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The Body speaks its Mind: The BodyMind Approach® for Patients with Medically Unexplained Symptoms in Primary Care in England

Hghlights

This article documents an experience of providing an innovatory clinic in the National Health Service (NHS) in the UK. Delivering anything new even if based on previous research is problematic particularly when negotiating within the context of the changing NHS England. An evidence-based intervention, offered by a University of Hertfordshire's new spin-out company Pathways2Wellbeing, is called Symptoms Groups to patients and The MUS Clinic to health professionals. The groups use The BodyMind Approach (TBMA)®¹, based on a bio-psychosocial model derived from dance movement psychotherapy, which has been specifically researched with patients with medically unexplained symptoms (MUS). These patients have no specific pathway for supporting their wellbeing and are high health utilizers at the interface of primary and community care. They suffer with chronic, physical symptoms or conditions which do not appear to have an organic, medical diagnosis. An overview of the pitfalls/challenges and some of the methods which were designed to overcome these is provided in this article together with two case studies, GP guidance for referral and an overview of the patient journey.

Keywords: Medically unexplained symptoms; primary care; The BodyMind Approach; innovation; innovative service delivery

¹ For more information about TBMA please visit <u>www.pathways2wellbeing.com</u> or email: info@pathways2wellbeing.com

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The Body speaks its Mind: The BodyMind Approach® for Patients with Medically Unexplained Symptoms in Primary Care in England

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Abstract

This article documents an experience of translating research into the real-world of the National Health Service (NHS) in the England. Transferring new knowledge from research is problematic particularly when negotiating within the context of the changing NHS England. An overview of the pitfalls/challenges and some of the tried and tested methods which were designed to overcome these is provided. The evidence-based intervention, offered by a University of Hertfordshire spin-out company Pathways2Wellbeing, is a service called Symptoms Groups to patients, and termed The Medically Unexplained Symptoms (MUS) Clinic to health professionals. The groups use The BodyMind Approach (TBMA)®², based on a bio-psychosocial model derived from dance movement psychotherapy, which has been specifically researched with patients with MUS. These patients have no specific pathway for supporting their wellbeing and are high health utilizers at the interface of primary and community care. They suffer with chronic, physical symptoms or conditions which do not appear to have an organic, medical diagnosis, previously now as psychosomatic conditions **Keywords:** Medically unexplained symptoms; primary care; The BodyMind Approach; innovation; service delivery; university spin-outs

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Introduction

This article documents the embedment of an innovative intervention The BodyMind Approach (TBMA)®, which uses the inter-relationship between physical and mental health for the treatment of patients with persistent medially unexplained symptoms (MUS). The original research into the intervention took place at The University of Hertfordshire (Payne 2009; Payne & Stott 2009; Payne 2010). This University's new spin-out social enterprise company 'Pathways2Wellbeing' is the vehicle for the service delivery within the NHS. The Department of Health (DH) initiative 'Quality, Innovation, Productivity and Prevention' (QIPP) scheme funded the service in a competitive bid from the then Hertfordshire Primary Care Trust. The delivery took place in Primary Care in Hertfordshire, a large county near London. The treatment, TBMA, aims to bridge the gap between mental and physical health with patients with chronic MUS.

Medically unexplained symptoms

Previously known as psychosomatic conditions, medically unexplained physical symptoms, as defined by Edwards et al (2010) is 'a clinical and social predicament that includes a broad spectrum of presentations where there is difficulty in accounting for symptoms based on known pathology' (Edwards et al 2010 p209). Therefore, having to select either an organic or a psychological explanation for MUS can be obviated. Instead it enables an all-inclusive, bio-psychosocial treatment that addresses both hypotheses simultaneously.

Symptoms include conditions such as irritable bowel syndrome (IBS); ME; chronic fatigue syndrome; chronic pain; fibromyalgia; palpitations; insomnia; tinnitus; numbness; skin conditions; chest/joint/muscle/abdominal pain; headaches; back pain and more. Most patients also suffer anxiety and/or depression.

These patients are high health utilizers. In secondary care in the USA, for 1,000 medical outpatients 16% of the presenting symptoms had a documented organic cause, 10% were presumed to be causally related to psychological variables, leaving three out of four complaints unexplained medically (Kroenke & Mangelsdorff 1989). For 191 new referrals to a general medical outpatient clinic, 52% of patients' physical symptoms were medically unexplained (Van Hemerta 1993) and 'no serious medical cause' was the diagnosis in 25% - 50% of all primary care visits (Barsky & Borus 1995).

