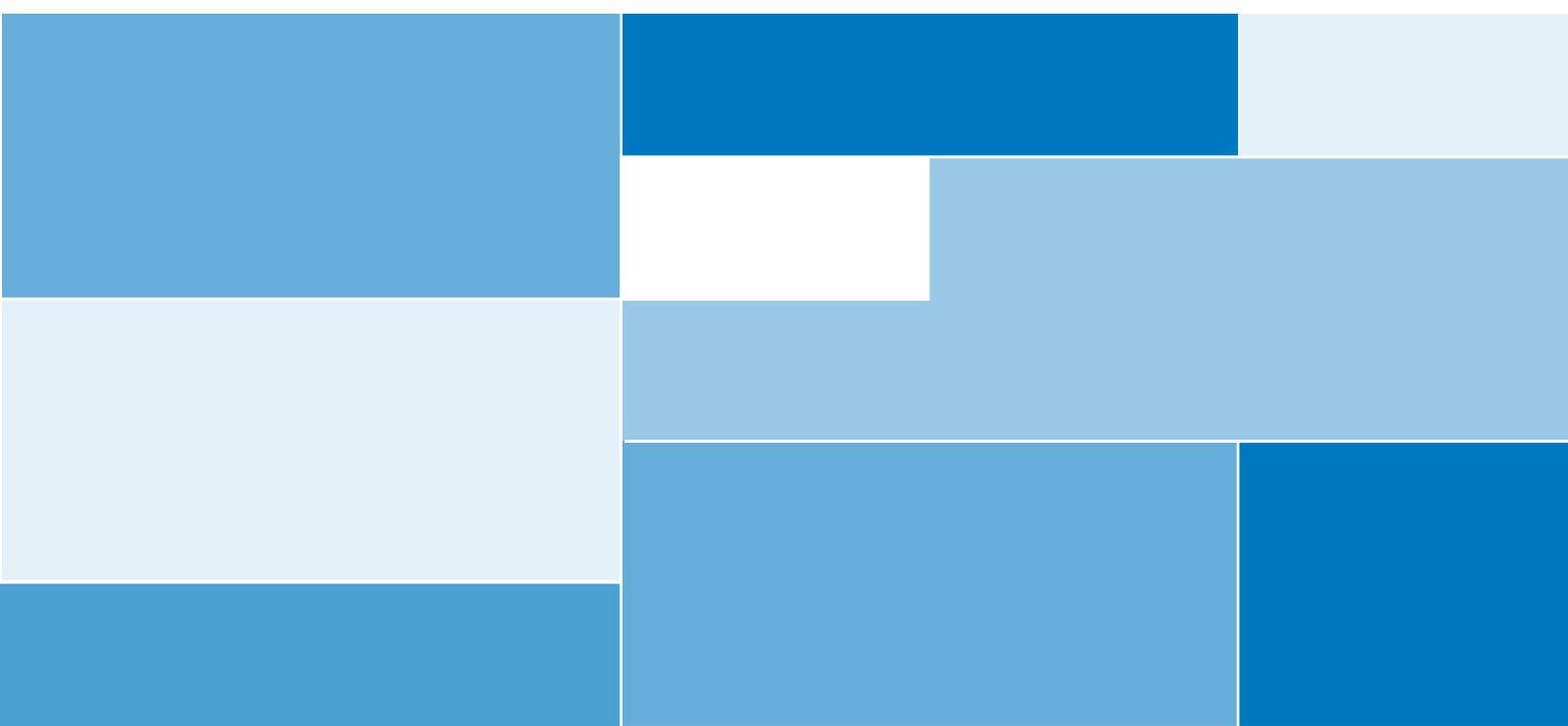


Medically Unexplained Symptoms/ Functional Symptoms

Positive Practice Guide



July 2014

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1. Background

- 1.1 Medically unexplained symptoms or syndromes (MUS) is a term commonly used to describe physical symptoms which cannot be explained by disease specific, observable biomedical pathology. The symptoms can be long-lasting and can cause significant distress and impaired functioning.
- 1.2 These symptoms constitute a clinically, conceptually and emotionally difficult area to tackle, with clinical presentations varying greatly, from people who regularly attend GP surgeries with minor symptoms to people with recognised functional syndromes (see section 2) such as chronic fatigue syndrome who can have severe enough symptoms to be bed-bound.
- 1.3 MUS are common, accounting for as many as one in five new consultations in primary care¹. The unexplained symptoms can cause significant distress to the patient and, in some circumstances, impair functioning.
- 1.4 Between 20% and 30% of consultations in primary care are with people who are experiencing MUS and have no clear medical diagnosis. It is estimated that this rises to an average of 52% in secondary care where a substantial proportion of secondary care resources are used by frequent attenders whose symptoms remain unexplained². Most of these patients currently receive little or no effective treatment or explanation for their symptoms so continue to be high users of health care and remain both distressed and disabled by their symptoms.
- 1.5 A recent systematic review of the economics of MUS found two main results: first, medically unexplained symptoms cause direct excess treatment costs per patient (between 432 and 5,353 USD per annum); second, interventions targeting GP's diagnostic and patient management skills as well as CBT for patients have the potential to improve patients' health status and to reduce costs³.
- 1.6 Irritable bowel syndrome is a commonly occurring MUS. A recent Scandinavian study concluded that irritable bowel syndrome (IBS) alone, incurs substantial direct and indirect costs corresponding to a share of up to 5% of the national direct outpatient and medicine expenditures⁴. A UK IBS study published over 10 years ago

¹ Bridges, K.W. and Goldberg, D.P. (1985) Somatic Presentation of DSM-III Psychiatric Disorders in Primary Care. *Journal of Psychosomatic Research* 29:563-9

² Nimnuan, C., Hotopf, M. and Wessely, S. (2001) Medically unexplained symptoms: and epidemiological study in seven specialities. *Journal of Psychosomatic Research*, 51: 361-7

³ Konnopka, A. Economics of Medically Unexplained Symptoms: A Systematic Review of the Literature (2012) *Psychother Psychosom* 81:265–275

⁴ Hillila MT et al., (2010) Societal costs for irritable bowel syndrome--a population based study. *Scandinavian Journal of Gastroenterology*. 45(5):582-91

conservatively estimated that IBS costs the UK £200 million per year but that the cost could be as high as £600 million⁵.

