Functional Neurological Symptoms in North East Neurology Services

A Health Care Needs Assessment

Andy Graham – Public Health Registrar, Public Health England North East Centre
June 2016
Contents

1 Executive Summary

2 Introduction
2.1 Aims
2.2 Context
2.3 Scope

3 Needs Assessment
3.1 Health Care Needs Assessment
3.2 Concept of need

4 Context
4.1 Medically unexplained symptoms
4.2 Terminology
4.3 Functional neurological symptoms (FNS)
4.4 National context
4.5 Regional context

5 Evidence review
5.1 Common functional neurological symptoms
5.2 Treatment
5.3 Costs associated with FNS

6 Epidemiological need
6.1 Epidemiology
6.2 Neurology Services in the North East
6.3 Prevalence of FNS in the North East
6.4 Comparison with National estimates

7 Comparative need
7.1 Comparison of existing provision

8 Corporate need
8.1 Thematic analysis
8.2 Patient interviews
8.3 Clinician discussions

9 Conclusion and recommendations

10 References
1 Executive Summary

The issue of Medically Unexplained Symptoms (MUS), and more specifically Functional Neurological Symptoms (FNS), is a complex one. Symptoms are experienced as real and physical by the sufferer and cause considerable distress, disability and dysfunction. This problem accounts for a large proportion of healthcare utilisation and research shows that as many as 31% of new referrals to Neurology outpatient departments are suffering from FNS. The costs associated with MUS are large and are estimated as £3.1bn directly to the NHS, with up to £18bn lost when indirect costs are considered. There are also very real psychological and social costs incurred by the patient and their families.

This HCNA collected data from the three Neurology outpatient departments and established that in the North East the equivalent figure to that quoted above is 34%, with an overall prevalence of 29% amongst both new and existing patients. This demonstrates that there is considerable unmet need in FNS patients in the North East. The availability of agreed approaches and guidance on FNS is patchy, as is the provision of adequate services across the North East. The issue of local level commissioning means that patients in some areas are able to access treatment, while those in a neighbouring area are left with no options. This unfair and avoidable difference in access should be addressed.

The evidence shows that a matched care approach is most effective. As part of a system that co-ordinates the work of different organisations and staff across primary and secondary health care, such an approach would provide tailored treatment options for patients from a range of healthcare professionals. This would not only be of clinical benefit to patients, but would result in savings to the healthcare system. With these observations in mind it would be beneficial for stakeholders to investigate further the potential to increase the provision of matched care service approaches for FNS patients in the North East.
2 Introduction

2.1 Aims

This health care needs assessment aims to provide information on the level and nature of unmet need among patients with functional neurological symptoms (FNS). As part of the health care needs assessment process the following objectives have been set:

- Establish sources and generate data to estimate the prevalence of FNS amongst patients attending neurology outpatient departments in the North East of England and to consider these findings against existing research findings.

- Describe existing services provided to treat these patients and consider this against identified scale of need in order to develop a better understanding of gaps in provision.

- Consider the evidence for effective service provision and examples of best practice, including the likely costs associated with this.

- Provide a report which will form the basis of a business case to support service development to improve access to, and quality of, care for those patients affected.

2.2 Context

Under normal circumstances if a patient is aware of a symptom they will consult a doctor for advice and the doctor will attempt to diagnose a disease which explains the symptoms. Advances in medicine over time have reinforced this process and for many it results in effective treatment. However, for a significant proportion of patients the symptoms remain unexplained - that is, no underlying pathology is found that explains the symptom/s or the symptom/s are disproportionate to any pathology found. These patients are found in every medical speciality, but within conventional medical specialities treatment pathways do not exist.
2.3 Scope

Recognition of this issue led clinicians from the Mental Health, Dementia and Neurological Conditions Northern England Strategic Clinical Network to identify medically unexplained symptoms in neurology, otherwise known as functional neurological symptoms (FNS), as a specific issue which required further assessment. Through the Clinical Network’s Functional Neurological Conditions Special Interest Group (SIG) some initial information had been gathered which suggested the widespread nature of FNS, in line with the experience of staff working in neurology clinics.

Members of the SIG therefore requested some input from Public Health England, as it was felt necessary to carry out a health care needs assessment on this issue in order to estimate the scale of the problem in the North East. It was decided that the health care needs assessment should apply specifically to patients attending neurology outpatient departments in the North East of England. It is hoped that the findings will prove useful in reviewing existing, and planning new, services to meet the needs of this patient group. The ability of these patients to benefit from health care will be demonstrated by providing an overview of the scale of the problem and current service delivery\(^1\).
3 Needs Assessment

3.1 Health Care Needs Assessment

Health care needs assessment is a systematic method for reviewing the health issues facing a population. It leads to agreed priorities and facilitates the targeting of resources to improve services that better meet need and therefore improve health and reduce health inequalities\textsuperscript{[2]}. Health care needs assessment can therefore be described as:

- a recommended public health tool to provide evidence about a population on which to plan services and address health inequalities

- a forum for engagement with specific populations and enable them to contribute to targeted service planning and resource allocation

- a forum for cross-sector partnership working and developing creative and effective interventions

3.2 Concept of need

There are differing views of what need is, but given the scarcity of resource health needs have often been differentiated as need, demand and supply. The complexity of measuring need has often led to demand and supply being used as surrogate measures for need\textsuperscript{[1]}. However, the concept of need is separate to demand and supply, as what is demanded and what is supplied is not always needed, and vice versa.

Because the term need is used by a range of health, and non-health, professionals, in different and varying contexts it is useful to consider the term further. Several methods of categorising need have been proposed, the most widely known being Bradshaw’s taxonomy:

- Normative need (based on professional views)
- Felt need (based on individual's perceptions of variations from normal health)
- Expressed need (the vocalisation of need or how people use services, and broadly equivalent to demand)
- Comparative need (based on judgements by professionals as to the relative needs of different groups)\[^3\]

However, this categorisation lacks consideration of the evidence base and of epidemiological need, which are requirements for any assessment of health care need\[^1\]. In a public health context, need has been described as the capacity to benefit from health care, and such benefits are ideally assessed by an approach that combines epidemiological and effectiveness factors, supplemented by corporate and comparative methods\[^4\]. For purposes of clarity, the following terms will therefore be used throughout this document:

- Epidemiological need – reflection of the epidemiology of the condition and the effectiveness and cost-effectiveness of interventions and services.
- Comparative need – reflection of current service provision and the differences in provision received by the population in different parts of the Region
- Corporate need – reflection of the views of stakeholders (normative, felt and expressed need)

There is also an important distinction to make between the need for health and the need for health care. The former concerns those who are needy in general terms and is measured by morbidity, deprivation and socio-demographic measures. In this sense, need for health includes those problems which have no realistic treatments\[^1\]. If we are to consider the public health context of need as the capacity to benefit from health care\[^4\], then there is a need to recognise this as more specific and dependant on the potential of preventive or treatment services to remedy health problems.

Assessment of health care need is therefore a systematic method of identifying the unmet health care needs of a population and making changes to meet these unmet needs. This requires an estimate of the scale of the problem, of the availability and responsiveness of services and preventive
initiatives and the evidence of their effectiveness. A range of activities provide the information to plan, negotiate and change services for the better, including:

- Assessment of incidence and prevalence
- Identifying effective interventions
- Mapping existing services
- Making recommendations
- Prioritising
- Monitoring
- Action planning
- Evaluation

The information that informs this range of activities can be represented by figure 1, which shows how the multiple data sources within the three components of epidemiological, comparative and corporate form the basis of triangulation. This in turn provides health care planners and commissioners with the necessary information to determine the best policy direction.

*Figure 1*
4 Context

4.1 Medically unexplained symptoms

Medically unexplained symptoms (MUS) can be defined as:

“physical symptoms persisting for more than several weeks and for which adequate medical examination has not revealed a condition that adequately explains the symptoms”[5].

There is a long history of patients presenting to care providers with symptoms for which no obvious cause is apparent. It has been estimated that in around 25–50% of all symptoms presenting in primary health care, no support for an underlying physical disease can be found[6, 7]. Some sources suggest the proportion is higher, with MUS being so common that they comprise up to half of all consultations in some secondary care outpatient clinics[8, 9]. One recent systematic review and meta-analysis including over 70,000 patients suggested that up to 49% of primary care patients complain of at least one ‘medically unexplained’ symptom[7].