Only 10% - 15% of the 14 common, physical symptoms seen in half of General Physician (GP) consultations over 12 months are found to be caused by an organic illness (Morriss, Dowrick, Salmon 2007). The remaining 85-90% of these physical symptoms is of unknown biological aetiology and is referred to in the literature as "medically unexplained symptoms" (Katon & Walker 1998). Therefore it is well known that these patients visit health professionals frequently and use a great deal of resources, accounting for as many as one in five new consultations (Bridges & Goldberg 1985). Khan et al (2003) call for better management strategies to be developed in primary care for prevalent, medically unexplained, persistent somatic symptoms which are a health care priority. Other than Cognitive Behavioural Therapy (CBT), which is inaccessible to these patients since they do not have a psychological explanation for their symptoms, there is no pathway for the support of these patients. Their costs are escalating for the NHS and society as a whole in England.

The BodyMind Approach®

TBMA has been designed specifically for integrating mental and physical health in people with chronic MUS. It uses a mindful, kinetic practice, a model derived from dance movement psychotherapy (Payne 1992; Payne 2006a; Payne 2006b), mindfulness, experiential learning through experimentation/exploration, group analysis and theories and practices from Authentic Movement (Whitehouse 1999; Adler 2002; Chodorow 1992; Payne 2006a). Authentic movement is an aspect of dance movement psychotherapy - a body based

psychotherapy - which aims to integrate body and mind. TBMA honours and engages with the patient's relationship to, and perception of their bodily symptoms. It is bio-psychosocial, focussing on the whole person holistically.

TBMA differs from CBT, psychotherapy or counselling in that it focuses on the physical symptom and any verbal communication and/or meaning–making emerging from bodily responses to the practices. There is no explicit discussion of psychological, biographic or causal relationship with the symptoms unless patients make such connections themselves, nor are psychodynamic or psycho-educative components involved in this intervention. There is an evidence base for the use of CBT with some specific conditions included in the MUS category such as IBS or fibromyalgia. TBMA however, addresses a range of symptoms for a number of patients in the same group with various accompanying aetiology such as alexithymia and attachment style (Payne 2015).

Body based psychotherapy methods such as Focusing, developed by (Gendlin 1996) and the Hakomi Method (Kutz 1990) give full appreciation to the role and importance of acceptance in a mindfulness-based process (Weiss; Harrer & Dietz 2010). Mindfulness practice is similar to the moving meditation process and witnessing states found in the discipline of Authentic Movement.

The patient enters a process of becoming engaged in a state of inner mindfulness as she/he moves in the presence of a witness/facilitator. Weiss (2009) refers to this dialogic practice as assisted meditation. The facilitator guides the patient from everyday consciousness into mindfulness whilst attending to their sense of wellbeing. The patient directs her/his attention to embodied, inner experiences of self, actively reflecting and commenting on bodily sensations as they are raised into awareness. Gradually participants become more connected to their embodied, direct experience of self and may then be able to act as their own witness and as a witness for others. Embodied, experiential learning exercises which the patient can practice between sessions form an integral part of the intervention, such as correct breathing methods.

From the earlier research studies, including a proof of concept study, (Payne & Stott 2010; Payne, Eskioglou & Story 2009; Payne 2009) patient benefits from TBMA intervention included: improved wellbeing and activity levels; decreased symptom distress/anxiety/depression levels; improved self-management of symptoms; lower or stabilized medication levels. For GPs the benefits can include reduced attendance at the GP and/or secondary care referrals; and/or reduced medication.

For every 50 patients completing Symptoms Group treatment using TBMA savings approximate 22K (at 2008 figures) (after the costs of the programme are deducted). A health economic analysis of TBMA compared with CBT showed that the cost savings would be large in primary care but that secondary care they would be even greater (Payne & Fordham 2008; Department of Health 2012).

TBMA is an integrative approach underpinned by the general principles of experiential learning cycles, dance movement psychotherapy, humanistic psychotherapy as well as the recent research on mindfulness. It uses the recovery model for mental health and incorporates research from attachment theory and neuroscience as part of the rationale.

The treatment is termed 'Symptoms Groups' to patients since they are pre-occupied with their chronic symptoms and usually believe there is a physical explanation for them but this has not yet been diagnosed by the medics. Normally this patient population are resistant to attending therapy/psychological interventions often due to their explanatory model and the stigma attached to these treatments.

The group is central to the approach since it addresses the isolation patients often experience as a result of their symptoms. Other members of the group act as an additional secure base and support each other.

There is a reliance on a specific 'attitude of mind' of the group facilitator who can direct participants' attention in a particularly mindful way within a group formation. The facilitator cultivates her sense of purpose, 'presence' and non-judgemental attitude. She does not aim

to fix anything nor change thought patterns but by 'being alongside' makes space for action, imagination, sensations, thoughts and feelings witnessed as they arise and are reflected upon. The facilitator's task is highly complex involving simultaneously the perception of the participants' verbal and non-verbal expressions and the self-regulation of one's own perceptions and counter transferences.