- 1.7 Although models exist proposing that MUS are somatised forms of depression, there is increasing evidence of distinct differences between patients with MUS and those with a primary anxiety and depressive disorders. Although it may be possible to treat anxiety and depression comorbid to MUS, treatment approaches that have shown most efficacy for people with MUS are especially formulated for these conditions (see section 4 on treatment). Treating the anxiety and depression will not necessarily treat the physical symptoms or associated disability.
- 1.8 Community mental health teams and primary care mental health services have not been successful in engaging with patients experiencing MUS, as patients often do not perceive their condition to be related to mental health problems, and attempting to engage them in traditional mental health approaches is often ineffective.
- 1.9 Commissioning treatment that focuses specifically on evidenced based treatments for MUS, offered by health professionals trained in these approaches, is likely to offer the best health and cost benefits.
- 1.10 Currently there are relatively few therapists skilled in this area and specific training and ongoing supervision in this area needs to be a priority so that the correct treatment is more readily available to patients who need it.

⁵ Akehurst, R.L. (2002). Health-Related Quality of Life and Cost Impact of Irritable Bowel Syndrome in a UK Primary Care Setting, *Pharmacoeconomics*, 20: 455-462

2. Issues of terminology

- 2.1 Although the term MUS is commonly used in healthcare practice and academic articles it is unsatisfactory for a number of reasons. Foremost, it fails to engage patients in treatments as patients feel it invalidates their symptom experience and infers that their symptoms are 'all in the mind'⁶. In order to increase access to psychological therapies for this patient group it is crucial that our terminology is both accurate and acceptable to potential patients.
- 2.2 Other reasons cited for why we should not use the term MUS summarised in Creed et al.⁷ include:
- 2.2.1 It reinforces dualistic thinking and the idea that illness is either biological or psychological.
- 2.2.2 The term defines the illness by what it is not: i.e. it implies no organic cause which is not necessarily accurate and affords no treatment utility.
- 2.2.3 Research has shown that most patients want a positive description of symptoms i.e. an explanation of what it is rather than what it isn't.
- 2.2.4 The term may appear dismissive and provides the message that nothing can be done. This is inaccurate as there are evidenced based approaches which show that methods such as CBT and graded exercise are effective treatments for these conditions.
- 2.2.5 Similar approaches also assist patients with well recognised medical conditions reduce the severity of symptoms and disability associated with the symptoms. Therefore the fact that psychological treatments works does not mean that the illness is psychological.
- 2.3 The IAPT MUS Task and Finish group strongly advises that when engaging or treating patients, the term MUS is not used. The experience of experts working in this field is that where possible patients should be given a specific diagnosis of a syndrome which describes their central symptom(s) without inferring that the aetiology is psychological. Common syndromes include:
- Fibromyalgia
 - Irritable Bowel Syndrome
 - Chronic Fatigue Syndrome

