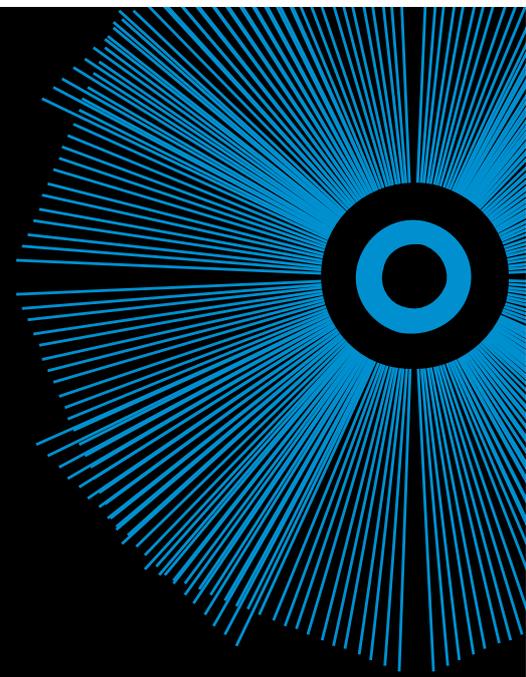




**Shine**



# Shine 2014 final report

Project title:

**Innovative and integrative care pathway  
for patients with Medically Unexplained  
Symptom conditions**

Organisation name:

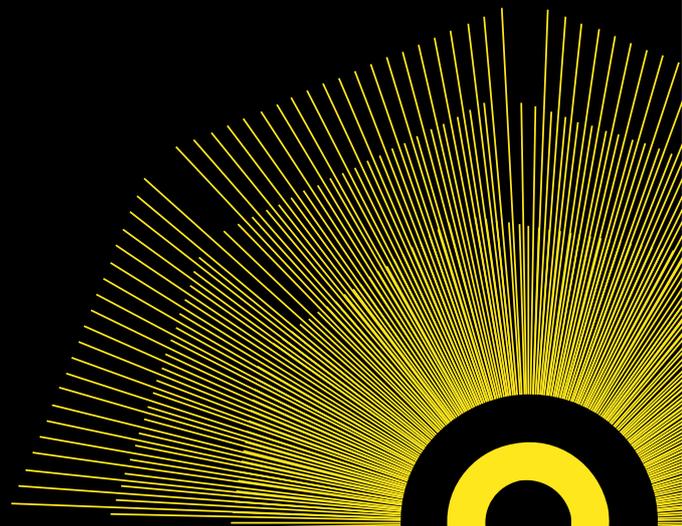
East London NHS Foundation Trust

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September 2015

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The Health Foundation  
Tel 020 7257 8000  
[www.health.org.uk](http://www.health.org.uk)



## Part 1: Abstract

**Project title: Innovative and integrative care pathway for patients with MUS (Medically Unexplained Symptoms) conditions**

**Lead organisation:** East London NHS Foundation Trust

**Partner organisation:** NA

**Lead Clinician:** Professor Frank Röhricht, *MD FRCPsych*

### Abstract

Currently, patients with MUS (also called somatisation disorder or “functional symptom/distress disorder” in newer classification systems) have unmet health needs as a result of incorrect diagnosis and because it is often difficult to engage these patients in holistic care. Consequently treatment is often ineffective despite frequent presentation at primary and secondary care services, resulting in high cost pressures to the health economy. Existing models have not met the complex needs necessary to achieve positive health outcomes for this group

The Health Foundation funded trial project evaluated the feasibility and explored the cost/clinical effectiveness of a novel care pathway that provides a holistic Primary Care service. Health care for patients with MUS was delivered in a “one-stop-shop” fashion in GP surgeries including the following steps: Identification, Assessment, Engagement and Group Interventions – Mindfulness Stress Reduction (MBSR) and Body Oriented Strategies for Better Living (SBLG). Both interventions were entirely focused towards helping patients to improve their overall coping and to foster wellbeing, without challenging and patient’s health beliefs and or explicitly working psychologically.

The findings of the project analysis demonstrate that despite difficulties regarding GP and patient take up / acceptance, patients who participated in the project gained significant improvements in symptom levels and this resulted in corresponding significant reduction in health care utilisation (GP contacts / consultations and referrals to specialist services).

In our project a total number of N=145 patients were referred and assessed for eligibility, and N=93 were included in the trial intervention; N=18 declined to participate, N=31 did not attend baseline assessment, three patients did not meet inclusion criteria.

In addition to receiving an in-depth comprehensive and psycho-educational baseline assessment of their condition, 61 patients took up the offer to participate in one of the two group interventions (N=44 SBLG, N=17MBSR).

We collected outcome data for all 93 patients from GP electronic recording systems (service utilisation) and through questionnaires (symptom levels and health-related quality of life).

The analysis of qualitative data (feed-back from patients, therapists structured accounts) suggested that patients who participated in the intervention had additional health benefits in terms of a more inclusive understanding of / insight into their health condition and improved self-management control / coping skills.