TBMA is not a technique but a process. It honours the legitimacy of the participant's physical symptoms and helps to identify the psychological and social factors needed for healing. The bodymind notion is consistent with, and supported by, neurobiological models which draw on central nervous system mechanisms to explain medically unexplained symptoms.

The approach relies on somatic awareness, a normal part of consciousness, to resolve the body – mind dualism inherent in conventional multidisciplinary approaches. Somatic/bodily awareness has the potential to enhance understanding and conscious use of inner healing mechanisms at the basis of the placebo effect. This awareness also allows for a linear application of the bio-psychosocial model. TBMA is used in the Symptoms Group to promote changes in, for example symptom perception/distress experienced, the nature and/or purpose of the symptom, coping styles, illness beliefs, medication/GP dependence and personal dynamics necessary to achieve a reduction in symptom distress and an increase in the feeling of control.

Key Underlying Values of Symptoms Groups:

There are a number of values which support the delivery of TBMA. For example, the empowerment of the patient to self-manage their symptoms and framing the sessions as a social rather than a medical model thus promoting inclusion. TBMA utilises the patient's strengths and resources rather than focussing on remediation and deficits as in other approaches in mental health care. TBMA also validates the symptom as opposed to other approaches which invalidate and/or negate the symptom e.g. terms such as psychological therapies/psychosomatic conditions which result in patients not feeling believed. TBMA

group sessions are conducted a non-stigmatising, non-medical venue in the community which is designed to be more anonymous than a GP setting or a room within the psychological services setting. It considers patient lifestyle and goals and encourages the development of an action plan which the patient can undertake post-sessions to promote independence and self-care. Rather than relying on verbal expression alone is uses a variety of creative methods of embodied experiences. By starting where the patient is, the sensory, physical, bodily symptom is acknowledged and worked with as an ally, promoting a positive re-association with the body which has often become the 'enemy'. TBMA fosters a greater connection and attunement to the self, encouraging self-regulation as well as honouring the wisdom of the body by using the fundamental inter-relationship between body and mind, hence the term The BodyMind Approach rather than the mind-body approach. Finally TBMA works on the principle of recovery, giving hope to people to live well with their symptom rather than promising a cure or having to learn to live with it

An example of the TBMA process

The TBMA intervention, which has been manualised, may include the following elements in a session:

1. Checking in: requesting each participant respond to the questions 'How are you today/this week?'; 'anything left over from last time?' 2. Sitting/standing in a circle participants are invited to warm-up their bodies through simple gentle movements directed by the facilitator using the breath, self-massage (e.g.hands), somatic awareness techniques. 3. Individually gently isolating and moving body parts mindfully with the sensory experience of symptoms in mind engages the body-felt self, the limits and the possibilities together with an exploration of inner, personal and general space. Where in the body is the displeasure and where is the more pleasurable experiences located in the body? Sitting in chairs, facing the wall, away from the circle with eyes closed (and/or with a non-moving partner as witness with eyes open) directed exercises are presented to a tight time frame. This aims to encourage

connections between different layers of self-experience, again with the symptoms in mind – as though moving out of and through the gateway of the symptom. Eyes closed (or half closed/open) movements are made from an inner impulse/bodily sensation/feeling or image (or otherwise), witnessed by another (or not), just the fingers or the whole arm or body etc. 4. After a transition period postures/gestural movements; images; sensations; kinaesthetic experiences; relationships from the somatic experience are recalled and spoken about to the witnesses and/or facilitator who gives a spoken offering in the presence of that experience, if invited. A dialogue ensues and participants are asked to consider their findings as sensemaking in the light of their symptom and life in general. Writing, clay modelling and mark-making may be encouraged as part of the process. 5. Check out and closure: in a circle each one verbally reflecting on the experiences, support is given to help integration, refocussing on self with a simple exercise. Journal writing of how any insights and metaphors could apply to behaviour/lifestyle before final closure'.

The MUS Clinic

Following extensive consultation with GPs in a market research study by Payne, Eskioglou & Story (2009) a need was identified by the GPs and primary care counsellors for a pathway for the treatment and support of this patient population. When TBMA was described to these GPs as a possible pathway it was welcomed with open arms.

'The MUS Clinic' was a suitable nomenclature for GPs as was the name 'Symptoms Groups' to patients. The name 'MUS Clinic' is the term we have given to the service delivered using TBMA. It is not a normally a clinic within the NHS in England, it is a construct used to enhance the acceptability of the approach to health professionals and patients. This could be replicated in any other health system.

