.......just get on with it; 744.2 P GP’s to listen to how your symptoms / illness make you feel. Don’t just focus on the physical; 629.4 O understanding of what health professionals need to help them aid patients; 629.3 O understanding of may be "good enough" to balance risk Vs benefit; 659.1 P New treatments, alternative procedures like acupuncture provided for free; 27.1 P When symptoms lack a clear explanation, would it make sense to give money directly to patients so that they can use it to improve their own lives however they see fit, rather than having money directed to healthcare staff? If MUS researchers make false claims in their papers and refuse to correct them, should they face financial penalties? What systems of accountability need to be in place in order to dissuade medical professionals and researchers from making exaggerated claims about their ability to help patients? Have patients with MUS been treated fairly by healthcare staff over the years? When they are not treated fairly, what disciplinary action is taken, if any? If there has been a pattern of poor treatment, and a failure to take appropriate disciplinary action, what changes to the systems of oversight surrounding healthcare could be introduced to ensure any future problems lead to meaningful accountability? Who should be allowed to hold positions over power and authority over MUS? Should there be a form of democratic process in place to prevent insiders from appointing those patients expected to support their own interests as patient representatives? 627.2 HP What’s the most acceptable way to explain what’s happening; 627.1 HP What is the best way to help people to live with/ recover from these symptoms; 251.1 P I had all the MRI Test and EEG and Sleep EEG all come back with Non Epliletic seizures. Consultant said i have FND and discharge me. Im still have numbness in my left side of leg and weakness in my left arm and left leg. More worse when i am tired. I have Complex Post Traumatic Stress Disorder gone through two years of EMDR therapy and Hypnosis and thought i was cured now i got FND. I have words that get muddled, memory poor, and skin sensations like a crawly feeling that i want to scratch all on left side. Muscles are tight. Just got my driving licence back just dont drive when im tired. These twitches in my lower leg and jerks looks like i have to just put up with it; 539.10 P How to support the family and carers of people with MNYES; 539.22 P Identify how to best support family and carers of people with MNYES; 539.9 P How to support social participation in people with MNYES; 539.14 P Identify effective fatigue management techniques for MNYES; 539.15 P Identify effective pain management techniques for MNYES; 539.18 P Identify how to improve the holistic wellbeing of people with MNYES; 539.20 P Identify effective peer support mechanisms for people with MNYES; 542.1 P How can patients be supported? MNYES are impacting my life, stopping me working and causing heightened anxiety yet all I can do is call my GP who is stumped; 229.1 P Is there a better way to help treat patients even if there is an unknown cause? 151.1 P IBS how can I isolate food groups that cause my persistent diarrhea? 292.1 C I am Concerned that individuals are left to deal with chronic symptoms which completely impact on their quality of life. My son in particular has been badged as having IBS without complete consideration of other related conditions. We feel completely on our own with this!; 454.1 HP develop a service that is a beer match with patients explanatory belief system, i.e. an embodied approach; 455.1 HP How to best engaged patients? 486.1 HP What treatment intervention approach has been able to demonstrate an improvement in patients' abilities to manage symptoms? 615.1 HP How to help patients who are in denial of the effect of adverse life experiences; 684.1 HP What value are community services in supporting this client population? 691.1 HP How best to support MNYES in community settings; 694.4 HP For occupational therapists specifically guidance for decision making around when to provide compensatory equipment (such as manual handling equipment) and does this prevent/delay recovery of function; 705.1 HP Is there any evidence to support early intervention for FND? 716.3 HP Are there any guidelines to the services need to treat these patients and get a positive outcome? 723.1 HP How to confidently tackle malingering; 730.1 HP What is the best discharge pathway for patients with MNYES? 730.3 HP What team treatment approaches are most effective for pts with MNYES? 109.5 HP No questions as I have trust and faith in this research; 109.3 HP Should the focus be on other aspects of their lives and not on the symptoms/treatment etc? 121.4 P Why do apples, cider, lactosr and onions make me ill? Why do coeliacs get follow up treatments but people without a formal diagnosis but with similar if not more severe issues with gluten do not? 137.5 HP In what setting are aptients most liekly to attend to been seen in a non-stigmatisinf way; 244.3 P How can people without a diagnosis feel reassured? 