Experience from a nationwide pathfinder project in the UK suggests that patients with MUS from ethnic minorities are very difficult to engage and even less likely to benefit from the treatments. In this project about 75% of patients included were from ethnic minorities and a high percentage had very limited English language skills; the findings of the study indicate that the novel care pathway can successfully provide care for this difficult to engage patient group.

Some systematic and significant barriers as well as enablers to pathway implementation and also in respect of patient identification and patient uptake of the intervention were identified and will be included with the teaching and training package of the revised care pathway specification.

## Part 2: Quality impact: outcomes

*Course of the care pathway delivery with interventions, and adjustments made throughout the project:*

Half-way through the project life time it was decided to expand the number of project sites and to include another large surgery with a list size of over 10k patients for two reasons: 1. the recruitment figures were lower than anticipated and 2. The ethnic distribution of those referred to the project appeared to be too one-sided with more than 80% of patients from Bangladeshi and Pakistani background and corresponding difficulties of very limited English language skills.

### Identification and assessment:

Applying systematic healthcare technologies, a case-finder system was implemented by the project research assistant (doctor) at each participating surgery, utilising an algorithm for patient identification and sign-posting to the project. Criteria for identification (same data collected for pathway evaluation) included clinical characteristics (see appendix) and high level of service utilisation in the absence of coded significant and associated physical health diagnosis.

The project plan aimed for continuous education/up-skilling of the participating general practitioners with the view to improving their abilities to correctly diagnose/identify and engage MUS sufferers. A key learning point from the first 3-4 months of the project was that GPs did not have enough time to fully implement an active case finder system which is why the emphasis shifted towards engaging practice managers and help them to apply the case finder algorithm to identify potentially suitable patients.

### Engagement:

Given the specific characteristics of this patient group and their health/explanatory beliefs, a range of active engagement processes was employed, including specific information leaflets distributed by the GP, weekly patient health advice/psychoeducation groups, hand-outs with educational material regarding the nature of the problem for patients and posters advertising the care pathway for self-referral in surgery waiting rooms.

The attendance at the scheduled psychoeducation events was very low despite the fact that they were delivered at GP surgeries close to patients home. Feed-back from service users suggested that time constraints (family commitments during the day), language barriers and also a lack of understanding regarding the nature and purpose of these events were the main reasons for non-attendance. The project shifted therefore its emphasis to providing participants during the baseline assessment session with educational materials to take home. This part of the care pathway requires better engagement from practice staff (particularly nurses and GPs) to encourage and motivate patients to engage in these activities.

### Interventions:

During baseline assessments all patients were offered the opportunity to take part in a group intervention of 8-10 sessions (weekly) based upon an informed choice of either MBSR or

SBLG. Participation in the intervention (2.4 sessions mean attendance out of 8/10) was compromised due to a number of barriers such as the fact that no evening sessions could be offered, premises at GP surgeries sub-optimal, cultural barriers (women from ethnic minority background not prepared to attend mixed gender groups), etc..

### **Outcome measures & Findings:**

Outcome measures were defined prior to establishing the project and adhered to throughout; following initial assessments the measures were reviewed and it was decided to drop the one scale and to concentrate the Subjective Quality of Life measure towards the 'overall health today' rating (from the EQ-5D scale) without making any other changes to the planned evaluation strategy (assessments at baseline and follow-up for all patients regardless as to whether they only received assessment / psychoeducation or participated in group intervention).

These are the specific assessment/rating instruments used to assess patients:

- Number of patients accessing specific group intervention and their experience in doing so (quotes from patients on free space provided on Client's Assessment of Treatment (CAT) questionnaires, summarised according to themes)
- MUS specific symptom improvements: symptom questionnaire Primary Health Questionnaire (PHQ-15) and health-related quality of life questionnaire: Health Survey Form (SF-36). The other symptom measure (Somatic Symptom Scale, SOMS-7) was only used to characterise the severity of the MUS condition in this sample at baseline (only completed at follow-up by small number of patients).
- Subjective overall health related quality of life: EQ-5D health status measure
- Patient's evaluation of treatment by Client's Assessment of Treatment / CAT scale.

All participating patients were offered the opportunity to be seen in person for a follow-up assessment and interview; those who did not attend twice received questionnaires (PHQ-15, SF-36 and CAT for self-ratings/assessments) by mail.

### Data quality, reliability and validity:

All measures used in this study are instruments with established track records in health care research and also specifically in the area of somatic stress disorder / MUS; their psychometric properties have been tested and they have good validity/reliability. Self-ratings / assessments obtained from questionnaires were directly obtained through guided face to face assessments at baseline where service users had the opportunity to discuss any questions with the researcher for clarification of the questionnaire items. Those who received the questionnaires for completion by post were already familiar with the instruments from the baseline assessment. Service utilisation data was collected from ("EMIS") electronic patients record (GP time per activity calculated according to NHS references/unit cost data information, including the following activities: surgery consultations / telephone contacts, GP letter, home visits) according to a modified version of the Client Service Receipt Inventory tool.

## Results:

The information regarding study recruitment data / process is summarised in the CONSORT diagram flow chart in Figure 1.