⁶ Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., MacKenzie, L., Warlow, C.P., Sharpe, M. What should we say to patients with symptoms unexplained by disease? The "number needed to offend". *BMJ* 2002;325;1449-1450

⁷ Creed, F., Henningsen, P., & Fink, P. (2011). *Medically unexplained symptoms, somatisation and bodily distress*. Cambridge: Cambridge University Press.

- Temporomandibular Joint (TMJ) dysfunction
- Atypical facial pain
- Non-Cardiac chest pain
- Hyperventilation
- Chronic Cough
- Loin Pain haematuria syndrome
- Functional Weakness / Movement Disorder
- Dissociative (Non-epileptic) Attacks
- Chronic pelvic pain/ Dysmenorrhoea

2.4 Many of these conditions have published diagnostic criteria which can be used in diagnosis.

2.5 Other terms in use which appear more acceptable to patients include persistent physical symptoms or functional syndromes/symptoms (FS)⁸. The term “functional” here is used because it is assumed that the disorder is one of function, which may be physical and/or psychosocial function, rather than anatomical structure. Sharpe⁹ likens this distinction to a car that needs tuning rather than a car which has mechanical damage. More recently, physiologically explained symptoms have also proposed as an alternative. For the rest of this paper we will refer to functional symptoms or syndromes (FS) rather than MUS.

⁸ Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., MacKenzie, L., Warlow, C.P., Sharpe, M. What should we say to patients with symptoms unexplained by disease? The "number needed to offend". *BMJ* 2002;325;1449-1450

⁹ Sharpe, M. (2000). Functional somatic syndromes: Etiology, diagnosis and treatment by Peter Manu (book review). *Biological Psychology*, 53, 93-97

3. Assessment and referral pathways

- 3.1 Commissioners need to understand their local community fully, including local demographic profiles and epidemiological data, if they are to secure Improving Access to Psychological Therapies (IAPT) services that are appropriate for the whole population, including people with FS.
- 3.2 FS often occur in children and increase as people age into adulthood. Women are three to four times more likely to experience FS than men.
- 3.3 Presentation with FS is associated with twice the standardised mortality ratio for cancer, accidents and suicide. FS is sometimes associated with serious mental illness such as severe depression with high suicide risk. Therefore, it is important that people experiencing FS are carefully assessed before diagnosis and referral. Most FS are diagnoses of exclusion by which possible alternative medical or psychiatric diagnoses to explain the symptoms are ruled out. Published guidelines for most of the conditions listed in section 2 above exist and guide GP's and in some cases specialist care, on which assessments and tests to complete to confirm the diagnoses of exclusion. Appropriate treatments must be offered for any co-morbid conditions wherever possible.
- 3.4 At the same time it is important not to continue to look for possible disease once a rigorous diagnostic work-up has been completed. Ongoing referral and testing serves to increase patients' anxiety and can be iatrogenic in that it prevents patients from moving forward into appropriate treatment.

IAPT Pathways to care:

- 3.5 With the role out of IAPT to include patients with FS, careful thought needs to be given as to where treatment should be provided. Our pathfinder sites are currently investigating different care pathways.
- 3.6 IAPT is traditionally a mental health service and patients are referred into the service or self refer. Patients seeking help for persistent physical symptoms (FSS) may feel that a referral to a mental health service invalidates their symptoms or show a lack of understanding of their symptoms. This has the potential to decrease rather than increase access to therapy. Other pathways to consider are;
 - 3.6.1 IAPT working within primary care (may be best pathway for PWP interventions)
 - 3.6.2 IAPT clinicians work as part of a multi disciplinary team in acute services or within an interface primary care team. Alternately, IAPT clinicians linking with clinical health psychologists and/or liaison psychiatrists in Acute Trusts (supervision,

consultation, training) in order to improve communication and movement through the pathway. In this model patients with IBS would be treated within gastroenterology, fibromyalgia in Rheumatology, non-cardiac chest pain in Cardiology etc. The advantage here is that psychological treatment is part of standard care package which can be offered to all patients in need presenting to a secondary care service. It also ensures integration in the psychological and physical care of these patients.