280.3 O Why are we so hung up on labelling illnesses, and why is it difficult (or impossible) to access help/treatment without a lable, even if the symptoms are all there. (From experience, I was given no help at all until a neurologist gave me the "fibro" label. My symptoms were left untreated for years beforehand); 563.4 P What support systems are need for people with MNYES? 588.2 HP How to help people stop taking chronic pain medicines; 599.2 HP A full and Frank discussion about any mobility adaptations in home and how this may not be helpful in the longer term; 602.3 HP GP role - building on Salmon's work about communication; 626.2 HP What is the best way to provide integrated (mental and physical) care to patients to avoid the mind/body split; 632.2 HP Best way to communicate this diagnosis; 633.3 HP Why are services diverse in their thinking; 636.2 HP Best ways to engage patients in the discussion about their health? |  | HP=27, P=25, C=1, O=3Total =56 |
| 39 | What is the prevalence of injury (physical and psychological) due to MNYES and/or its treatment? | 289.1 C Quantification and identification of Injuries secondary to FND such as PTSD from horrific medical treatment, or adult onset scoliosis due to constant one-sided muscle spasms, and why being “psychogenic” is considered justification for the hesitation or refusal to treat somatic symptoms causing measurable damage; 709.1 HP Prevalence of injury sustained due to FND symptoms. |  | HP=1, P=1Total =2 |
| 40 | What factors affect outcomes for MNYES? | 696.6 HP People who have recovered Thier opinion on what works; 704.1 HP What are the outcomes for people living with MNYES and what input results in the most improvement? 181.3 HP What affects outcome / predictors; 291.4 P Can educational material for clinicians and/or patients improve outcomes? 569.6 HP How does availability of good quality information to patients about MNYES affect patient outcomes? 597.9 HP What are the determinants of outcome in this disorder? 636.3 HP Life course of symptoms? 417.1 HP Statistics around prognosis (full recovery VS lifetime management.); 716.4 HP What percentage of these patients recover? 7.1 O Can it be life threatening. | Gelauff et al., 2014van Eck van der Sluijs et al., 2018 | HP=8, P=1, O=1Total =10 |
| 41 | What affect do MNYES have on mental health? | 576.1 P What the impact of MNYES has on the individuals in terms of mental health. |  | P=1,Total =1 |
| 42 | What treatment factors affect outcomes for MNYES? | 613.2 HP how much does treating medical and psychiatric co-morbidities influence function/quality of life (e.g. OSAS/migraine/anxiety/insomnia etc etc); 274.6 P What is the impact on patient outcomes of having separate consultants for each section of the digestive system without one person taking ownership; 576.4 P What proportion of MYNES are actually resolvable/have a diagnosis/treatable? 253.8 P Is there chances that this will be a constant thing and we will continue to get relapses and will now need to monitor the way we live? |  | HP=1, P=3Total = 4 |
| 43 | What is the most appropriate way to measure treatment effect for MNYES? | 685.1 HP It would be valuable to identify some relevant standardised outcome measures that are being used consistently across the FND client group in treatment; 694.5 HP what is the most effective outcome measure for this client group to measure the impact of interventions; 569.3 HP What are the most relevant and appropriate patient outcomes that interventions should be judged against? |  | HP=3Total =3 |
| 44 | What outcomes matter most to patients with MNYES? | 597.10 HP What outcomes matter most to patients? 696.5 HP Peoples opinions on recovery. |  | HP=2Total =2 |
| 45 | What health service factors affect outcomes for MNYES? | 694.3 HP What impact does an early negative experience of healthcare services have on outcomes; 716.2 HP Is there any recommendations as to what approaches have the best outcome ie MDT working rather than AHPs working alone with a patient; 291.2 P Can allowing more clinical time for patients with MNYES improve outcomes? 569.5 HP How does active management of patient expectations by health professionals affect patient outcomes? 569.4 HP How does early identification of MNYES affect patient outcomes, compared to late? 576.3 P Can the forming of a multidisciplinary medical team make a difference to the outcomes for people with MYNES; 613.3 HP does early intervention by specialist when needed influence outcome (e.g. RCT on early vs late physiotherapy +/- specialised psychiatric care in 1st presentation in acute inpatient setting); 617.4 HP How long from presentation to access specialist psychologically informed intervention, and correlates with outcomes; 619.4 HP Does having an MDT clinic affect outcome? 642.2 P do people who get referred to secondary mental health services stand a better chance of getting better than those who don't? |  | HP=7, P=3Total =10 |
| 46 | How do MNYES symptoms change over time? | 519.3 P Will I ever regain my memories and short term memory? 120.2 P Will my condition continue to deteriorate over time? 652.2 P Do this change over time? 635.1 HP Long term follow up studies of trajectory of illness over life span; 283.2 P Why does it seem to get worse/more frequent over time? | Steinbrecher et al., 2011 | HP=1, P=4Total =5 |

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