These symptoms are experienced as real and physical by the sufferer and should not be considered trivial or minor. They result in considerable distress, disability, and dysfunction[10]. As a result, functional symptoms account for a large proportion of health care visits in both primary[11] and secondary care[12]. MUS can be related to any bodily system and are common in a range of medical settings[13], including primary care, psychiatry, cardiology, gastroenterology, rheumatology, neurology, respiratory medicine, and gynaecology – see figure 2[14].
It can be seen from the above list of medical specialties that the types of symptoms are very varied. In addition, many of these problems overlap with each other in terms of symptoms, aetiological factors and response to treatment creating a complex situation for which standard medical procedure is unprepared. Often symptoms are grouped together and result in syndromes such as chronic fatigue syndrome and irritable bowel syndrome, and while this may be convenient, there is often such heterogeneity within them that patients with the same symptoms may have entirely different aetiological factors and thus require completely different treatment approaches. For example, in irritable bowel syndrome, one person may develop chronic abdominal pain from a single event trauma, another may have no trauma history and simply had a gastroenteritis that seems never to have quite resolved and continues to cause the same chronic abdominal pain as the first patient.
4.2 Terminology

Terminology in this area is challenging, not least because many descriptive terms have developed over time creating a confusing picture. Some of the more commonly used terms include:

- abnormal illness behaviour
- chronic multiple functional symptoms (CMFS)
- conversion disorder
- functional illness
- functional problems,
- functional disorders
- functional symptoms
- functional somatic symptoms and syndromes
- hysterical conversion disorder
- hysteria
- MUS and medically unexplained physical symptoms (MUPS)
- non-organic symptoms
- persistent physical symptoms (PPS)
- psychosomatic disorder
- somatisation
- somatoform disorder
- somatic distress
- somatic symptom disorder

As can be seen from this list, the potential for confusion is considerable, not least when it comes to trying to classify the condition, where there is the difficulty of trying to base a diagnosis on the absence of an explanation. This has been reflected within classification systems such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Statistical Classification of Diseases and Related Health Problems (ICD). More recent efforts to clarify classification systems have seen the introduction of terms such as ‘undifferentiated somatoform disorder’.

DSM-V has attempted to clarify the situation by removing the distinction between medically explained and unexplained symptoms, but criticism
suggests that the information is contradictory and clinically unhelpful\textsuperscript{[16]}. In addition, the traditional dualistic mind-body approach in medicine and psychiatry can lead to different approaches to classification and diagnosis, meaning that depending on which profession is consulted, the same patient with the same symptoms might receive differing diagnoses and treatment\textsuperscript{[14]}.

Terminology can itself be a barrier to improved care. The term MUPS, for instance, has been widely used as a descriptive term, but is not acceptable to some patients and doctors as it defines the patient's symptoms by what they are not, rather than by what they are\textsuperscript{[17]}. Unfortunately, there is little agreement on which labels are the most appropriate and even anachronistic terms such as “hysteria” are occasionally still used despite the capacity to offend and alienate\textsuperscript{[18]}. Jon Stone, a Consultant Neurologist from Edinburgh who was involved in the SNSS study referred to previously, suggests the term functional because it describes a mechanism and rather than an aetiology, whilst sidestepping an illogical debate about whether symptoms are in the mind or the brain\textsuperscript{[15]}. The term functional, in this sense, implies a problem due to a change in function of the nervous system rather than a change in the body’s structure. Generally speaking a functional problem in this sense would be potentially reversible.

The focus of this health care needs assessment is neurology outpatient departments so for consistency and simplicity, the term functional neurological symptoms or FNS will generally be used in this document.

4.3 Functional Neurological Symptoms

FNS symptoms can be defined as:

“Those symptoms which include, amongst others, blackouts, paralysis and abnormal movements which suggest the presence of a neurological disease such as epilepsy, multiple sclerosis or stroke – but are not explained by any neurological disease. They are due to, and can be maintained by, a complex combination of physical, psychological and social influences on brain function\textsuperscript{[19]}.”
Instances where the criteria for the above definition are met are abundantly prevalent in the general population\textsuperscript{[20]} with the most common FNS being non-epileptic attacks and functional weakness, which may be mistakenly diagnosed as epilepsy or stroke\textsuperscript{[21]}. However, patients also experience symptoms causing blackouts, pain, fatigue, and visual cognitive and sensory disturbances\textsuperscript{[15]}. Studies in neurology departments estimate that up to 50% have a functional symptom problem of some kind, even if it is not their main problem, while about 30% of new neurology outpatients have main presenting symptoms that are “somewhat or not at all explained” by organic disease\textsuperscript{[22]}.

There are a variety of explanations for what underlies FNS and it is likely that genetic influences, adverse early childhood events and a predisposition to anxiety and worry all play a part to some degree. Where a person is vulnerable in these terms, it is more likely that stressful events may cause a stress reaction where cognitive, behavioural and physiological factors interact. Psychosocial stressors (negative life events, difficult living conditions, work-related problems, stress, trauma, sexual abuse) appear to play a causal role in FNS\textsuperscript{[6]}.

Beck’s Cognitive Behaviour Therapy model explains emotional distress through the three P’s - Predisposing, Precipitating and Perpetuating factors. Predisposing factors reflect susceptibility or nature, and exacerbating factors may include infections or a stressful life event. Perpetuating factors are often behavioural factors that can inhibit recovery, for example, reduced exercise can result in maintenance of low back pain, and continuously seeking help can maintain symptoms\textsuperscript{[6]}, causing symptoms without underlying pathological illness to persist over time.

4.4 National context

Though commonly encountered, there has been remarkably little academic interest in FNS. UK neurologists have described patients with FNS as the ‘most difficult to help’\textsuperscript{[23]}, perhaps because these patients typically have a longstanding pattern of presentation with various FNS and have had multiple referrals for investigation\textsuperscript{[24]}. This perception is perhaps reflected in the lack
of past research into this issue. There are no NICE guidelines on how to treat patients with FNS. In the absence of comprehensive guidance, Scotland has been most proactive in carrying out research into and attempting to meet the needs of those suffering from FNS.

In 2005, NHS Quality Improvement Scotland funded the Scottish Neurological Symptoms Study\textsuperscript{[25]} (SNSS) in an attempt to identify the nature and extent of the problem, and in 2011, a range of healthcare professionals attended a Healthcare Improvement Scotland event to discuss how best to help people with functional symptoms referred to neurological services. This resulted in a guidance report which proposed a comprehensive approach to the management of FNS and remains a key source of recommendations towards the care of patients with FNS\textsuperscript{[19]}.

In England, the Government published No Health Without Mental Health in 2011, a cross Government mental health outcomes strategy for people of all ages\textsuperscript{[26]}. This document referenced the problem of MUS, suggesting that cognitive behavioural therapy is an effective treatment. An accompanying document was Talking Therapies: A Four-Year Plan of Action which set out policy priorities, including the expansion of the Improving Access to Psychological Therapies (IAPT) programme to include people with Long Term Conditions and/or MUS\textsuperscript{[27]}. This in turn has led to the development of Positive Practice Guidance for MUS/FNS\textsuperscript{[28]}. An additional piece of guidance is a leaflet for health professionals on MUS provided by the Royal College of General Practitioners and the Royal College of Psychiatrists, through the Forum for Mental Health\textsuperscript{[29]}.

### 4.5 Regional context

The relative lack of guidance, in addition to the complexities of the subject, has contributed to a piecemeal response to this issue nationally. Unsurprisingly, as in the rest of England, there is also an inconsistent picture when it comes to practice and to service provision for FNS patients in the North East. This partial approach has resulted in patients receiving conflicting diagnoses, or in some cases no diagnoses, and varying responses in terms of treatment.
Services dealing with FNS, or a specific element of it, exist in some localities and are few in number. They are commissioned by Clinical Commissioning Groups (CCGs), as in the case of an intervention in North Durham, or from within Liaison Psychiatry, for example, the Durham and Darlington MUPS service. The small number of services places a limit on the numbers of patients that can be dealt with. With regard to equity most people would acknowledge that services should be available according to need, but unfortunately this is not the case. This issue of inconsistent service provision, and the frustration and suffering this causes for patients, has been recognised by the Functional Neurological Conditions SIG. The existing service coverage is discussed in more detail in section 7.1.
5 Evidence review

5.1 Common functional neurological symptoms

Patients with FNS are not an homogenous group and may present with a diverse range of symptoms\textsuperscript{[5]}. It would appear that FNS exist on a continuum with those patients suffering single, transient and relatively mild symptoms at one end, through to those with multiple somatic, cognitive, behavioural and emotional symptoms which are chronic and extremely debilitating unexplained complaints at the other\textsuperscript{[14]}.

A review of the literature reveals the extent of FNS which account for a large proportion of health care visits in secondary care\textsuperscript{[12]} and represent one of the most common reasons for seeking neurological advice\textsuperscript{[30]}. Symptoms encountered in neurology outpatient departments can be broadly placed into the following groups\textsuperscript{[15]}:

5.1.1 Dissociative or non-epileptic seizures

- seizures which have no electrophysiological correlate or clinical evidence for epilepsy
- nearly half of all people brought in to hospital with suspected serious epilepsy have had a dissociative seizure
- dissociation refers to a group of mental disorders that affect consciousness. A dissociative seizure is one type of dissociative experience.