3.6.3 IAPT practitioners trained in models of LTC/MUS could also provide training and supervision to specialist and practice nurses, physiotherapists and occupational therapists in low intensity techniques. This could include providing primary care and acute services with relevant information sheets which provide psychoeducation for patients on the nature of their symptoms, the prevalence of these symptoms and what normal test results mean.

3.6.4 IAPT clinicians working alongside specialist services already set up as multi-disciplinary teams to treat these conditions e.g. CFS or pain services.

3.7 Figure 1 below provides a diagrammatic view of how these different pathways may inter-relate. The Figure shows how IAPT may dovetail with primary care, acute trust services and specialist FS services. The Figure also provides referral guidance so that patients can be matched to the best level of care. Whilst it is possible to step up or step down where appropriate (arrows within the steps), for many patients it may work best for them to match to the appropriate level of care (arrows shown on the right of the figure). Treatment failure may result in patients becoming quickly disillusioned with a psychological approach to treating their symptoms.

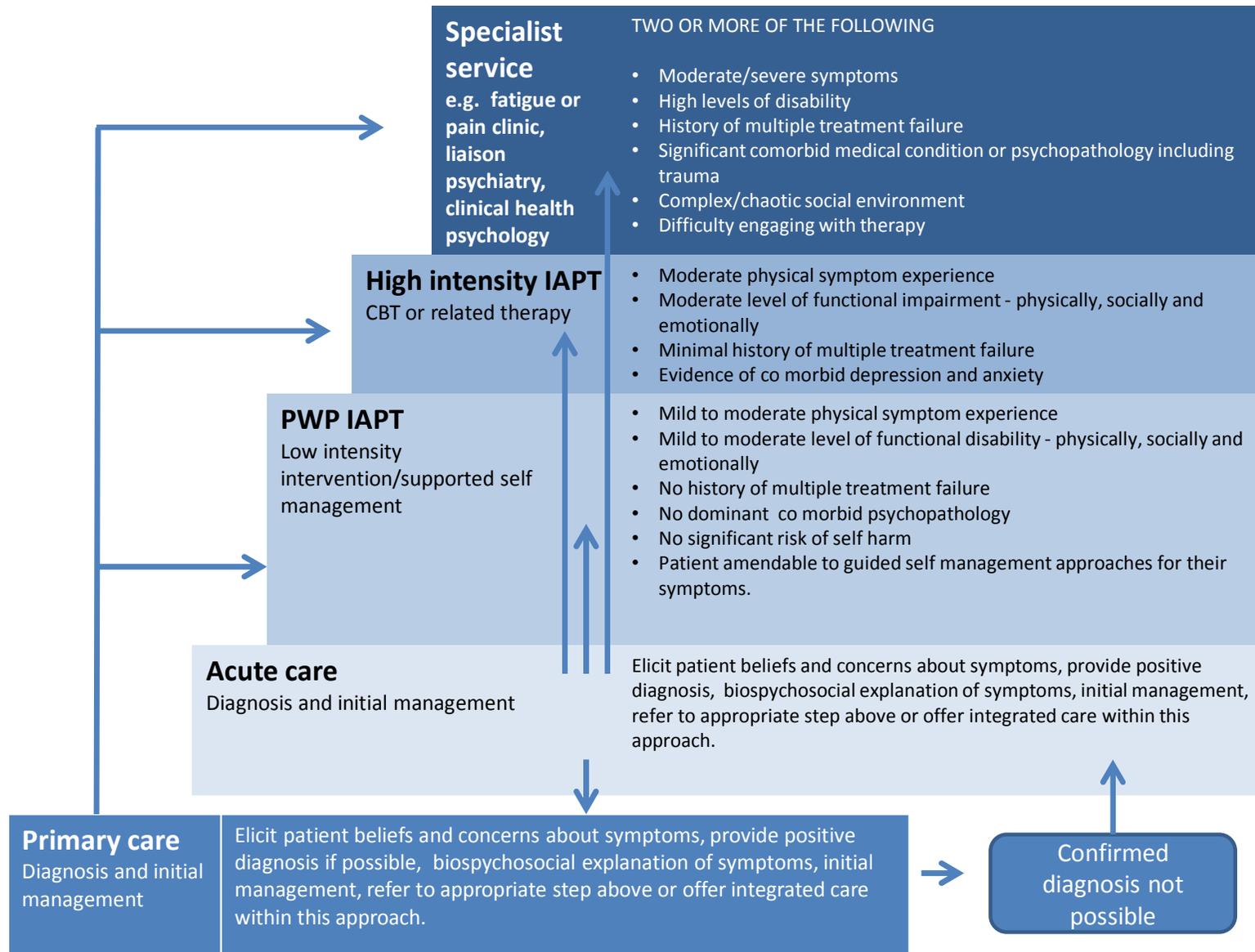


Figure 1: Matched Care Referrals for FS Treatment for GPs, Acute care, IAPT and Specialist Services.

4. Benefits of psychological therapies

- 4.1 There is no specific NICE guidance for treating medically MUS or FS. There are, however, NICE guidelines for treating IBS and CFS. There are also relevant Cochrane reviews summarizing treatment effects for different FS.
- 4.2 Reattribution therapy has been a popular recent treatment option for people with FS, particularly in primary care but a recent review suggests this approach is not particularly effective.
- 4.3 Currently CBT and graded exercise therapy (GET) have the strongest evidence as effective treatments for FS. There are also smaller trials of other psychological approaches such as Interpersonal Therapy, Acceptance and Commitment Therapy (ACT) and mindfulness therapy which suggests these approaches may also be beneficial.
- 4.4 CBT and GET are based on a CB behavioural formulation of FS which is briefly summarized below.

Understanding FS from a Cognitive Behavioural Perspective