Out of 145 referred patients a total of 93 patients with a wide range of MUS conditions were included for participation. All patients fulfilled the main inclusion criteria, i.e. presenting with physical symptoms not explained by any organic pathology (as established through GP assessment). The most frequent conditions included chronic/generalised aches and pains, headaches, back pain and fatigue as well as more specific conditions such as Irritable Bowel Syndrome, Fibromyalgia, and Chronic Fatigue Syndrome.

### Patients clinical and demographic characteristics (N=93, some data missing):

Mean age 48 years (range 21-75); Female 76 (81.7%) and Male 17 (18.3%); Ethnicity: White British 17 (18.3%), White other Caucasian 7 (7.5%), Afro-Caribbean 6 (6.5%), Black African 10 (10.8%), Indian 11 (11.8%), Pakistani 16 (17.2%), Bangladeshi 23 (24.7%), Chinese 1 (1.1%), Arabian 1 (%).

The majority of patients (N=59, 63.4%) was unemployed, and patients reported to receive state benefits as follows (N=): State retirement 6, Statutory sick pay 9, Working tax credit 9, Housing benefit 41, Council tax benefit 35, Disability living allowance mobility component 12 and Care component 10, Incapacity benefit 5, Income support 20. Most patients (N=68, 73.1%) confirmed that they received family support in relation to their health problems; the mean number of hours was reported as 19 per week (varying from 1-84 hours).

Somatic symptom levels at baseline assessments were extremely high by comparison with findings from other studies in this patient population. The data for PHQ-15 on somatic symptoms from questionnaires was completed on baseline and at follow-up by 44 patients. The results are summarised in table 1 and 2 (paired-samples T-Tests):

Table 1: clinical baseline (pre) and follow-up (post) data comparison (somatic complaints and quality of life scores)

	<b>PHQ-15 Total symptom score</b>	<b>SF-36, QoL Physical health component</b>	<b>SF-36, QoL Mental Health component</b>	<b>EQ5 Health score</b>
Pre	18.3 (5.5)	25.7 (23.1)	36.6 (24.9)	39.9
Post	14.9 (6.9)	34.4 (36.0)	45.0 (30.3)	45.9
T/df	3.7 / 43	-.2.1 / 43	-2.2 / 45	1.4 / 49
p	0.001	0.045	0.056	n.s.

Table 2: service / support utilisation baseline and follow-up data comparison (mean / sd)

	Number contacts with GP	Number contacts specialists	Number A&E visits	Number Physio-therapy sessions	Number hours Family support	Number prescribed medication
Pre	14.5 (10.3)	3.1 (3.0)	0.9 (1.5)	1.8 (3.3)	16.6 (21.8)	4.1 (2.5)
Post	9.8 (6.6)	2.4 (2.4)	0.4 (0.8)	0.4 (1.2)	15.1 (22.6)	4.3 (3.9)
T/df	4.9 / 87	2.3 / 86	2.8 / 85	4.3 / 88	.08/ 31	-.39 / 89
p	0.000	0.022	0.007	.000	n.s.	n.s.

#### Further analysis of patients in group therapy

For the group of 61 patients who accepted to participate in the group intervention, the number of sessions attended varied between 1-10 (max. offered), mean: 2.4 sessions. Comparing outcomes for those who attended a minimum of five sessions (N=24), hence having been exposed to the intervention, a positive trend in terms of better outcomes on all measures (symptom levels, quality of life scores and service utilisation) was observed, the results however did not reach statistical significance due to the small sample size. Analysing the Client's Assessment of Treatment scores showed high level of satisfaction with the intervention and the qualitative analysis of patient's statements revealed the following themes regarding therapeutic benefits: shared understanding of problems with other patients, better coping with symptoms, learning new skills, feeling accepted with problems, symptomatic relief, empowerment, learning how to help myself.

(a detailed account of patient statements in table 3)

Client's assessment of treatment scores obtained from 36 patients who participated in the intervention demonstrated good satisfaction levels with the group programme (mean scores across all questions 6-7/10); the question "Has treatment/care here been helpful for you?" had the best response with a mean rating of 8.9/10.

The majority of these patients (77%) answered that they would want to attend more sessions if offered to them.

The therapists summarised the change processes they noted as follows (extracts):

#### *Therapist 1 (SBLG):*

The patients who attended these groups seem to have particularly benefitted in four areas:

1. Learning how to conduct and utilise breathing properly and experiencing the positive impact of the breath in controlling pain, reducing stress and relaxation.
2. Connecting with negative emotions such as anger, frustration and fear through specific structured tasks that validated these feelings and allowed them to be expressed in an active way so that they were no longer repressed and held in the body

3. Making a connection between the pain, feelings and experiences, i.e. that the pain is often negatively affected by stressful experiences and vice versa.
4. Sharing these experiences together in a group and not feeling so isolated made the patients feel much better.

*Therapist 2 (SBLG):*

The participating GP practices in the project were located in Newham, East London, where a history of migration into Britain dates back centuries. Patients from diverse cultural backgrounds were referred to the mixed gender sessions but the prevalent cultural group attending the groups were female members of the Bangladeshi (Muslim) community. For most patients, participating in a group of this style was described as a new experience. As common ground was sought, sharing a dialogue of their experience of physical pain became the initial foundation for group cohesion. In time the groups allowed this to shift from the identification of physical symptoms into the wider realms of the narrative of their emotional suffering; at times dependent solely on group metaphor but occasionally taking bold steps to frame the individual autobiographical process within.