5.1.2 Weakness

- limb weakness which can be disabling by causing problems a number of problems, for example with walking or a ‘heaviness’ down one side, dropping things or a feeling that a limb just doesn’t feel normal or part of the patient
- due to a problem with the functioning of the nervous system but not caused by damage or disease
- often mistaken for signs of stroke or multiple sclerosis
5.1.3 Movement disorders

- abnormal movement or positioning of part of the body due to a problem with the nervous system but not caused by damage or disease
- a variety of gait disturbances which increase the risk of falls and cause problems with walking
- functional tremor is the most common movement disorder and presents with uncontrollable shaking of part of the body usually an arm or a leg
- dystonia or spasm which typically results as fixed abnormal postures, such as clenched fist or inverted ankle, and often accompanied by severe pain

5.1.4 Sensory symptoms

- a feeling of altered sensation down one side of the body (more commonly the left) - usually involving the face, arm or leg in various combinations
- fleeting sensations including twitches, buzzing sensations, electric shock sensations

5.1.5 Pain

- chronic pain (e.g. headache, bowel, back) is a very common symptom in patients with functional neurological symptoms

5.1.6 Fatigue

- fatigue is the commonest symptom in association with other functional neurological symptoms
- can also be thought of as another symptom related to a problem with nervous system functioning

5.1.7 Cognitive symptoms

- absent mindedness, poor concentration and amnesia may all present and frequently co-exist alongside functional and dissociative symptoms
- Neurologists and neuropsychiatrists working in regional neuroscience centres are frequently referred patients who complain or are concerned
about memory symptoms, but whose symptoms can be clearly identified as unrelated to dementia\textsuperscript{[31]}.

5.1.8 Visual symptoms

- May include visual blurring, photophobia, reduced vision or even complete blindness

5.1.9 Some other functional symptoms

- Globus - a sensation of something being stuck in the throat, typically not when swallowing
- Dysphonia - typically a whispering speech pattern.
- Drop attacks in young people can be a form of dissociative attack without loss of consciousness
- Panic is also a common feature at onset in those patients whose symptoms develop acutely

It is important to appreciate that these symptoms cause substantial suffering in patients as they are experienced as real and physical and result in considerable distress, disability, and dysfunction\textsuperscript{[10]}. A complication in diagnosis and treatment is that many of these problems overlap substantially with each other in terms of symptoms, aetiological factors and response to treatment and it is important to appreciate that there is a lot of heterogeneity within them. Patients with the same symptoms may have entirely different reasons for developing them\textsuperscript{[15]}.

A further difficulty is a phenomenon called ‘functional overlay’ in which existing neurological disease is present in addition to FNS, for example some estimates suggest that between 20 – 40% of patients with epilepsy have comorbid non-epileptic attacks as well. Another group of patients are those who have had a stroke, but also develop ‘functional stroke symptoms’, and this combination means that these people are less likely to be picked up by specialist services.
5.2 Treatment

There is no NICE guidance on how to treat patients with FNS and the most comprehensive guidance comes from Healthcare Improvement Scotland which considered how best to help people with functional symptoms referred to neurological services. This guidance proposed a comprehensive approach to the management of FNS and is a key source of recommendations towards the care of patients with FNS\(^{[19]}\). In brief these consist of a stepped care approach which has the following elements:

- Functional neurological symptoms need to be diagnosed and appropriately explained by a neurologist as the first step in successful management
- Brief and effective treatments should be offered for functional neurological symptoms when explanation alone is unsuccessful
- Services for patients with severe and intractable functional neurological symptoms
- A co-ordinated national network to deliver training, care and research

This highlights three important elements in approaching the FNS problem. Firstly, there is the need to correctly identify those who are suffering from FNS and ensure this is done consistently. FNS are diagnosed through exclusion, by which possible alternative medical or psychiatric diagnoses to explain the symptoms are ruled out\(^{[28]}\). Consequently, patients may find themselves involved in a protracted process whereby they are subjected to many investigations, some of which are arguably unnecessary.

Secondly, the issue of identifying FNS demonstrates a workforce development aspect to management. Clinicians need the background knowledge to be able to identify FNS, but also have the communication skills to raise the issue, which is often difficult given the contentious terminology\(^{[17]}\) and perception that a diagnosis of FNS suggests that symptoms are ‘all in the head’ or a mental health issue\(^{[14]}\). In some cases, it is suggested that psychological care should be delivered within medical pathways as these patients identify with this more readily, being less likely to engage with mental health pathways\(^{[28]}\).
Thirdly, the complex nature of the problem means that even when a diagnosis is made there is no single best treatment option, and so a range of options need to be available so that these can be matched to the individual. These can include enabling patients to understand the nature of FNS in a clear and empathic manner; initiating self-management; securing access to cognitive behavioural therapy and graded exercise therapy which currently have the strongest evidence as effective treatments; through to involvement of more specialist services such as liaison psychiatry[28].

Effective treatment of FNS requires input from a range of professionals. Take the example of a patient who is suffering from functional weakness. Ideally this person first needs to be recognised as a potential case and receive a referral. This has implications for training of clinicians to ensure they have a basic level of knowledge and a set of criteria against which to make a decision. They would then require an assessment in order to diagnose the problem. This may be carried out by a neurologist able to use techniques such as establishing positive signs of inconsistency of limb weakness. Next there would ideally be a triage to assess the nature and severity of the problem, possibly carried out by a psychologist, to consider the most appropriate treatments for the patient.

In the case of someone with movement disorder this may consist of a range of interventions which may include physiotherapy to address physical symptoms, occupational therapy to maintain and improve daily living and work activities, and therapy to address any underlying psychological issues, for instance cognitive behavioural or acceptance and commitment therapy. Other interventions may be provided through liaison psychiatry, clinical neuropsychology, neuropsychiatry, speech and language therapy, and social support among others. As we can see a multi-disciplinary approach is required which takes the individual needs of patients into account and selects an appropriate combination of interventions that best addresses those needs.

There is a need for clear leadership and coordination at a high level to ensure that the elements of the problem are addressed in a consistent fashion. This applies to the need for a shift in knowledge and attitudes among both
clinicians and patients, as well as a service element that can enable an agreed and equitable approach to identification, referral and investigation across primary and secondary care.

While there are many references to FNS in the literature and Government documents, at present the response to this final point on coordination remains patchy. The Government’s mental health outcomes strategy No Health Without Mental Health\textsuperscript{[26]} references the problem of FNS, and suggests that cognitive behavioural therapy is an effective treatment. It’s accompanying Talking Therapies document\textsuperscript{[27]} highlights the problem of ensuring that more people with FNS are routinely offered evidence-based psychological treatments when appropriate, and as part of personalised care planning.

More recently, as part of the Improving Access to Psychological Therapies programme, a Positive Practice Guide for FNS has been published. This mirrors the Healthcare Improvement Scotland guidance and advocates the model of ‘matched care,’ suggesting assessment/triage as an entry point, with patients then placed at an appropriate stage of an embedded ‘stepped care’ process\textsuperscript{[28]}. As such, it means that patients are allocated to the most appropriate interventions as a first base, rather than everyone entering care at a set point. Meanwhile, a guidance leaflet for health professionals is also provided by the Royal College of General Practitioners and the Royal College of Psychiatrists, through the Forum for Mental Health\textsuperscript{[28]}.

In summary, there is broad agreement that what works is a matched care approach. The main objectives of this are to define the problem in a way that is acceptable to both the patient and the doctor; to reduce unnecessary anxiety and discomfort; and to improve the patient’s functioning in somatic, cognitive, emotional, behavioural, and social dimensions\textsuperscript{[6]}. This approach may feature a range of treatment options including cognitive behavioural therapy; graded exercise therapy; reattribution therapy; physiotherapy; progressive muscle relaxation and related techniques; and occupational therapy \textsuperscript{[6, 19, 23, 26, 27, 29, 32, 33]}. This matched care approach should ideally be part of a system that co-ordinates the work of different organisations, and
staff across primary and secondary health care, from prevention and self-management, to identification, assessment, therapeutic interventions, and recovery\textsuperscript{[34]}. It should also incorporate workforce development.

5.3 Costs associated with FNS

Costs can be considered from two viewpoints. Firstly, there are the resources that are required for investigation and treatment, and these represent the direct costs. Secondly, there are the productivity losses arising primarily from morbidity-related sickness absence, which represents an indirect cost\textsuperscript{[35]}. It is difficult to fully estimate the costs related to FNS, not least because of the logistic difficulties of getting access to the patient data to consider health care utilization across primary and secondary care and across different organisations. However, efforts have been made to calculate the costs associated with MUS more generally and these represent the best available estimates.

Discussions with clinicians suggest that there is reluctance among some to diagnose a patient with a MUS/FNS disorder due to concerns about possible future complaints. There is recognition that psychological explanations of this problem may not be well received by patients who are conditioned to expect physical explanations for physical symptoms. The stigma associated with mental health also contributes. This often results in repeated referrals for more opinions in different specialities, more investigations and more tests in the hope that a medical explanation will be forthcoming.