This paper documents the transfer of TBMA from the pilot research study into practice. Since it has an evidence base it was accepted by the NHS. People with MUS are often resistant to psychological therapies so it makes sense for them to attend a group where their physical symptoms are honoured. For people who are more psychologically-minded in their explanatory models of their physical unexplained symptoms it offers another perspective on their body mind connection. It is complimentary to CBT/psychotherapy and cross referrals have been encouraged during the service delivery. The MUS Clinic offers an experiential learning framework using TBMA for up to ten patients per group. Each session is two hours for 12 sessions over eight weeks (the first two weeks having two sessions per week). Groups run locally in a suitable community setting. Following the groups in phase one, phase two over the following nine months maintains contact with the patient by other methods (see patient pathway below).

Assessments are conducted pre, post and at six months follow up together with a request for case reports to be completed by the GP practice in month three and six to gather further information.

The drivers in the context of primary care

There are several drivers for the conceptual framework derived from firstly the pilot research study and secondly the QIPP project process recently completed.

There is DH directive (Department of Health 2012) which encourages mental and physical health integration. TBMA fits this directive as it is based on the inter-relationship between body and mind.

Patients with MUS are a worldwide problem, the costs to the NHS in England is around £3 billion per year (Bermingham et al 2010) rising to £18 billion if quality of life, benefits and absence from work is included. We know from the health economy study conducted in 2009 that TBMA has the potential to dramatically reduce costs of MUS to the NHS and society at large.

One third of all medical outpatients have MUS (Bass 2003). TBMA has demonstrated (further to the pilot study previously conducted) that the number of referrals to secondary care reduced for all patients during the treatment and at follow up over six months.

The DH requires evidence-based practice (for details please see National Institute for Health Care and Clinical Excellence). TBMA is based on research from the University of Hertfordshire and has in addition, collected practice-based evidence. It is hoped that a control group will be collected over time from patients withdrawing after the first pre group assessment. However, as there are few who withdraw this may take several years.

Patients are frequent health seekers Reid et al (2002) and it has been shown that TBMA has reduced the number of GP visits by patients both in the pilot study and in the QIPP project. Those GPs who have referred during the QIPP service delivery (N=52) have given spontaneous feedback that they have been pleased with the patient benefits and are encouraging their colleagues to refer.

Although these patients are often resistant to psychological approaches (Allen & Woolfolk 2010; Gonzalez et al 2005) it is clear that TBMA appeals to both psychologically minded and psychologically resistant. Attendance rates are extremely high with only 5-10 per cent not completing the treatment.

Patients with MUS have high prescription costs. From both the pilot study and the QIPP delivery these costs were reduced for some patients, others remained the same.

Psychological therapies in England tend to offer only CBT despite government initiatives to increase patient choice. Therefore patient and GP choice of treatment is important (Gonzalez et al 2005). TBMA widens the treatment options for patients and GPs. Psychological therapies are only accessed by patients who are psychologically ready to make use of them. Many people with MUS drop out or fail to attend the first appointment which is very wasteful of scarce resources.

TBMA as well as being effective in its own right can also act as a gateway to psychological therapies. People develop more insight about their psychological needs once having attended the TBMA group and they may become more committed to other psychological services. Participating in TBMA helps them to begin to make the link between body and mind and thus more easily access the psychological therapies, if needed, at a later date.

Referrals to The MUS Clinic:

Referral guidance to GPs was based on the criteria implemented in the pilot study. The criteria were given to the GPs during awareness-raising presentations and in the referral form for example, confirming that MUS was present/diagnosed for at least six months; that the patient was a frequent attendee (i.e. more than five visits for that symptom in the past 12 months); that there was co-morbidities of depression and/or anxiety and that the patient was a fluent English speaker.

Furthermore, exclusion criteria, also based on the pilot study were given to the GPs in advance and included no current relevant diagnosed physical health problems; fewer than four GP consultations in previous 12 months; no trauma in the previous six months; no current relevant physical disability; no complex bereavement in previous six months; no primary diagnosis of ANY psychiatric condition in the previous 12 months (including chronic anxiety/depression) and/or currently being treated in secondary care; no current substance misuse or in past six months; no diagnosed eating disorder.

Put Figure 1 GP guidance flow chart here

The MUS Clinic patient pathway

Following referral patients enter a pathway containing two phases, including assessment, face to face contact and other communication over a 12 month period. The total face to face contact is 27 hours.

In Phase 1 the patient is referred and a welcome letter/brochure sent as well as text reminders for each appointment. There follows a pre-group telephone assessment with a clinical psychologist for 30 minutes (using standardised clinical tools for depression, anxiety, somatisation and general functioning). Thereafter an individual Intake meeting is held with a facilitator of 30 minutes. Then treatment group commences with sessions12 x 2 hours. On completing the group there is an individual Exit meeting with facilitator of 30 minutes. Then patients attend a further post group assessment with the psychologist using the same standardised instruments as in pre-group assessment to collect outcome data. Their GP is sent the attendance record and an overview of the outcomes post group compared with pre-group.