It was clear that despite a revered shyness, and the newness of the language skills proposed in the group, most of the women participating in the work benefited from being in an all-female environment. Some were able to concretely define how they would be unable to speak if “men were here” and often descriptions of wedding dances, where women and children would celebrate together were evoked, validated and reframed. Many expressed how their initial journey to the UK had not been one of choice but one of legacy; committing to prearranged marriage requests to men already living in the UK.

The group and individual metaphors that were found and shared bridged the work towards the potential for individual change, growth and empowerment. Imaginatively women collectively grew “new plants”, taking turns to add the light and water to nature growth. Loss was mourned, and even symbolically laid to rest. And people allowed themselves to return in mind and spirit to a place where they had been well and everything had been ok.

Participants left with a new set of tools, potentially a new way to language their pain and move forward their experience.

*Therapist 3: (MBSR):*

A problem that was persistent throughout the year was poor levels of attendance despite apparently healthy recruitment numbers. I feel that there are a number of reasons for this. Some attendees struggled with the practice exercises due to poor mobility and so an opportunity to work with this is likely to be of great benefit to the group.

A further improvement for mobility problems would be to source a building that is ground floor with disabled access. Access was limited to the surgery where the group was being held - the first floor. Two participants dropped out because of this.

Another area of improvement would be a pre-session meeting to undertake psycho-educational work, offer Q&A, undertake a risk assessment and to use some clinical measures for mindfulness measured by compassion.

There were aspects of the year that went very well. The practices were well received. Feedback about practice was always positive for those who attended. Those who attended the first 3 sessions tended to finish the group.

It felt like the groups that had 3 or more regular attendees experienced extra benefit from rich learning achieved through extended narratives linking practice to problems during practice enquiries. One participant reported that the course had inspired her to change her life (mindfulness can bring about various positive effects on the psychology of self). This includes increased wellbeing, reduced psychological symptoms and emotional reactivity as well as improved management of behaviour.

In my opinion, the year has been enormously rewarding and supportive of well-being for the group participants and the writer. A lot has been learned that would benefit further study in

this area. There are numerous learning edges as discussed previously. I feel that further funded study and the opportunity to do so would be extremely beneficial for the health and well-being of residents of Newham.

*The research assistant (doctor in psychiatric training):*

Initially, there was a lack of engagement from some surgeries taking up the project, and referrals rates varied substantially across surgeries. It required a number of meetings in order to engage surgeries more.

The surgery generating most referrals was also the busiest one, and there was a weekly challenge of needing to ask several trainee doctors whether they could vacate their room in order for me to use to assess referred patients. Changing to a Saturday clinic meant that this was solved, while it also had the unexplained result of clinics being well-attended by patients who were not able to attend during the week for various reasons.

I have found that uptake by patients has been variable. It particularly helps when I explain that, whilst I am a psychiatrist, for the purpose of this service I am not working as a psychiatrist but in the field of "well-being", which patients seem to appreciate and praise the surgeries / service for having such perspective, rather than strictly medical management.

Something worth looking at is the matter of choice. People with primarily rumination problems tend to opt for MBSR, and people who primarily identify with a problem in their physical body, tend to opt for SBL, and perhaps this could be included in the discussion. This is only a very small tendency, but it may be important to note that people who are more insightful about the role of rumination on physical symptoms, are more likely to want to target causes rather than only coping with the physical symptoms, which is what the less psychologically minded people tend to opt for.

Factors playing a part in people's attendance included assessment and treatment sessions coinciding with children finishing from school, Muslim prayer times, and lunch. The fact that people were assessed from a wide number of surgeries meant that some patients were assessed at surgeries whilst being offered treatment at other surgeries. Patients, particularly those with mobility problems, explained that it would be difficult for them to attend treatment sessions at surgeries other than the surgery they are registered with, due to limitations with their ability to use public transport or travel the distance. A number of people were returning to work or on work placement or work-related training, and quoted this as the reason for their inability to attend.