- 4.5 Functional syndromes (FS) are best explained in terms of a multifactorial biopsychosocial model¹⁰. One biopsychosocial model commonly used to guide therapeutic approaches in this area is the cognitive behavioural (CB) model which incorporates predisposing, precipitating and perpetuating factors¹¹. This model comprises biological, affective, behavioural and cognitive elements of the illness. The fundamental assumption of a CB model is that the perpetuating domains interact to maintain symptoms, disability and distress, and that change in one domain will effect change in the others. What should perhaps be highlighted in the application of this model to FS is that this constitutes a previously undescribed disease mechanism, one which produces and/or maintains physical symptoms in the absence of either overt physical pathology or psychopathology. The basic hypothesis at work here is that of a systemic dysregulation which becomes self perpetuating¹².
- 4.6 For example, evidence suggests that predisposed people may be highly achievement orientated, basing their self-esteem and the respect from others on their abilities to live up to certain high standards. When these people are faced with precipitating factors which affect their ability to perform, such as a combination of excessive stress

¹⁰ Moss-Morris, R & Wrapson, W. Representational beliefs about functional somatic syndromes. In: L.D. Cameron and H. Leventhal (Eds), *The Self Regulation of Health and Illness Behavior*. London: Routledge, 2003, pp. 119-137

¹¹ Surawy C, Hackmann A, Hawton K, and Sharpe M (1995). Chronic fatigue syndrome: a cognitive approach. *Behav Res Ther* 33:535-544

¹² Deary V, Chalder T, and Sharpe M (2007). The cognitive behavioural model of medically unexplained symptoms: a theoretical and empirical review. *Clin Psychol Rev* 27:781-97

and an acute illness or injury, their initial reaction is to press on and keep coping. This behaviour leads to the experience of ongoing symptoms which may be more closely related to pushing too hard than to the initial insult or injury. However, in making sense of the situation, patients attribute the ongoing symptoms to the original trigger. The common response to an acute illness is to rest. However, reduced activity conflicts with achievement orientation and may result in bursts of activity in an attempt to meet expectations. These periodic bursts of activity inevitably exacerbate symptoms and result in failure, which further reinforces the belief that they have a serious illness. As time goes by, efforts to meet previous standards of achievement are abandoned. Patients become increasingly distressed by their symptoms and increasingly accommodate to their illness. This accommodation to the illness and distress reinforces the symptoms through physiological changes related to poor sleep-wake cycle, lack of a daily routine and autonomic arousal with consequent insomnia. This results in chronic disability. Three prospective studies of the development of IBS, CFS and post-concussion syndrome after acute infection or injury, provide sound evidence for this model in three distinct functional syndromes^{13, 14, 15}.