Phase 2 includes sending a letter from patient to self and at a later date sending a personalised letter from the facilitator outlining their action plan for change which they agreed in the final group session. There follows a text asking them how they are. Depending on their response discharge is advised or a self-help or further facilitated group is offered. Six months post group a follow up assessment with the same tools is conducted with the psychologist. There is a random selection of patients inviting them to qualitative interviews after one year. All patients complete a participant experience form evaluating their whole experience since referral.

Put figure 2 patient journey flow chart here

Lesson learned

Many obstacles had to be overcome during the process of delivering the service in a primary health care setting in the NHS. For example, the name of the intervention to patients had to be modified from 'Learning About Your Symptoms' to 'Symptoms Group' after receiving feedback from patients and health professionals. This name was more acceptable because it addressed their pre-occupation with their bodily symptoms. Significant insight was gained into the terminology most frequently used in health care such as the term 'Clinic'. Consequently, it was agreed that the service would be termed 'The MUS Clinic' to health professionals making it more easily fit within their culture. It is an MUS Clinic within which there are Symptoms Groups.

It was thought to be crucial to re-frame the service to enable access to patients who were resistant to a psychological explanation of the bodily symptoms. This resistance derives from the stigma attached to mental health services and the fear that any label might result from such as referral. These patients have a physical symptom, most do not make any links with psychological/lifestyle to this symptom, at least initially.

There have been difficulties in liaising with the service in primary care for mental health called Increasing Access to Psychological Services (IAPT) which takes referrals for anxiety and depression, some of these patients will also have MUS. However, the IAPT service does not address the patient's MUS but instead concentrate on the anxiety/depression associated with the symptoms. With this in mind the importance of cross referrals has been discussed and avenues opened with other providers such as the well-known London-based clinic The Tavistock.

Other obstacles to be worked around included the GP lack of knowledge about MUS patients. There is no category for collecting data on these patients. They are filed under conditions such as IBS etc. Hence the overall picture remains hidden and GPs are unaware of the scale of the problem. Many GPs appeared to have difficulties in identifying patients with MUS and in making relevant referrals, hence the need for training. GPs appear to be

concerned about missing a diagnosis and the possible legal ramifications. Therefore support in how to consult with such patients is crucial and GPs need reassurance that the service is 'in addition to any other investigations/treatment' rather than as an alternative.

Their culture concerning referrals, their fear of making a mistake as well as indifference to the costs to the NHS of these patients all made it difficult to gather enough referrals at the outset. Furthermore GPs are normally traditionalists and are naturally uncertain of any new service. In order to gain their confidence in this new service, awareness-raising presentations are conducted in which overall outcomes were shared, as well as outcomes for individual patients. GP awareness was further raised and their trust engendered by enlisting an NHS commissioner and GP champion to forward information about The MUS Clinic. It was clearly stated that it was a 'both-and' intervention rather than 'either/or' and that other referrals could be made at the same time if desirable and indicated reducing fears, creating confidence and reassurance.

As a new entrant in the market, and as a social enterprise company offering a new MUS service, there was suspicion as well as the lack of awareness to overcome. Although GPs are accustomed to private services and referring patients to them, they were unfamiliar with the approach and did not feel confident in explaining it to patients. Nor did some appear comfortable with explaining to their patients the fact that there appeared to be no medical explanation for the symptoms.

In order to educate, raise awareness and to support GPs to identify and consult on these matters with their patients and to refer to the MUS Clinic the following strategies were undertaken, for example, invitations were sought from GPs to conduct presentations in their settings. GPs and patients were requested to give verbal feedback on service design and delivery via meetings/phone calls. Referrals were encouraged through letters being sent from the GP Mental Health leads/Joint Primary Care Trust commissioners to GPs. Case Report Forms were designed and distributed to GP practices to gather the frequency of GP

visits and secondary care referrals for GPs to delegate to the practice nurse for completion post treatment so that they could assess the patient benefit and advantages to their practice. Information was provided to support GPs to refer (also available at meetings and on the website). For example, GP and patient brochures about the service were produced as was a GP narrative to support consultation with patients, including a sentence on how to refer and why. A 'tick box' inclusion/exclusion criteria screening tool was developed to assist GPs in identifying suitable referrals. An on-line GP registration for referrals was added to the website together with two five minute videos on TBMA/referral process. A discharge letter with their patient attendance and outcomes data was produced for the referring GP. Finally, we were invited by the local post graduate medical centre to train GPs, and trainee GPs in their final year, in the nature of MUS and the referral system to the Clinic at regular up-dating events/CPD which has helped raise awareness of the problem and our solution, encouraging more referrals from local GPs.