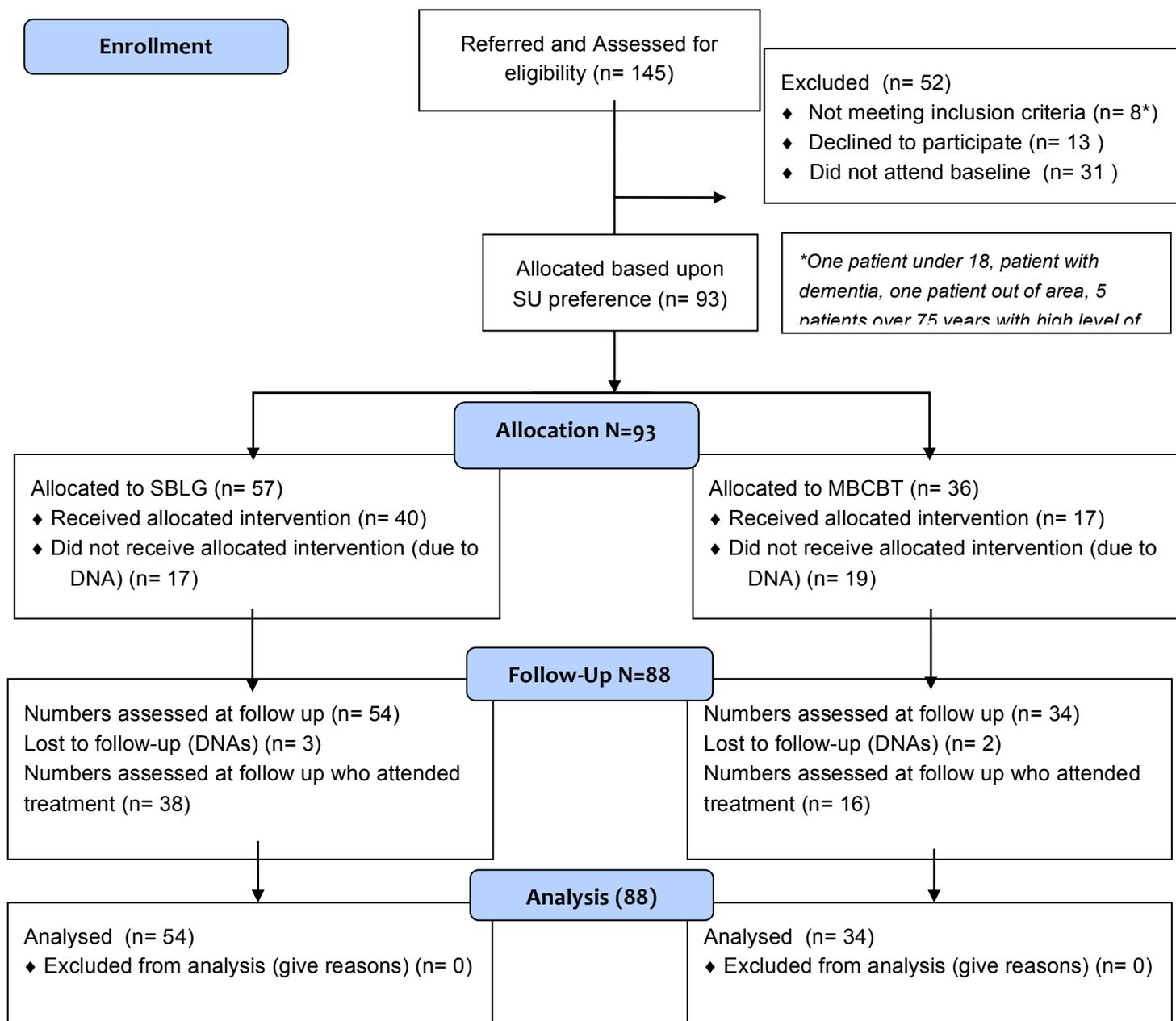
The amount of information required (questionnaires at assessment) may seem to be of high volume, and it does take up a little more than 45 minutes per patient, considering that patients also wanted to provide their stories and additional time was required to explain the treatments on offer and to take informed consent. A further challenge was language, given the large South East Asian population in the catchment area, some requiring interpretation by professional interpreters or family members, and at times requiring rescheduling for a second appointment.

It was noted (during follow-up sessions) that a number of Muslim female patients were grateful for their group to be female-only, as they could be "more free" to express themselves. In general, participants were grateful for the group aspect as they felt they could listen to other people's problems, which had the effect of putting their own problems into perspective, whilst also being listened to and taken seriously by others - including by the therapists who were all described as "very nice, very helpful and very engaged" in their care.

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**Figure 1, MUS-SHINE Final Report**

*Frank Röhricht & Nina Papadopoulou*



**Table 3: statements obtained from patients after attending the group intervention programme (MBSR or SBLG, SHINE-MUS project).**

Themes, interventions etc perceived as beneficial:
“Coping with the pain. The pain is still there but I don't get frustrated.”
It was good to talk to somebody but I also need to relieve my pain. I most enjoyed that she listens to your problems.... I enjoyed sitting and doing massage on my own body with a ball. I enjoyed several exercises including standing on which colour I feel like. I enjoyed the women-only group go as I felt that I don't have to be shy or restricted.”
“The good lady, she liked moving, crossing and jogging. Would have liked it is to be nearer to home. It has greatly relieved my problem with chronic constipation.”
“I enjoyed going there to meet other patients and to get involved in other activities. The people and the lady were very nice. It is very helpful but my problems are not going away.”
“I am now helping myself rather than depending completely on family and I'm able to cope better with the symptoms.”
“I liked the meditations. I started getting my tension under control and things didn't get to me no more. I felt I was doing so well the world looked like a beautiful place all together. If I haven't done the course I wouldn't have gained these skills.”
“I enjoyed two exercises: one with the ball on the back and one dusting off closes as if holding it from four corners, it helps to relax the muscles.”
“During the group the pains goes away but at night they return. I generally feel more relaxed when doing the exercises. I am doing the exercises at home. I feel that the exercises helped significantly reduce the pain for several hours and then come back at night.”
“I have enjoyed every moment. It was useful to find out that there are ways in which I can exercise without moving much. When I was there I found I was not the only one going through these problems which I think are unexplained.”
“I came for coping strategies to manage my anxiety and stressful feelings. I learned not to be negative about the therapy end to give it a chance end continue”.
“I came because I needed help solving end understanding my mental and physical problems. I learnt how to fix my problems and how to be a better person. It is the only thing that has helped me solve some of the biggest problems in my life.”
“I have learnt to cope with my pain and stress. It was a benefit to me as I have learnt to manage my pain and stress through the program. I will continue to use strategies to help me deal with any future pains.”
“It made me realise I was in denial about the wider picture of my life.”
“Out of coming I got really some way of handling my pains, I learned how to use my breath of handling the pain sitting and standing... I learnt what I have never used to handle my pains. I have improved a great deal I have been in pain clinic before it did not work.”
“I learned to be kind to myself....It has really turned my life around and empowered me.... Really, mindfulness has changed my life for the better and others comment on this change as it is visible.”
“I found to be coming to the mindfulness sessions gave me a better perspective and gave me some coping strategies. I find the breathing exercise a good tool for lowering stress levels also be guided body scan was useful for me.”