Patients with MUS are therefore more likely to present to health care providers on multiple occasions than other patients with similar symptoms\textsuperscript{[36]}. Barsky et al\textsuperscript{[10]} suggest that this group have approximately twice the outpatient and inpatient medical care utilisation and twice the annual medical care costs of other patients. The repeated referral of patients with MUS to secondary medical care incurs substantial healthcare costs\textsuperscript{[37]} with large proportions of these costs caused by hospital stays, diagnostic procedures and medical treatments\textsuperscript{[35]}. The capacity needed to deal with both increased attendance and medical investigation in this group is significantly greater than for other patients.
An analysis of 2008/09 NHS figures showed that these patients account for as much as 25% of outpatient care appointments, 8% of inpatient bed days and 5% of A&E attendances. In terms of direct cost to the NHS this level of utilisation amounted to £3.1 billion. When indirect costs were considered it was found that costs attributable to lost productivity were £5.2 billion while the cost of reduced quality of life was estimated to be £9.3 billion, with a final total annual burden among working-age adults in England estimated at nearly £18 billion per year\textsuperscript{[38]}.

In primary care for the same period it was estimated that as many as one in five new consultations and 7% of all prescriptions were accounted for by these patients\textsuperscript{[38]}. An analysis carried out in three GP practices in London calculated the healthcare utilisation and costs associated with 227 patients over a two year period. This found that these patients had around 9,000 GP contacts in this time which equated to £13k per month, while total spend was closer to £42k per month or £1 million over the two years\textsuperscript{[34]}.

With regard to FNS, the Scottish Neurological Symptoms Study estimated that direct costs for patients with FNS amounted to £11.3 million per year - £1.3m for outpatients, £6.01 million for inpatients (including 13,887 bed days), and £4.01 million for primary care. However, this did not include indirect costs, meaning the true figure would be much higher due to the fact that many of these people are unable to work and the consequent need for state provided benefits\textsuperscript{[19]}.

It is also important to remember the personal costs to patients and carers associated with FNS, which may be physical, psychological and social in nature and lead to high levels of disability and personal distress. There is a higher risk that patients experiencing functional symptoms will also incur costs in the form of iatrogenic harm. This is often due to the inconsistent way in which this issue is dealt with and this can result in unintended consequences. For instance, over investigation, inappropriate information and advice given to patients and inappropriate prescription of medication may contribute to the intractable nature of some MUS\textsuperscript{[36, 39, 40]}. 
The costs associated with MUS, including FNS, highlight the potential cost savings available through alternative forms of identification and management that reduce high numbers of referrals\textsuperscript{[37]}. For example, it has been suggested that an investment of around £70m in CBT approaches for people with MUS might result in NHS savings of approximately £180m, with savings to individuals from improved workforce productivity of around £60m over a five year period\textsuperscript{[26]}. In another example, it was estimated that a reduction in outpatient attendances and one emergency admission over two years would pay for 0.75 of a psychologist providing 10 sessions per year to 70 people and would save £70,000 per year\textsuperscript{[9]}. The alleviation of MUS and consequent improved mental and physical wellbeing is therefore a potentially highly cost effective intervention\textsuperscript{[41]}. The Government has subsequently suggested that the cost of inappropriate use of limited health resources is now so significant that action needs to be taken to address MUS\textsuperscript{[27]}. 
6 Epidemiological need

6.1 Epidemiology

The complexity of FNS means that there are barriers to gaining a clear understanding of the epidemiology of this issue. Such barriers include establishing a case definition given the difficulties of classifying FNS discussed previously and the plethora of descriptive terms in use. A second barrier is that the need for a neurological examination for diagnostic purposes limits the numbers for study to those in contact with neurological services, making it difficult to generalise.

However, a large range studies considering various aspects of the problem, in different countries and using different methodologies have been carried out. Despite this lack of homogeneity, consistent themes emerge from the literature, and among these is the scale of the problem. Carson et al. highlight reasonably consistent incidence rates of between 4 and 12 per 100,000 population. Studies also suggest that MUS accounts for up to 30% of primary care consultations, with a corresponding figure for secondary care of up to 50% of outpatient appointments. In neurology outpatients specifically, attempts to identify the nature and extent of the problem established that 31% of people attending clinics had FNS.

FNS also appears to affect all age groups, but prevalence tends to be higher amongst younger people. In the SNSS study, mean age was 46 years old, while Nimnuan et al. suggest that FNS tends to peak before the age of 30. That is not to suggest that older age groups aren’t also affected, although the available data suggest that prevalence rates decline after the age of 65 years. FNS also tends to be more common amongst women.

In terms of possible underlying causes, epidemiological studies have highlighted a range of risk factors for the occurrence of FNS. The risk factors are generally similar to those described for emotional disorders such as anxiety and depression. Other factors include:

- A history of recurrent depressive disorder
- Longstanding difficulties with personal relationships
- Substance abuse
- An association with emotional deprivation in childhood
- Childhood physical and sexual abuse
- General disturbances of personality
- Childhood illness and family illness\(^{[24]}\).

FNS is ubiquitous and affects all cultural groups and while FNS is a common phenomenon in the ‘developed’ world, it is also important to recognise that somatic presentations of emotional distress are common in the developing world\(^{[43]}\).

### 6.2 Neurology services in the North East

In the North East there are several centres from which neurology services are provided. The Regional Neurosciences Centre is located at the Royal Victoria Infirmary in Newcastle and as a centre of excellence for training and research is one of the top regional units in the UK. It provides a comprehensive range of specialist tests, treatments and procedures for all types of neurological conditions involving the brain and nervous system.

Sub-regionally there is also a neurosciences department based at JCUH in Middlesbrough. This comprises a number of inpatient and outpatient services based there and at satellite sites. In addition, Sunderland Royal Hospital has a neurology department which provides in-patient, out-patient and day care services to the local population of Sunderland and South Tyneside. Northumberland, Tyne and Wear NHS Foundation Trust also administer the Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry for people with a disability caused by injury or disease affecting the brain, spinal cord or muscles.

### 6.3 Prevalence of FNS in the North East

#### 6.3.1 Methods

In order to inform the potential to commission services to address FNS, commissioning colleagues had requested local information about the scale of
the problem. While there was good information available from the SNSS about prevalence, it was not clear if this was applicable to the North East and so options were considered. Initially there was some thought about reviewing Neurology clinic letters to gain an insight into the scale of the problem, but in discussion with Dr Stone in Edinburgh it was apparent that this would underestimate the size of the problem considerably. With this in mind, it was decided that there was a need to collect primary data.

After some negotiation, Neurology colleagues in Newcastle, Middlesbrough and Sunderland agreed to undertake data collection on all outpatient appointments during the course of March 2016. Dr Stone supplied the data collection tool that had been used in the SNSS in order to try to replicate the method and to be able to compare findings with the Scottish results. This tool was intended to provide some understanding of the numbers of clients referred to neurology outpatient clinics that were suffering from FNS and was completed during a first appointment for new referrals and at a follow up appointment for existing outpatient clients.

Information requested was minimal so as to be as simple as possible and not to increase workload. Information requested included referral type (new or existing), clinic type (general, urgent or other), age group, sex, and main symptom. Most importantly, the tool asked Neurologists to make a judgement as to the extent that patients’ symptoms were explained by organic disease using a four item scale as shown below:

1. Not at all explained by organic disease
2. Somewhat explained by organic disease
3. Largely explained by organic disease
4. Completely explained by organic disease

Following the definitions from the SNSS, for the purposes of this exercise, and recognising that any attempt at divisions of this nature is imperfect, organic disease was defined as:

- Migraine; Any neurological disorder with a known pathological basis;
  Neurological disorders with defined and characteristic features, but without a
clear pathological basis (e.g. Gilles de la Tourette syndrome, Idiopathic focal dystonia); Physiological explained processes NOT linked to emotional symptoms (e.g. micturition syncope); Psychotic disorder.

Non-organic disease was defined as:

- Tension Headache; Aetiologically controversial symptom ‘syndromes’ (e.g. Chronic fatigue syndrome, Fibromyalgia, Irritable Bowel Syndrome); Physiologically explained processes which are thought to be linked to emotional symptoms (e.g. Hyperventilation); Emotional disorders (e.g. Depression, Anxiety, Panic disorder)

On this basis, patients whose symptoms were rated as “not at all explained” or only "somewhat explained" were classified as having FNS and those with symptoms rated as "largely" or "completely" explained as having symptoms that could be explained. Almost inevitably, during data cleansing it was noted that some of the requested fields were missing, the most important of these missing values being those that indicated the neurologists judgment of the four point scale for ‘organicity’ of symptoms. Where more than 10% of cases in a survey have missing data, it is recommended that statistical techniques such as re-weighting or imputation are used\[44\], however, as numbers of cases with missing data items were considerably lower than this 10%, it was decided that they could be excluded.