The on-line referral system, set up through the company's management information system was designed to take GP referrals directly (paperless) but required the local NHS information governance security clearance. It was given at level two security for information governance, higher than most GP practices at that time. However, the reticence of GPs to use the on line system resulted in deferring to the GP culture of paper-based referrals which has now been accepted instead of insisting upon referrals on-line.

Very few self-referrals have been made by patients to date. Patients opting to self-refer on line or via the telephone (with their permission the GP would be contacted to confirm a suitable referral) would require a different belief about their symptoms i.e. that their symptoms were more than solely bodily based. However, their explanatory model is that there is an organic cause which has just not yet been detected. A different message such as 'learn to live well with your bodily symptoms' and 'learn to improve your wellbeing' is being disseminated to patients to encourage self-referrals.

Elements in NHS England which supported the delivery of the MUS clinics and TBMA in particular included the lack of interest by patients of enrolling in CBT inherent in this patient population because of the stigma associated with mental health services. TBMA offered patients a choice to avoid the stigma of the mental health route by attending a clinic addressing their physical symptoms in primary care setting instead. Another helpful element in the NHS is the use of the recovery model used in mental health services of which most health care professionals are aware. Some of the aspects employed in the recovery model also underpin TBMA such as the instillation of hope, achieving a better quality of life; diminished symptom distress; feeling more in control; feeling happier; having good health again and/or moving forward with life. Furthermore, a supportive health care system which puts patients at the centre of the system was acknowledged as crucial in the framing of the model. Demonstrating the cost effectiveness of the approach aided GPs and commissioners to accept an otherwise completely new approach to supporting patients with MUS. The clinical assessment tools were selected specifically to reflect those already employed by the 'talking therapies' in the NHS which helped to show parity when evaluating outcomes comparatively. The fact that GPs in the NHS need to receive continuing professional development which takes place, for example, at hospital post-graduate medical centres, and in their practices at lunchtime, enabled presentations to be conducted to groups of GPs on the nature of MUS and the solution proposed by clinical service offered. This facilitated referrals from GPs to the MUS clinic. Finally, one NHS commissioner in particular championed the inception of the service in primary care. He and the mental health GP lead promoted the MUS clinic to GPs to increase awareness and which also resulted in further referrals.

Therefore the contribution of elements in the NHS which supported the provision of the MUS clinic will already be standard practice in many other countries or could be adopted by them to embed MUS Clinics. Consequently TBMA is a transferable model to most health care

systems. There may be some elements, yet to be determined, where the model may need to be modified to fit with local health care settings.

A number of important lessons have been learned so far whilst delivering this new service in NHS England. It is crucial to evaluate the outcomes and the lessons to be learned as a result of transferring research knowledge into real world, everyday practice. Furthermore, it is important to continue to build the evidence base for providers of services via practice-based methods in order to be judged on the efficacy of the delivery.

Case Study 1

MR ³is a 20 year old young woman, living with her mother. Her family was filled with stepand half-siblings. She had suffered continuous physical and emotional violence from her father from a very young age. She had many symptoms, and was confined to a wheelchair. However no medical explanation had been found. She had been referred to neurology several times. Her passion was for horse-riding and previously before being confined to a wheelchair was studying midwifery. Both had been interrupted as she was not safe engaging with either. Several medications were prescribed to help her dystonia, to alleviate the muscle pain, to stop the tremors, to relax her right jaw etc but unfortunately her condition had not improved. Emotionally she was drained both from her traumatic past and from a life confined to a wheelchair.

In the group she showed enormous energy, used her good humour to hide her feelings, and appeared to be incredibly optimistic. She developed new ways of coping with her condition, for example, the relationship to others in the group was important to her given her previous isolation. Furthermore, there was no panic from them or the facilitator when she had fits which was unlike her mother's reaction. The facilitator showed her that she could be in control, despite the facilitator at times not feeling so calm in fact, which helped MR to feel less scared and enabled her to attend to her strength to recover. The facilitator encouraged

³ The name and identifying features have been changed to protect the anonymity of the patient.

her to leave her wheelchair to move on the floor during some sensory-motor exercises which helped her to feel empowered, another resource she could use. The floor is safer than her two legs or her bed. She could make contact with others via feet and hands from the floor. She developed more optimism for the future and became more a part of the group through these experiences. She befriended her body through moving across the floor. Conveying to the group the facilitator's compassion and belief about perceiving the body in a different way fostered a more positive way of living with, and the diminishing of, symptoms.

Through mindful-movement practices the abandoning of the victim position and entering a more active space where the pain is not in charge of the whole body can promote a strengthening of mind so she felt more in control in her body.