<p>"I enjoyed exercises: breathing, ball to support back pain, stretching exercises. Group session was enjoyable and I can't really fault any procedures. I would suggest to continue the exercises to help with my health condition better".</p>
<p>"I like meeting the group and the discussion we had. The group can't help you with your problems you've got, as a result it looks like wasting your time".</p>
<p>"Learning a new way to help me in bettering myself that costs nothing and is always available. I enjoyed exploring my thoughts and feelings with the therapist and not be judged (there is no wrong answer). Sadly by week six I ended up alone with the therapist, this disheartened me a little...I think the course should have been longer or a part as it ended and I feel I want further training".</p>
<p>"I liked the fact that there were other people in the group that were also suffering from similar conditions. I think 8 weeks is too short, it went really fast".</p>
<p>"The therapy was very easy to master and I felt able to carry it out easily while others struggled. I felt immediate effects of a positive nature and it made me question my life choices involving my health and inspired me to make changes. It really helped me to move forward and refocus on what really matters in my life: my health!"</p>
<p>"I found new ways to cope with my emotions when interacting with other people".</p>

## Part 3: Cost impact

Analysing the cost impact and the clinical cost-effectiveness both the health gains and their implications and the cost associated with / necessary for the delivery of the novel care pathway have to be taken into account.

Non-health care costs associated with the health condition include social care costs, the secondary costs resulting from family/friends who provide support and (even though not only and primarily as a result of the MUS health condition) to a certain extent also the costs to the wider economy in terms of unemployment rates and state benefits paid. Given the short-term nature of the intervention significant impacts upon this expenditure could not be achieved through this project and as predicted no changes in unemployment rates, access to state benefits were observed; neither did the hours of family / friends support reduce from baseline to follow-up.

In respect of health care expenditures we conducted an analysis of costs resulting from service utilization according to data from GP electronic files, comparing the overall health care costs for the patients in the study sample over a period of six months prior to the baseline assessment with a six months period after being enrolled in the study project. The analysis refers to NHS unit costs as per standard documentation, listed here for all services included with the analysis:

### Unit Costs of Health and Social Care 2014

- Compiled by Lesley Curtis (Personal Social Services Research Unit Cornwallis Building The University of Kent)
1. General Practitioner Unit costs:
    - Per telephone consultation lasting 7.1 minutes: £28
    - Per surgery patient contact lasting 11.7 minute: £46
    - Per clinic patient contact lasting 17.2 minute: £67
    - Per minute of patient contact : £3.90
    - Therefore: Average per contact = 12 minutes = £46.80
  2. Outpatient procedures (costs including qualifications given in brackets)
    - Weighted average of all outpatient attendances: £109
    - Registrars £40 (£60) per hour (48 hour week)
    - Associate Specialist: £97 (£124) per hour (40 hour week).
    - Consultant medical: £101 (£140) per contract hour.
  3. A&E Average cost per person £100
  4. Counseling services in primary medical care: £50
  5. Community physiotherapist session: £32 per hour

## Cost estimates for 88 patients

(pre=baseline, post=follow-up, mean/sd, paired samples T-Test):

	Number contacts with GP	Number outpatient appointments	Number A&E Attendances	Number Counselling sessions	Number Physiotherapy sessions	Number prescribed medication	Total
Pre	14.5/10.3	3.1/3.1	0.8/1.5	0.5/1.9	1.8/3.8	4.1/2.5	
Post	9.8/6.7	2.4/2.4	0.3/0.8	0.3/1.7	0.40/1.2	4.3/3.9	
Unit cost	£46,80	£109	£100	£50	£16		
Total Cost pre	£59.717	£29.735	£7.040	£2.200	£2.534		£101.226 = £1.150 per patient
Total Cost post	£40.360	£23.020	£2.640	£1.320	£563		£67.903 = £772 per patient

Overall reduction in health care cost from baseline to follow-up: £33.323 (£378 per patient)

The biggest amount of spending from the Shine award budget was related to the cost of the researcher (Speciality Doctor) and only those aspects of the researcher activities directly related to the delivery of the care pathway (training of primary care staff and psychoeducation of patients) constitute input costs relevant for a business case arguing for sustaining the intervention. Given the learning from the project those activities could be picked up by a Clinical Psychologist with specific expertise in MUS conditions.