6.3.2 Royal Victoria Infirmary, Newcastle

The data from the Royal Victoria Infirmary was the first to be returned in May 2016. Neurologists had filled in a data collection form for each patient and this had then been transferred by clerical staff into the template spread sheet provided for this purpose. As mentioned above, for a number of individuals, the key data field of FNS score had not been completed by the clinician carrying out the survey. In addition, during data cleansing it was apparent that some fields had been incorrectly completed. However, none of these missing fields represented more than 10% of individuals and were therefore omitted from the calculations. For instance, with regard to the score for level of organic disease data was missing for 9 individuals which represented approximately 1% of the total number of cases.
The data collection period ran from 1st March to 31st March 2016. During this time 671 patients attended the RVI Neurology Department for outpatient appointments and once those with missing scores and referral type were removed, 662 cases were included in the analysis. Of these 371 were existing patients attending follow up appointments, while 286 were new referrals to Neurology. In five cases it was not stated whether the patient was a new referral or an existing patient and therefore these particular individuals were only included in the grand total rather than the results for existing and new cases. Among existing patients, the proportion that was considered to have FNS was 26%. Among new referrals the proportion of those considered to have FNS was 29%. Among all 662 patients that were included in the data set the overall prevalence of FNS was recorded as 27%.
In terms of the other measures collected, it was found that where the data was available, 52% of patients were female, and 48% male. Meanwhile, patients’ age was categorised as 0-15 years, 16-24 years, 25-44 years, 45-64 years and over 65 years old with approximately 70% of those suffering from FNS in the range of 25-64 years. The age breakdown can be seen below:

Figure 5
6.3.3 James Cook University Hospital (JCUH), Middlesbrough

The data collected at JCUH was also collected from 1st March to 31st March 2016. During this time 278 patients attended neurology outpatient appointments and once those with missing scores and referral type were removed, 276 cases were included in the analysis.  

*Figure 6*

Of these 162 were existing patients attending follow up appointments, while 114 were new referrals to Neurology. Among existing patients, the proportion that was considered to have FNS was 15%. Among new referrals the proportion of those considered to have FNS was considerably higher at 40%. Among all 276 patients that were included in the data set the overall prevalence of FNS was recorded as 25%.

*Figure 7*
In terms of the other measures collected, it was found that where the data was available, 59% of patients were female, and 41% male. Meanwhile, patients’ age was categorised as 0-15 years, 16-24 years, 25-44 years, 45-64 years and over 65 years old with approximately 65% of those suffering from FNS in the range of 25-64 years. The age breakdown can be seen below:

*Figure 8*

![Neurology patients - JCUH](image)

### 6.3.4 Sunderland Royal Infirmary

The data collected at Sunderland Royal infirmary was also collected from 1st March to 31st March 2016. During this time 235 patients attended neurology outpatient appointments and once those with missing scores and referral type were removed, 227 cases were included in the analysis. Of these 66 were existing patients attending follow up appointments, while 161 were new referrals to Neurology.
Among existing patients, the proportion that was considered to have FNS was 29%. Among new referrals the proportion of those considered to have FNS was considerably higher at 39%. Among all 227 patients that were included in the data set the overall prevalence of FNS was recorded as 36%.

In terms of the other measures collected, it was found that where the data was available, 59% of patients were female, and 41% male. Meanwhile, patients’ age was categorised as 0-15 years, 16-24 years, 25-44 years, 45-64 years and over 65 years old with approximately 66% of those suffering
from FNS in the range of 25-64 years. The age breakdown can be seen below:

Figure 11

<table>
<thead>
<tr>
<th>Age groups</th>
<th>Numbers of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-24</td>
<td>10</td>
</tr>
<tr>
<td>25-44</td>
<td>80</td>
</tr>
<tr>
<td>45-64</td>
<td>70</td>
</tr>
<tr>
<td>65 or above</td>
<td>60</td>
</tr>
</tbody>
</table>

6.3.5 Summary

When we sum up the results from the three centres to provide a North East Regional estimate of FNS among neurology outpatients we find the following:

Figure 12

<table>
<thead>
<tr>
<th>FNS scoring</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all explained</td>
<td>Existing patients</td>
</tr>
<tr>
<td>Somewhat explained</td>
<td>New referrals</td>
</tr>
<tr>
<td>Largely explained</td>
<td>Total</td>
</tr>
<tr>
<td>Completely explained</td>
<td></td>
</tr>
</tbody>
</table>
We can see that 23.4% of existing referrals within the Neurology outpatient departments across the North East can be considered to have symptoms that are either not at all or only somewhat explained by organic disease. The relevance of using these two categories is that it is these patients who would benefit from a FNS treatment and management pathway. The equivalent figure for new referrals is 34% while the overall prevalence figure for all referrals is 28.5%.

Figure 13

While data for sex was not collected by clinicians for all patients in the survey, it is still interesting to consider the differences in scores between males and females. This shows that across for scores 1 and 2 across the region that there are consistently more females presenting with FNS.
6.4 Comparison with National estimates

As discussed earlier, the data that was collated for the SNSS in Scottish Neurology departments established that approximately 30% of new referrals had symptoms that were considered to be 'not at all' explained by organic disease (12%) or only 'somewhat' explained by organic disease (18%)[22, 25]. From the Regional data above we can see that the direct comparison with the SNSS data shows that for the North East centres, 34% of newly referred patients can be considered to have symptoms that are 'not at all' explained by organic disease (16.6%) or only 'somewhat' explained by organic disease (17.5%).
One of the main objectives for this health care needs assessment was to establish the scale of FNS in the North East. It would have been possible to use the data which already existed in Scotland as indicative of the scale in the North East however there was a consensus that there was a need to have a more local picture in order to inform commissioners about this issue. We can now say that on the basis of the data collected locally, the North East may actually exceed Scotland in terms of the challenge faced.
7 Comparative need

7.1 Comparison of existing provision

7.1.1 National

A number of services have been commissioned in England to address FNS, but this tends to be on a locality basis and there is a lack of consistency in what is available for patients. One such service is based within the Neurosciences Psychotherapy Service at Sheffield Teaching Hospitals NHS Foundation Trust. This service treats patients identified by Consultant Neurologists as suffering from non-epileptic attack disorder in which people suffer seizures which have a non-organic cause.

Non-epileptic attack disorder may be similar in appearance to an epileptic seizure, but is not caused by abnormal electrical activity in the brain. Non-epileptic seizures happen because of difficulties in handling thoughts, memories, emotions or sensations in the brain. Up to 30 in 100,000 people have non-epileptic attack disorder, and it is estimated that nearly half of all people brought in to hospital with suspected serious epilepsy are actually suffering from non-epileptic attack disorder\(^{[45]}\).

The Sheffield service provides dedicated, outpatient clinical psychotherapy within the context of the multidisciplinary team, for patients of the Department of Neurology diagnosed with non-epileptic attacks. This type of treatment can be associated with complete seizure cessation in one in four patients and a >50% improvement for a further 40% of patients. The intervention is associated with significant improvements in health care utilisation\(^{[46]}\).

Other activities have been informed by recognition of the potential of cognitive behavioural therapy as a treatment for FNS. The IAPT service in Plymouth was an early adopter in using a whole systems approach\(^{[47]}\), while latterly the expansion of the IAPT programme mentioned above led to the identification of 13 pathfinder sites to introduce a stepped care approach to managing long term conditions and MUS\(^{[48]}\).
In primary care, Commissioning Support for London identified six GP practices as pilot sites\cite{49} for a whole systems approach to test the theory that identification and management of MUS would result in savings to practice based commissioning budgets\cite{34}. The Primary Care Psychotherapy Consultation Service operating in City and Hackney is a good example of this.

More recently, in April 2016, a service dealing with Persistent Physical Symptoms (PPS) has been commissioned in Cumbria. This service deals primarily with those suffering from Chronic/ Persistent Pain, Chronic Fatigue Syndrome (CFS), FNS and MUS. The service aims to reduce the number of steps that a patient experiences by ensuring that the most appropriate care is received, in the right place, provided by the most appropriate clinician, and in a timely manner.

Funding for the service, which covers West, East and North Cumbria, came from the CCG which recognised that there was unmet need and that many people currently accessing secondary care services might be better served by a service of this type. There is also recognition that this will potentially reduce financial costs. The service is community based and incorporates a single point of access system to provide consistency across the area. Referrals, once accepted, are signposted to one of two locality teams using a shared referral form.

A biopsychosocial rehabilitation approach is used and provides physiotherapist, psychologist, neuro-psychologist, CBT therapist and rehabilitation assistant support to patients. This is provided on a matched care basis whereby patients first receive a multi-disciplinary assessment before being allocated to the most suitable treatment, for instance, a group using acceptance and commitment therapy (ACT). Importantly, the service also allocates a proportion of its budget to providing training on PPS with primary care in an attempt to improve management and appropriate referral. Initial results are good and while referrals are taken from all specialties, there is particularly high uptake among GPs in the area.
7.1.2 North East

In terms of current provision in the North East, the most comprehensive specialist service is based in Durham. This is designated as a MUPS service has been available in Durham for some time and was set up as an extension of the Liaison Psychiatry Service with Tees, Esk and Wear Valley NHS Foundation Trust. This service is unique within the North East and means that Durham and Darlington have service provision. The service comprises of 1 psychologist, a liaison nurse, psychiatrist and 2 part time support workers. Referrals are discussed at the team meeting and if appropriate are scheduled for initial assessment within 2 weeks. There is no waiting list.