She seemed empowered by being allowed to lead others and to mirror movements of her choice, for example. She liked her group from the beginning. As a result of feeling trust in the group and facilitator, after a while she could share both her positive and negative experiences of her symptoms quite freely. In the sessions when her body went into spasm or her leg/arm jerked she got scared and forgot to breathe. Gradually she learned to be guided to recover her breathing by the facilitator gently touching her back and encouraging her to breathe. Her mother was taught by her daughter, from what she had learned from the facilitator in the group, how to anchor her breathing in this way when she had spasms at home. She adapted herself to actively participate in all the group practices such as mindful sensing of the body (e.g. pointing toes/heels), attending to each movement (e.g. walking by stamping on the floor), authentic movement and acting as a speaking witness in dyads from the wheelchair (or by sliding from the chair onto the floor). She became emotional several times during the movement process and learned about moments of intimacy with herself which was also seen and communicated by her witness.

After a few weeks of attending the group, she felt confident enough to go back to horseriding. Her outcomes demonstrated an increase in self- management of her symptoms and

reduced anxiety/depression. She remained on her medication however, did not visit her GP so often even at the six month follow up.

Case Study 2

Lyn⁴ was a middle aged woman in full time employment visiting her GP for overly-long consultations lasting approximately 36 minutes each time. These visits of approximately 13 + times per year were over two years in a GP practice of four GPs in South East England. She presented as tense, a bundle of nerves and complaining of muscular cramps, insomnia, headache and feeling low and tired. She often visited A&E with headaches and muscular cramps.

Her symptoms began after a traumatic event in the past. When stressful situations arose in everyday life she had panic attacks and could not function nor self-manage. She was unable to sleep well, found it hard to go to work as she felt tired and could not concentrate. She had frequent absences from work.

Her GP was unsure whether she needed investigations but sent her for two scans and for blood tests four times. It was made clear by the GP to the patient that the investigations would probably come back negative. When discussed the patient was reluctant to attend CBT as she insisted on a physical explanation for her symptoms not wanting to consider a psychological one. The frequent referrals for tests and scans increased her belief that there would be a physical, medical explanation which just had not been discovered as yet. Her reluctance to engage with psychological therapies was based on her fear that she would be given a mental health label. She explained her depression as being concerned with a reaction to the lack of medical explanation.

Discussions about the possibility that psycho-social causes and stress at work were exacerbating symptoms did not appear to help her to make the link. When she visited the

⁴ The name and identifying features have been changed to protect the anonymity of the patient.

other GPs in the practice she had similar experiences. This was understandable since her GP ensured colleagues had an appreciation of the patient and copied letters to clinicians involved to ensure a shared view that the patient may have MUS.

Her GP documented all contacts with the patient and the action/inactions agreed. The GP continued to discuss the case with fellow GPs and the specialist colleagues. They also had peer collaboration in formal clinical meetings and in informal discussions in order to support the difficult decision of not referring for any more tests/investigations. The GP shared the decision with the patient about why referrals were no longer going to be made and discussed with her the idea of attending a supportive group treatment (The MUS Clinic) focussing on her reducing her symptoms and improving her quality of life as being helpful in the meantime.

The GP used the Pathways2Wellbeing consultation document with the narrative suggested for GPs in order to give her the relevant Information and answer queries so that she was able to participate in a shared decision-making process to attend the group. The GP also ensured safety-netting by developing a contingency plan to inform colleagues about any triggers for a further referral, and to inform the patient about when they should re-present.

Subsequently, with the patient's buy-in, the GP referred her to the group at The MUS Clinic which she attended on 10 out of the 12 occasions. She began to explore her breathing patterns through various breathing exercises. For example, she was curiously looking at the facilitator's modelling and explanation of how to breath properly. She soon realised something was different and discovered the right way of breathing which she practised frequently. This seemed to have given her more vitality for life, contrasting to her fatigue, stress low energy levels especially at work. In the group she looked happier and seemed more energised. She reported to the facilitator and group she was now sleeping better and enjoying work. She said that the new breathing pattern had become second nature to her. She appeared to increase in confidence at every session. She improvised in movement

practices such as stretching and exploring movement on the floor. This helped her to reconnect with her body in a pleasurable way. The facilitator suggested that she move in a dance-like way during one mindful-movement practice. During the following reflections she said that this provoked her recollection of a dance class as a child where she was informed she could not enter the class because she was not 'good enough'. She said that lost confidence in her body and in her ability to move as a result. Through the synchronous group movement circles (Chacian) she found she was well co-ordinated and gracious in her movement, had a good sense of rhythm and could dance! She now enjoys dancing around in her kitchen pain-free! She has reported six months later that the group experience 'changed her life'. Lyn has not needed to return to her GP or A&E again for these symptoms and enjoys a better quality of life. When her symptoms return, which they do from time to time, the bad days are not so bad and she can self-manage them so that she feels far more in control. Her medication for depression and pain relief reduced to almost nil.