We calculated that a Band 7 Psychologist with 0.5 wte at the cost of appr. £21k could deliver the care pathway as per study population covered (plus one-off implementation funding in order to train staff and to implement the case finding system).

The potential cost benefits to NHS outweigh the input costs required. NHS Commissioning support for London conducted an analysis following a pilot in London with six GP practices looking at 24 months retrospective activity for patients with severe MUS. 80% of this cohort had secondary care referrals and the associated cost was £300k (range from £33 to £20k per patient, average across the cohort was £1.5K, hence £750 per annum, a third of this total cost was in GP time alone. Recurrent funding can establish a more robust care pathway and is likely to include and engage more patients with more substantial and lasting health benefits, resulting in even better cost- and clinical effectiveness (better use of resources).

## Part 4: Learning from your project

### Learning from the SHINE-MUS project:

Our project proposed to establish a care pathway that provided a holistic Primary Care service which would offer Identification, Assessment, Engagement and Treatment to patients with MUS. Overall we achieved what we set out to achieve although, as we implemented the project, we had to make modifications in some areas, some of which we had anticipated in our original application, i.e. in the engagement of GPs and patients and in the treatment programme offered to patients, and others which were not anticipated, i.e. staff illness.

#### Enablers:

Our NHS Trust:

East London Foundation Trust staff provided solid background support to the SHINE MUS team. They assisted and advised in relation to HR matters in employment and contracts as we employed three members of staff, had to deal with long term illness and setting up a bank contract for a new member of staff. We also received excellent financial management support which was offered to the Project and Clinical Lead and Project Manager by the ELFT Specialist Services Finance Manager.

The support and advice we received throughout the project from our Healthcare Consultant from Springfield Consultancy was invaluable.

The project had a small staff of very dedicated professionals with different roles who all worked together very effectively. These were:

Project and Clinical Lead, overseeing and advising on whole project;

Project Manager: attending to the day to day setting up and running of the project; Specialist Doctor/Researcher working directly in the GP surgeries engaged in patient recruitment, identification and assessment;

Two psychotherapists: one delivering Mindfulness Stress Reduction Groups (MSRG) and the other delivering Strategies for Better Living Groups (SBLG).

The GP leads of a cluster of 6 GP surgeries were keen to embed the project in their surgeries as, after presentations and training by the Project/Clinical lead and Project Manager, they realised the potential benefit of the interventions for their patients. The GP surgery administrative staff were very helpful in setting up clinical consultation and therapy rooms, finding storage space for props, and generally ironing out admin issues that arose in relation to patients attending for appointments either to see the specialist doctor or the therapists.

All those involved in the delivery of this project realised the enormous benefit it could bring both to patients, in terms of managing their health problems more independently and more effectively, and to GPs in terms of offering this 'very difficult to treat' group of patients other treatment options, thus reducing their dependence on GP and specialist consultation time.

#### *Challenges:*

There were several main challenges, which slowed our project down rather than stopping it from being successful.

1. A central member of the small MUS SHINE staff was, completely unpredictably, diagnosed with a severe physical illness three months into the project for which she required extensive treatment and had to leave the project immediately. We were able to re-jig the budget, which enabled us to pay both the statutory sick leave benefits to our sick staff member and employ a replacement for her. This delayed us by three

months as it took some time to for us to employ a new member of staff, induct her into the project and arrange her payments against the budget.

2. In principle, GPs were very enthusiastic about the project (as mentioned above). However there were a number of difficulties that they faced that prevented them from referring higher numbers of patients to the project. The first is that they (GPs) operate under intense time constraints, thus not allowing them to dedicate enough time to running the identification algorithm. Also the day-to-day running of surgeries is so tightly managed that it leaves hardly any room for research into additional treatments/interventions. The innovative approach our project was offering is a much more holistic approach and did not adhere to a traditional medical model. GPs were not always able to explain fully the interventions and benefits of this approach to patients. Some patients therefore did not have trust in this new approach.
3. Following on from 2, patient engagement was very challenging as the narrative for understanding their MUS is based on the medical model. Offering a holistic treatment was not always readily and positively received.
4. There were three strands to the treatment programme, i.e. two group interventions and a psycho-educational self-help group facilitated by the Specialist Doctor. It was found that patients did not make use of this group, so this psycho-educational information was disseminated in leaflets and as much as possible through primary care staff (following our teaching sessions and ongoing educational inputs).
5. DNAs in treatment groups: this was a noticeable problem in the running of the groups and for some groups we introduced an extra dimension of phoning patients to remind them to attend their sessions; this also offered us an opportunity to find out why they were not attending (mostly due to family commitments, difficulties getting to the groups during day hours and functional disability due to illness/pain problems).
6. DNAs in post treatment assessments: we decided to post a pack of re-assessment forms to patients if they had been unable to attend their re-assessment appointment.
7. Many of the patients who were referred were non-English speakers. This created some difficulties for the therapists especially as in each group there could be up to 3-4 different languages spoken. However as our care pathway included a very large non-verbal component the therapists very courageously worked with this. However, it is likely that if the patients had had a better command of English they could have benefitted far more from the interventions.