As this is the only such service in the North East requests to see patients from out of area referrals are often received, but may be rejected, contributing to some of the inconsistency seen across the Region. The service operates a stepped care model for patients based on the Healthcare Improvement Scotland guidance referred to in section 4.4. The stepped care model is used to ensure that the patient is given the most appropriate level of intervention in the most cost effective way. It also facilitates matching multidisciplinary skills to patient need.

In 2009 a pilot for a neuropsychology service for people with non-epileptic seizures was started in Newcastle. This comprised a Clinical Psychologist in Neuropsychology and was supervised by a Consultant Clinical Psychologist, with experience of working with Medically Unexplained Symptoms. The therapeutic approach was based on psychological models of physiological arousal and dissociation in trauma with reference to cognitive behavioural models of medically unexplained symptoms, panic and anxiety disorders. Therapy included a thorough psychological assessment, psychoeducation around the psychological understanding of non-epileptic attacks, developing a joint formulation of the patient’s symptoms and goal-focused therapy. This format has since been adapted and North Durham CCG now commissions a Dissociative Seizures Service based in GP surgeries which provides psychological treatment for patients suffering from non-epileptic seizures.
The Neuropsychology at JCUH in Middlesbrough links with Neurology Services and provides some capacity to provide psychological treatment for patients with FNS. In addition, Darlington and Durham was involved in the IAPT pathfinder project for long term conditions which recognised the impact of MUS, and so saw some training of practice nurses on this issue. However, it does not see patients with FNS. Meanwhile, Sunderland Psychological Wellbeing Service (which encompasses IAPT) provides an eight week Persistent Physical Symptoms class. However, some areas, such as Newcastle, have no service at all except where health psychology may be involved in select departments within the RVI, while the picture is similar in most of Teesside.

This brief overview of available services in the North East very clearly demonstrates the issue of inconsistent service provision which in turn is a source of frustration and suffering for patients. The Functional Neurological Conditions SIG has noted this and made enquiries with commissioners about how this might be addressed. Initial discussions have taken place about how to address this through increased service provision. This highlighted that to consider further service provision commissioners would firstly require more local information on the nature and scale of the problem in the North East.
8 Corporate need

The corporate approach to needs assessment is based on the demands, wishes and alternative perspectives of interested parties, for example professional and patient views. In this way it represents normative, felt and expressed need. While it is acknowledged that this approach may blur the boundaries between need and demand, and between science and vested interest[1], it is however a valid source of contextual information. Consequently, it was important to ensure that both patient and clinician views were represented in this document. The following section summarises main themes from a series of meetings and interviews with stakeholders.

8.1 Thematic analysis

Thematic analysis is a qualitative method for identifying, analysing and reporting patterns within data and involves capturing important aspects of the data in relation to the question to be answered[39]. It provides a level of patterned response or meaning within the data. Themes were developed in a deductive way with a specific focus on the content on the interviews/meetings that ensured that they most closely matched the issues of interest which prompted the interviews/meetings.

The process involved familiarisation with the data and in the case of patients this was through transcription of the interview recordings, and for clinicians by repeated reading of meeting notes. This allowed consideration of issues of interest, before coding the data to generate an initial list of areas of particular interest. This then led to the collation of coded data into key themes. As an example, the end result of this process for the patient interviews is displayed in figure 16.
8.2 Patient interviews

8.2.1 Background

Three patients suffering for FNS symptoms to varying degrees were identified by clinicians. Two were from the south of the region and one from the north. In one instance, the patient’s partner attended to help due to communication difficulties suffered as a result of the symptoms experienced. One meeting took place at the patient’s home with the other two taking place in a hospital setting. In each case consent was gained for the interview and for recording.

8.2.2 Patients

Patient 1 reported being fit, healthy and working until the onset of symptoms in 2012 after some lower back pain. Over the course of time pain increased and was accompanied by spasms in the back and abdomen with associated breathlessness. This has limited mobility to such an extent that walking any distance is now too painful and the patient has had to give up work.
Patient 2 described being a fit and healthy gym user and working full time until 2015. At this point there was an episode of acute illness at work which was suspected to be a stroke. Following a period of hospitalisation and investigation the patient was discharged as no cause could be found, however they are no longer able to work, having suffered speech difficulties, memory loss, neck and back spasms and difficulty walking.

Patient 3 was also working full time and described as fit and healthy until 2010 when they noticed a tremor in their hand which progressed to stiffness and contraction of the fingers. These symptoms were later replicated in the foot on the same side. Over the course of three years this patient became debilitated to the point of using a wheelchair for mobility and is no longer in work.

8.2.3 Themes

Need for information

One of the key issues for all of the interviewees was the need for information and understanding about what was happening to them. This most obviously came up as the desire to have a diagnosis. In the context of a condition that is largely unexplained this is obviously a major issue and the search for some meaning underpinned a number of the other themes that became apparent. This is not surprising as a diagnosis is seen to provide reassurance of sorts – that their problem is identifiable and that this is a starting point in looking for a solution.

"I’m desperate for a diagnosis... would provide some piece of mind” Patient 1
"..It would provide a glimmer of hope”

However, there was also realisation that a diagnosis did not necessarily make a great deal of difference. For patient 3, who had received some specific support, the realisation that the best available diagnosis actually was FNS provided little relief because it marked the start of another round of searching for further reassurance. In this case this was in the form of personal research on the internet for information on the condition and for
potential solutions. Given the complexity of the issue and the mass of information available online this was ultimately frustrating.

“Initially FNS consumed me and a diagnosis was everything, but there is so little… spent a lot of time in reading up on the issue and feels quite tied up – can’t see the wood for the trees. I find the whole subject sketchy. I’ve made a commitment to not live in that world anymore”

**Impact**

The impact of FNS on these three individuals was very clear and provided a powerful reminder of how these symptoms are experienced physically, psychologically and socially by sufferers. They have experienced physical symptoms such as pain, spasms, breathing difficulties, weight loss or gain, and difficulties with mobility to such an extent that they were no longer able to work. This in turn obviously has an economic impact with patients ‘getting by’ on benefits. In some cases they have managed to get direct payments through the local funding panel to get help at home, though another patient had been unsuccessful at an individual funding request. Meanwhile the psychological and social implications are clear:

"Life gone down. Don’t remember what before life. Friends gone they look for old ‘patient’ but is gone. People don’t see me as a person. Feel like a toddler. Don’t know what say – changed life. Can’t do anything on own – can’t shower, can’t feed self when hungry, having to wear pads, have enemas, embarrassing. Can’t read, can’t write, don’t have life – life gone. Being told this it. Is sad, mad. Don’t remember how old am, where live – all gone. No memory now”

Frustration was a word that recurred again and again and was used most often to refer to how their experience of searching for answers and support. In the cases of two of the patients there was a feeling that the ‘system’ as it stands is not able to provide help in an appropriate manner. Finding out that a service existed for this issue in another part of the region, but that where the patient lived prevented them from being referred had been particularly frustrating and was felt to be “a disgrace”.

"feel like we’ve been ’kicked to the kerb’ and we’re just expected to get on with it”

“The system is disjointed. The GP is the gatekeeper, but there are referral criteria and limits of what they can provide – e.g. that’s not something I deal with, go back to GP and it just goes round in circles. I’m at the stage where I now suggests things to the GP”

All three patients were feeling isolated to varying degrees and often this was due to no longer being able to work. The patients found themselves less able to do things and so other activities, such as going to the gym, had also ceased. The fact that there was so little knowledge of FMS amongst the general public also added to this:

“Because it isn’t a physical disability people can’t understand – family and friends don’t understand and have stepped back”.

“It has been isolating. I don’t try to explain it to anyone other than close family as I don’t know how they will react”.

“Other conditions have advocacy and support groups, but this…there’s just nothing”

Worry/anxiety/stress

Much of what has already been touched upon results in anxiety and stress for patients with FNS. Two of the patients gave voice to the worry that FNS has caused. One particular issue was due to financial concerns due to loss of work. There were worries about paying rent and one patient had been to court in order to retain disability benefits they had been receiving after they were withdrawn under new social welfare rules. This also played a part, along with people’s lack of understanding of FNS, in patients worrying that that they would be perceived as a malingerer.

“I even worry about going to see the GP”
Another major source of worry was about the illness itself and the uncertainty it caused.

"We were scared to go home as didn’t know how to cope – there was no information and no answers. Things have got progressively worse”

"It’s a vicious circle of worrying about rapid decline and I worry I’ll be in a wheelchair soon”

The lack of consensus on what was causing the illness also contributed and patients found it really stressful waiting for the results of tests, often referring to the fear of discovering that they were suffering from one of the well-known major illnesses.