As a result there has been increased capacity for her GP and his colleagues. They have been freed up from her frequent visits to see other patients that they can help. The costs for tests and scans have been significantly reduced as the patient no longer insists on these. Medication costs have also been reduced considerably. A&E visits have stopped altogether reducing costs to the GP practice. The frustration felt by the GP in being unable to help this heart-sink patient has disappeared, improving their quality of life and job satisfaction. Lyn only visits the GP on occasion now for different conditions with organic explanations.

Participants, commissioners and GPs comments

Participant experience forms concerning satisfaction with the whole process are completed at the end of the groups. The levels of satisfaction are consistently excellent. Here are some extracts from patients' qualitative comments: 'there were relevant techniques, communication skills, overall wellbeing, and a friendly atmosphere'; 'It was pointed out that I need to think more of myself rather than being involved in other people's problems'; 'I

learned new strategies for coping with my symptoms'; 'It gives me hope'; 'I have an improved quality of life'; 'I will be better now'; 'The facilitator was inspiring'.

Commissioners have been involved since the outset and interim reports have been provided after each group together with a presentation on the whole service delivery. Here are some of their comments:

'We are very impressed with not only the quality of the service being delivered but also the thoroughness and professionalism of the organisation behind delivering this service' (commissioner)

'I can unreservedly endorse and recommend them as an organisation which will deliver their services to the highest professional and ethical standards' (commissioner)

'They have the benefit of having national leading expertise in the treatment of MUS and have proven themselves as extremely capable of running learning/treatment groups for patients and training staff' (commissioner)

'It should be the first port of call, it can do no harm' (GP at a presentation)

'A very valuable service, it has freed up my time, reduced cost of medication and secondary care referrals' (referring GP)

Summary

Setting up a new service is a process, a journey in which adaptations and refinements have to take place which could not be envisaged of when conducting the research. Real-world intervention is quite different from that being undertaken in a research bubble where patients are aspirational often - wanting to help others like themselves, motivated to support the research team and interested in outcomes. Sometimes people involved in roles pertaining to research act differently when engaged in their everyday activity. Research cannot reflect the context of everyday practice just as everyday practice cannot fully represent research.

Obstacles and challenges of transferring research knowledge into real world service delivery and practice can lead to positive developments of the research, sometimes to reductions in the parameters of practice, and/or restrictions in delivery. Patients are not participating in the service for research but for themselves which gives a quite different context to delivery when compared with research.

For the health service The MUS Clinic using TBMA can provide immediate support for the patient, leading to increased time for GPs to help other patients, more patient and GP choice and helping GP practices to meet their Quality Outcomes Framework targets. Once awareness has been raised and understanding generated GPs appear to be more willing to refer patients and receive presentations.

Although it is acknowledged that each country may have a different system of funding from England for health care the adoption of such a model should be easily transferred in the majority. Readers of this journal from such countries might recognise that there are equally receptive settings within which this sort of clinic may be a suitable fit. Conversely this clinic may not be easily adopted in some countries others may require some modifications for it to be successfully embedded. The research had to adapt to the real world of practice in the NHS just as the model may need to be slightly modified to other health care settings. The elements of the NHS in England identified above which supported (and inhibited) the embedment of the model may assist others in modifying it when implementing it within their own healthcare system. This will be another kind of journey in which the developers will need to heed the sub-culture and systems in place when designing the model to suit their MUS patient population's needs and those of their health care system. Most of the changes were superficial such as the terms used to make them more acceptable to health care professionals and patients.

There are now 18 psychotherapists and arts therapists trained as group facilitators in TBMA for patients with chronic MUS. It is anticipated that they will soon be facilitating groups in their locality privately under licence and in the NHS or private health care sectors⁵.

We welcome the opportunity to continue to improve the lives of patients with MUS and are keen to work alongside other providers such as IAPT to improve choice and access to treatment for these patients in the NHS. The MUS Clinic acts as a support for patients and as an entry point to them to enable access to the psychological therapies and compliments once they have completed the treatment groups. In this way the Clinic experience enhances the effects of the other approaches such as psychotherapy or CBT to the treatment of patients with MUS since post group the patients appear more confident of their usage to promoting their wellbeing. TBMA is effective for patients, affordable to the NHS and helpful in delivering savings in both primary and secondary care.

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⁵ Training courses, dates and information can be found at <u>www.pathways2wellbeing.com</u> Or email <u>info@pathways2wellbeing.com</u> twitter @p2w_Itd

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