- 4.7 The CB model needs to engage the patients in the therapy process but also obtain the best outcome for patients. Although many patients presenting with MUS have high levels of distress, treatment which focuses on reducing the severity of the symptoms or the acceptance of symptoms, and reducing the disability afforded by the symptoms often results in concomitant reductions in distress. Evidenced based models used in CBT approaches for these patients have distinct differences to the protocols used for treating people with a primary anxiety or depressive disorder.
- 4.8 Another simpler approach is to encourage a gradual return to previous activities, to reverse the changes secondary to inactivity. Such graded activity approaches are effective in helping patients with various functional syndromes to recover their health.

¹³ Hou, R., Moss-Morris, R., Peveler, R., Belli, A., Mogg, K., Bradley, B.P. How does a minor head injury result in enduring symptoms? A prospective investigation of post-concussional syndrome after mild traumatic brain injury, *Journal of Neurology, Neurosurgery and Psychiatry*, 2011, 83, 217-223
doi:10.1136/jnnp-2011-300767

¹⁴ Moss-Morris, R., Spence, M., & Hou, R. The pathway between glandular fever and chronic fatigue syndrome. Can the cognitive behavioural model provide the map? *Psychological Medicine*, 2011, 41, (5), 1099-1108. (doi:10.1017/S003329171000139X)

¹⁵ Spence, M & Moss-Morris, R. The cognitive behavioural model of irritable bowel syndrome: a prospective investigation of gastroenteritis patients. *GUT*. 56, (8), 2007, 1066-1071

5. Removing barriers to access

- 5.1 People experiencing FS often face a number of barriers that prevent them from having access to appropriate treatment including psychological therapies
- 5.2 As discussed under terminology, the IAPT MUS Task and Finish group suggest that health professionals and IAPT practitioners omit the term MUS from their vocabulary, in order to better engage patients, by referring instead to “functional symptoms” by their name, or to “persistent physical symptoms”.
- 5.3 GPs and other healthcare professionals may also prevent people who are experiencing FS from accessing services providing psychological therapies. GPs and other health professionals may:
 - Have time constraints in their surgeries which may not be sufficient for them to diagnose FS effectively;
 - Recognise the FS but fail to recognise that they can be effectively treated by psychological therapies or other treatments;
 - Believe that identifying, investigating and treating any physical health problems are a higher priority than offering CBT based treatment for managing symptoms and disability.
 - See people with FS not having symptoms ‘all in the mind’ and not deserving of treatment.
- 5.4 People experiencing FS may not receive psychological therapies because they may:
 - Believe they have physical health problems only and can’t understand how a psychological approach to symptoms may help
 - Have a fear of being stigmatised by other people’s attitudes to receiving psychological treatment
 - Have a belief that offering a psychological approach legitimises their symptoms.

6. Engagement

- 6.1 Proper and effective engagement with people experiencing FS is essential if their needs are to be met. This can be addressed by:
- Identifying successful and unsuccessful referral pathways (see section 3 on referral pathways); and
 - Working with service users who have experienced FS in designing the IAPT services.
- 6.2 GPs have an important role in ensuring people experiencing FS engage with IAPT services. GPs are usually the first point of contact for people with FS and they may need to prepare patients who present with FS for psychological therapies by explaining the biopsychosocial model of FS (see section 4). Commissioners need to ensure that GPs are engaged in the IAPT service and understand the benefits of referring their patients to IAPT services.
- 6.3 The venue or location of an IAPT service should be considered when looking to break down barriers for individuals who are experiencing FS (see section 3 and figure 1 on referral pathways) MUPS. With many patients believing their symptoms are entirely physical problems, a service that is located or embedded in a physical health framework may encourage engagement, i.e. within a pain clinic, part of a Clinical Assessment Service or Intermediate Clinical Assessment Team for musculoskeletal problems.
- 6.4 Commissioners setting up IAPT services may wish to seek specialist advice from local GPs (or other health professionals) who have a special interest in FS. This will ensure that special requirements for people experiencing FS can be incorporated into the service design and will allow other relevant physical health services and specialist liaison/clinical health psychology services to be linked into the care pathways of the people FS.

Acknowledgements

Membership of the IAPT Medically Unexplained Symptoms Evaluation Task and Finish Group (2012-13)

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