#### If we had to redo the project, plans for the future:

More in depth training sessions for GPs in how to engage and encourage patients to attend a new pathway and to understand the requirements of research would have been helpful.

We are keen to spread the innovative pathway we have developed and to this end we have submitted an application to HF to do so. This application has been successful and we will be holding a conference on MUS both nationally and regionally and we will train the workforce, both GPs and therapists to be able deliver this treatment pathway over 2016.

We are planning to engage with local and national commissioners regarding the development of this care pathway as the pilot revealed promising findings in respect of its clinical- and cost-effectiveness; in doing so we are implementing other learning points for the care pathway configuration:

1. Set-up phase in GP surgeries:
2. Some patient quotes showed a thirst for a deeper level of 'immersion' in the intervention: it seems that some patients were slower to respond, initially, to the intervention (partly due to language and cultural issues) and others struggled to

sustain the physical benefits they experienced outside of the therapeutic environment. Therefore our plans for sustainability include options for prolonged exposure to the intervention for individual patients, built into a clinical review process, offering initially 8 sessions only in order to establish early response and engagement characteristics individually and offering those patients who showed early benefits and/or actively indicate their motivation to continue with the intervention a total of 20 session.

3. In order to enhance patient adherence to both the psychoeducation sessions and the intervention group the initial contact and exploration of somatic complaints (structured interviews, questionnaires) will be conducted by the group therapists / facilitators instead of a doctor (as per research protocol) so that therapeutic engagement starts with the initial contact. This will also help the therapists to gain a deeper understanding of patient's problems. Applying a flexible approach, this should also include short joint appointments with patients with both GP and therapist being present (i.e. GPs utilizing their ordinary 10 min appointment slots together with therapist and leave then the room to see their next patient, whilst the therapist continues with the assessment of complaints and needs)
4. Flexible time arrangements for all sessions must be provided including an option for out-of-hours.
5. Choice of female only groups (particularly in areas with high percentage of Black & Ethnic Minority populations)
6. Setting for interventions in GP surgeries: aiming for a welcoming and understanding staff attitude and an adequate therapeutic environment for the intervention groups.

## **Part 5: Plans for sustainability and spread**

Negotiations with commissioners are under way to sustain the care pathway delivery in Newham where the pilot study was conducted (i.e. integrating the intervention with a musculoskeletal care pathway in primary care). In addition, ELFT is going to submit a business case proposal for the care pathway to its other commissioning partner organisations across East-London, Luton, Bedfordshire and Richmond.

Given the outcomes of the study we are confident of wider interest in adopting the novel care pathway approach and in providing the corresponding interventions. Therefore we (successfully) applied for a "Spreading Improvement: Supporting dissemination" grant from The Health Foundation and the plan for spreading / dissemination agreed with the Health Foundation for 2016 will include the following objectives and corresponding activities:

Our objectives are to:

- disseminate the findings of the Health Foundation funded clinical open trial (national information show-case event conference in London)
- raise awareness amongst major stakeholders in respect of the scale of the problem, associated burden to the health economy, specific clinical needs of the patient population and possible solutions in terms of care pathway developments
- enthuse commissioners in respect of setting up a novel and innovative care pathway that combines clinical and cost effectiveness and stands good chances of reducing expenditure

- gather a group of interested and dedicated GP mental health leads in order to develop champions for further spreading/implementation (local half-day show-case event through London Region Strategic Clinical Network for GPs)
- contribute to up-skilling primary care practitioners (GPs, practice nurses)
- develop the workforce for the delivery of the novel body-oriented interventions for MUS sufferers (MBSR therapists and specific teaching/training schemes already readily available)
- develop an information and networking platform for clinical staff and service users

We will embed the spreading of findings in the context of the wider evidence base relevant to providing clinical and cost effective care pathways for MUS sufferers and present the study results at Primary Health Care conferences (e.g. RCGP national event 'Energising Primary Care' in October 2016).

The teaching and training package will include:

- Guidance for commissioners (Clinical Commissioning Groups) about the logistics and technical/staffing requirements for local implementation of the care pathway and a cost-benefit analysis for an invest-to-save initiative. This will include an in-depth analysis of barriers and enablers for successful implementation of the care pathway.
- A training package for providers (GP surgeries) that will educate general practitioners and primary care nursing staff as well as practice managers to gain a comprehensive understanding of the nature of the clinical characteristics of the specific patient population and their corresponding care needs:
  - A.) modules regarding effective clinical engagement skills for this patient group with specific examples of solution focused / motivational interviewing;
  - B) training in a tailor made psychoeducation tool and delivery of corresponding teaching materials, patient leaflets and hand-outs;
  - C.) manual training for the delivery of “Strategies for better living groups”, tailored towards the specific characteristics of this patient group, utilising the existing evidence base regarding body oriented psychological therapies.