"I found the pressure of waiting for test results really stressful – was it MS, was it Parkinson’s disease?”

**Experience of treatment**

Access to appropriate care and support was something that all patients raised. We have already highlighted frustration at the disjointed nature of the service on offer, and in particular the fact that someone’s address determines whether or not they can currently access care and support. This led to a feeling that not only had they lost power from a personal perspective, but there also appeared to be no direction at a professional level which was demoralising.

"That a service exists in Durham, but I cannot get access because of where I live is a disgrace”.

"I was able to see Dr xxxx, but this was on their good grace rather than I had a right to be referred – had real trouble to get in”.

"I had previously been referred to ***** Hospital, but didn’t meet criteria. It feels like doors are being slightly opened and then kicked shut. Being passed from pillar to post”.
“People sit at desks and say the budget will be spent here or there – they don’t see the devastation this causes, they need to see the real person behind this.”

One patient felt fortunate in that they hadn’t had the access problems of some people. They had been able to see a local specialist and this had led to psychological support, access to a wheelchair, support from agencies, and the benefits agency had not ‘been on their back’.

"I really feel for the other patient I met who has not been able to get access to support. They only lived 10 miles away and you’d think we lived at opposite ends of the country. I want there to be more support, more services. I think everyone with FNS would benefit from some sort of psychological support”

The impact of the interventions that patients experienced when they attended appointments varied. The nature of FNS means that diagnosis tends to be through exclusion and patients receive plentiful input in terms of investigations and different services without there being a coordinated response. The patients here had attended pain clinics, yoga classes, meditation, psychology, neuro-psychology and psychiatry, among others.

"The pain clinic involved meditation and breathing techniques and yoga over 8 weeks but it didn’t help.”

Where access to a professional or service with an interest in FNS had been arranged, there was recognition that they were fortunate, but again results were varied:

"I’ve seen Dr xxxx twice, but there was nothing in the way of treatment provided – just referred to psychiatrist for assessment.”

"I’ve found Dr xxxx to be great, but there are still no answers. They arranged for me to see a psychologist each week at the moment and it feels like two
separate teams are involved, which is confusing. Feels like lines are drawn between services and it doesn’t feel like I fit – ‘having FNS means there is nowhere to hang your hat’.

The lack of service provision was apparent in that where someone had received a referral they waited around 18 months to be seen in clinic. This led to 2-3 sessions before they were then referred to another clinician.

“There have been no improvements in my symptoms from the treatments I’ve received. There has been occasional variation, but never real improvement.”

“When I first entered the system I had several years in limbo with an older consultant who didn’t really recognise FNS. It was horrific – young family, mortgage, didn’t know where I was, Jesus it could have all been avoided. I wouldn’t want anyone to go through that.”

The amount of health care that these patients utilised was striking and reflected the previous discussion that FNS patients have approximately twice the outpatient and inpatient medical care utilisation and twice the annual medical care costs of other patients. They reported repeated visits to GPs, and various hospital clinicians.

“I suppose I saw the GP first, and since then neurologists, neuro-psychologists, pain clinics, psychologists, and private back specialists on three occasions. I’d estimate I have attended hospital on at least 50 occasions for tests, appointments and CT scans, including A&E three times and three admissions.”

“I was first admitted to ***** Hospital for six days and had emergency CT and MRI scans. There was no sign of stroke so I saw the neurologists who performed various test – no medical explanation so discharged.”

“In terms of health service utilisation there have been 5 A&E attendances, 4 admissions, neurology, 3 MRI scans, 2 CT scans, psychiatric assessment,
lumbar puncture, many different blood tests, physiotherapist, OT and 10+ GP visits. I’m awaiting speech and language therapy appointment and psychology appointments.”

“I’d say I’ve attended the GP on at least 30 occasions about this problem and had lots of medications. I’ve had a radio isotope scan, CT and MRI scans, countless blood investigations, nerve conduction tests. I’ve had referrals to neurology, the mental health team, social work, occupational therapy, physio, wheelchair services, psychology and psychiatry. That’s without the transport services”.

**Psychological explanation**

The potential for psychological explanations for FNS has been discussed previously as had the difficulty that this can cause in terms of resistance from patients. The lack of consensus on this issue was apparent during the interviews. All patients were aware that there may be a psychological element to the problem, but generally seemed to struggle with the concept.

“*I’m open-minded and trying CBT at the moment, but can’t seem to get to grips with the mind as a potential cause. It feels a bit demeaning – like they’re saying I’m cracking up.*”

To varying degrees this feeling featured in all interviews with variations on ‘they think I’m imagining it’ and ‘it makes me feel like a fake.’ All patients either have or would try psychological input as:

“*There is a feeling of it being said that it’s all in the mind, but I’m at the stage where I will try anything so I’m willing to try CBT. Everything else has been chased down – GP clearly doesn’t know what to do with me.*”

That said, where a patient had had some longer term psychological input, they had found this really useful. While they wondered if FNS could be psychological, they tended to swing between explanations and generally favoured the neurological explanation. However, there was recognition that there is a stigma to the mental health issue. It was also recognised that
anxiety and stress can exacerbate symptoms and while the psychological support had not alleviated the FNS it had been helpful in addressing issues such as stress and low mood.

"The psychological support has been essential in dealing with the stress and depression - dialectical behavioural therapy has been good. Practicing mindfulness has helped with the pain. I now help out as a peer".

**Current health**

While there wasn’t the chance to investigate patients’ experience further, it was decided to include an opportunity for patients’ to summarise how they felt about their health at that moment. To do this the Euroqol visual analogue scale was included in the interview schedule\(^{[50]}\). This requires the respondent to self-rate their health on a vertical, visual analogue scale where the endpoints (0 – 100) are labelled ‘best imaginable health state’ and ‘worst imaginable health state’. The patients scored 35/100, 10/100, and 65/100, reflecting the difficulties that they were experiencing. The higher score was from a patient who had received more support and admitted to being an optimistic person by nature:

"It has had a massive effect on me and my family, his partner, his children. It’s not good for a relationship – not that long ago I was working, driving, taking the kids out and now there is role reversal. There have been really dark times – but lately there has been good support, and I want to give something back.”

**8.2.4 Summary**

This was a smaller sample of patients than had originally been intended and obviously it is therefore difficult to generalise. However, the respondents appeared to be giving genuine accounts of their experiences and the level of day to day difficulties they endured was striking. This was exacerbated by the lack of consistent information available to them both within and without their contact with services. Uncertainty driven by this seemed to be one underlying factor in high levels of stress and anxiety. These psychological factors were
enhanced by the considerable physical difficulties they suffered and both linked to social impacts like economic concerns and isolation.

Experience of medical intervention was variable and all were concerned by the disjointed nature of primary and secondary care. There seemed to be a lack of knowledge about FNS and inconsistent pathways to which access was hampered by apparent barriers and varying referral criteria between disciplines. All patients however had high levels of health care utilisation. Where this was specific to FNS there were some positive experiences, but there was a lack of understanding about the psychological factors that may underlie FNS. This was reflected as resistance among the patients, but there also seemed to be no consistent message on this from clinicians. That there was little specific service provision and that this introduced an unequal situation was considered a major issue by these patients.
8.3 Clinician discussions

8.3.1 Background

A series of meetings with clinicians involved in neurology, psychology, neuropsychology, service managers and psychiatry were carried out over the period September 2015 to February 2016. In addition, one meeting was arranged with a representative of the CCG and another with NHS England as specialised commissioners. In total, 25 discussions took place, either in person or by telephone. A series of ongoing email conversations also occurred during this period, including with Jon Stone who provided advice on data collection to establish prevalence of FNS.

8.3.2 Themes

Clinician concerns

One of the key observations from the clinician meetings was that the issue of FNS was considered to be a major concern. Some of the reasons for this view will be explored below, but it was also clear that there was a consensus that something needed to be done to address this. The main suggestion was that there should be increased service provision, but there was recognition that the problem is complex and no one really knows its scale, which is a constraint when making the case to commissioners.

One of the main areas of concern about these patients was that they create a particular burden. This reflects previous discussions about the amount of healthcare utilisation that is attributed to this group. Clinicians felt excessive amounts of their time were taken up with multiple appointments and it was suggested that these patients ‘clog up’ the system. A lack of consistent approach to the problem also meant that multiple referrals for investigations were required and that this added to costs. One clinician pointed out that the desire from patients for diagnosis, a label, was particularly unhelpful because when this is applied it can lead to a flood of extra patients and resource use.

Another area of concern that was apparent was the issue of terminology, which was touched upon earlier in the report. There are indeed a diverse range of terms used to describe FNS and many of these were apparent in the
conversations. Even those who are relatively comfortable with medical terms find this to be confusing subject area. Obviously, some terms are specific to the distinct problems encountered under the umbrella term, but even then there were often multiple terms for the same issue. For patients it is likely to be much more difficult to understand the subject when so many terms are in use. This adds to the complexity of FNS/MUS overall and indicates the need for more accessible terminology to be agreed upon.

**Perceived challenges**

A number of clinicians highlighted issues that they felt were the result of the ‘the way we do things’. An example of this was the traditional medical approach of diagnosis by exclusion which it was felt led to increasing numbers of referrals and investigations. This is certainly borne out by the experiences of the patients that were interviewed. It was recognised that to address this would require a conceptual/cultural change on the part of clinicians as this is an established way of working. It would also probably require changes in the system.

One problem that came up on a number of occasions was the perceived gulf between physical and mental complaints. As we have seen, both can be factors in FNS, but it was felt that the specialties are set up in such a way that it makes it difficult to bridge that gulf. One clinician very strongly identified this as a false distinction which was a significant barrier to providing a more holistic approach for these patients.

Another challenge identified was the breadth of symptoms that are encountered and how these can be managed. One approach to this was categorisation, which obviously links with terminology, where clinicians would consider patients to be suffering from either episodic or long term symptoms, or straightforward or complex symptoms. This obviously helped them to think about where patients should ‘fit’ in the absence of established guidance, but where a system is not consistent there is a risk that it further complicates the situation.
This is reflected in the description of one clinician of FNS overall being a ‘messy’ situation, difficult to define. It is easy to agree with this given that patients very rarely fit into defined categories or discreet specialties. They suffer from comorbidities and functional overlay is common meaning that often there is no one clinician who has oversight of the patient and it is difficult to know where responsibility lies. This perhaps reflects the patient view that they are passed from ‘pillar to post’.

**System factors**

We can define complexity as a problem which is complicated by a number of factors whose influence and interaction is uncertain. Taking this view we can certainly describe the issue of FNS and how to manage it appropriately as a highly complex problem. This was reflected in the discussions that took place with clinicians where many of the factors which they considered important were identified. Among the system factors raised was a concern about inconsistency of response. There was recognition that there is no agreement on how best to address the problem and this has led to unequal service provision and variation in patient experience. Several clinicians had concerns about patients that had a diagnosis of FNS, but were unable to access services because of referral criteria and geographical boundaries.

This is reflected in that there are no consistent patient pathways for FNS outside of the few services that are available. The problem of diagnosis by exclusion and the boundaries of different specialties also contribute to it being difficult to have an overview of the system and this makes it difficult to navigate for clinicians and patients. There was agreement that Neurologists were probably most skilled at diagnosis, but that the complexity described here often means appropriate referral is variable. Another complicating factor is that coding is inconsistent and this means that any data collection and subsequent monitoring is reliant on existing services and individual clinicians who have an interest in FNS.

**Clinician factors**

It was felt that for some clinicians there was a lack of clinical knowledge and/or communication skills when it comes to FNS. Both of these factors can
have a negative impact. The former means that FNS is less likely to be diagnosed, while the latter means that when it is, there is no consensus on how best to communicate the problem to patients. Linked to system factors, this is likely to have a detrimental effect on patients. Some suggested that ambiguous communication can be dependent on the clinician’s attitude to FNS with those newer to Neurology more comfortable in discussing the problem. This can lead to FNS being missed, either through a lack of knowledge outside of neurology, or reluctance to diagnose it within the specialty. Several people suggested that fear of complaints and litigation leads to not recording FNS as a diagnosis in patient notes – this was linked to dissatisfaction that patients may feel when they perceive that they are being told that the problem is ‘all in the head’.

**Patient factors**

The literature suggested that people suffering from FNS are often seen as problem patients and while the clinicians who contributed to this did not voice this of themselves they did recognise this perception amongst colleagues. This seemed to be linked to the fact that often it was difficult to know how best to manage people, especially when there are limited services available and they might not always be receptive to the idea that the cause of their problem may not be physical. We have seen how important it is for patients to feel that they can attach some meaning to their experience through a diagnosis.

It is interesting to consider that this is most likely as a result of the traditional medical approaches and yet when a condition such as FNS falls without these approaches, it is the patient who is often perceived as problematic. That is not to say that patients can’t be problematic. Clearly there is an expectation about what the system could and should deliver and when these expectations are not met the anger and frustration resulting from an unexplained illness can come to the fore. This may result in complaints or legal recourse and most likely underpins the reluctance of some clinicians to discuss or record FNS openly.
Solutions

There were many suggestions for how the challenges that had been discussed might be addressed. There was a workforce development element to this whereby knowledge of FNS among primary and secondary care clinicians in different specialties could be brought up to a basic level to increase chances of early identification, appropriate referral and management. This would be aided by agreed protocols identifying standard symptoms to be used for referral, for instance, within GP surgeries. This begins to look like an agreed patient pathway and this was also mentioned. In terms of management there was a consensus that a matched or stepped care approach which addressed biological, psychological and social factors would be the best case scenario.

8.3.3 Summary

The clinicians that were interviewed as part of this work had an interest in FNS to a greater or lesser degree. Almost all considered FNS to be a major concern. A variety of reasons was given for this and included the unmet need of patients and the burden to the system of not having a consistent approach to identification and management. The underlying causes of clinicians’ concerns about FNS included the heterogeneity of the illness, the complexity of the system that they work in, knowledge and skills of clinicians, and the difficulty of engaging with some of these patients. All thought that there was a need to take some form of action to allow better identification, referral and management.
9 Conclusion

Health care needs assessment is a systematic method for reviewing the health issues facing a population which leads to agreed priorities and facilitates the targeting of resources to improve services to meet need and reduce health inequalities. This HCNA aimed to estimate the prevalence of FNS amongst patients attending neurology outpatient departments in order to establish the scale of need in the North East and to consider this against existing service provision. Along with this information a review the evidence for effective services was carried out in order to provide the necessary context to inform future commissioning decisions.

The issue of MUS, and more specifically FNS, is a complex one. Symptoms are experienced as real and physical by the sufferer and cause considerable distress, disability and dysfunction, and account for a large proportion of healthcare visits. Many different types of symptom exist and each one is experienced in a unique way by the patient. In addition, there is also overlap of symptoms, aetiological factors and response to treatment for which standard medical practice is unprepared. The large and varied terminology is testament to the complex and confusing history of the issue.

There are significant costs associated with FNS. These are financial in terms of the large number of healthcare visits attributed to these patients, and the ensuing investigations, with direct costs to the NHS estimated at £3.1 billion annually (indirect costs increase this substantially). There are also costs incurred psychologically and socially by the patient and their families as clearly demonstrated by the patient interviews carried out in this HCNA. Clinicians recognise the personal costs associated with FNS, as well as the complexity and frustration of trying to deal with the problem in a system that does not always allow clinical judgement to develop into the required treatment.

Scotland is a leader in the study and treatment of FNS and one study estimated the prevalence of FNS in new referrals to Neurology outpatient departments at 31%. Using similar methods, this HCNA collected data from the three Neurology outpatient departments and established that in the North East the equivalent figure is 34%, with a prevalence of 29% overall amongst
both new and existing patients who attended. This underlines the scale of the problem faced in the North East and we can only speculate at the total financial and personal costs that this results in.

The availability of agreed approaches and guidance on FNS is patchy, as is the provision of adequate services nationally as well as in the North East. The issue of local level commissioning means that patients in some areas are able to access treatment, while those in a neighbouring area are left with no options. Again this was clearly demonstrated through patient and clinician interviews. In England, there is recognition of the issue of MUS more widely and moves to deal with the psychological element of this have been made with the inclusion of MUS as an issue for IAPT. However, it would also be a mistake to suggest that psychological treatment alone is sufficient for the issue, and evidence shows that a matched care approach is most effective.

The evidence shows that a matched care approach should be adopted. This should be part of a system that co-ordinates the work of different organisations, and staff across primary and secondary health care, from prevention and self-management, to identification, assessment, therapeutic interventions, and recovery. This in turn requires the clinical workforce more generally to be aware of the issue and have the knowledge to recognise potential FNS and refer consistently if a service is available.

Such an approach would reduce the chances of patients becoming involved in the protracted, costly, and frustrating results of diagnosis by exclusion. Even when a diagnosis is made there is no single best treatment option, and so a range of options need to be available and this requires that services are available which utilise a range of professionals. The adoption of a triage type approach when a patient is initially assessed would then ensure that options can be appropriately matched to the individual.

This HCNA has demonstrated that there is considerable unmet need in FNS patients in the North East. The patchy nature of service provision leads to unfair and avoidable inequality which should be addressed. This would not only be of clinical benefit to patients, but would result in savings to the healthcare system. With these observations in mind it would be beneficial for
stakeholders to investigate further the potential to increase the provision of matched care service approaches for FNS patients in the North East.
10 References


25. SNSS Study Group, Scottish Neurological Symptoms Study. 2005, University of Edinburgh Edinburgh.


