Managing Patients with Complex Needs in Primary Care

<table>
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<th>Presentation Slides</th>
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<td>Dr Rhiannon England</td>
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<td>Philippa Bolton / Claire Braid</td>
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Introduction: why changing the way we manage patients with complex needs in primary care is important for the future survival of the NHS

Dr Philippa Bolton
Clinical Lead for Primary Care Mental Health
Building Blocks

High intensity work
Specialist psychotherapy, liaison, acute trust clinics

Moderate intensity work
Physiotherapy, OT IAPT

Low intensity work:
Social prescribing, Patient groups, guided self help, IAPT

Primary care management:
GP and patient education and resources.
"It’s nice to be told: 'We want you to do these activities because we know you can' ... it's a form of encouragement. Drugs are telling you, 'You are ill' ... but activities are telling you 'You can do things'. You can get the right support."

Focus group participant
Commissioning for patients with complex needs in primary care

Dr Rhiannon England
GP Commissioner NHS City & Hackney CCG
Commissioning to address medically unexplained symptoms

Rhiannon England
GP MH lead
City and Hackney CCG
What I will cover

• Why are MUS important?
• What we have done locally
• How we have implemented changes
• What resources did we need
• Culture change needed.
• A few ideas.
Why is addressing MUS so vital?

Large part of primary care workload—often known but remains unaddressed.

Poor clinical care: unnecessary investigations, admissions, even surgery.

Large source of burnout for GPs.

Population effect of prioritising and legitimising physical illness.

Massive waste of money in a hard pressed system.

Poorly dealt with by secondary care and A&E.
MUS: wasting resources.

30% gynae OPDs, neuro OPDs, gastro OPDs…. A&E frequent attendance: MUS are large part. 30% primary care consultations: cost? London health programmes MUS costed at 100 million. Medication guesses/iatrogenic addiction issues: cost? So why not more national profile?- because it involves a degree of conflict/anxiety/risk management/challenge to prevailing views on health
Systematic approach to addressing MUS:

- Get on the radar: VTS trainers, nurse groups, practice meetings, med students, integrated care.
- Offer training tailored for primary care. Keep it simple and relevant. Address fears.
- Bring in to every specialty - eg audits in acute care.
- Ensure on all GP reg/med student training

Cannot get change without some resource - even small.
PCPCS

• Commissioned in 2009
• Mandate- primary care referrals only, no thresholds, complex MUS predominantly
• LSE evaluation good- savings- but too whom?
• Hugely popular with GPs
• Reached all surgeries- even those “non-psychological”
• Transformational –for GPs, therapists and secondary care.
PCPCS- examples of how transformational

- No protests at putting a psychotherapist in A&E to work with frequent attenders.
- No concerns about using the service to help with care plans for patients at risk of admission.
- Psychological help for physical illness/MUS seen as essential- good CCG engagement.
- Issues still with primary care consultations/long term needs of patients/efficacy of treatments
- Greater understanding of primary care mental health and how we manage complexity
Homerton hospital attendance figures for Sickle patients seen by Psychology since July 2012

* Figure for 2015 is predicted based on attendance up till end of June.
“I think that the main emphasis has to be on our holistic approach and the fact that psychology, social liaison etc are parts of the service. You cannot dissect the individual benefit from each intervention and you can only see how the whole functions. In other words, rather than trying to explain the specific benefits of having an arm or a nose, one should just point out that a body without them is dismembered, disfigured.”
Joining up MUS systems

Primary care: PCPCS, training, Tier 2 services

Outpatient care
IAPT, sickle project

Inpatient care acute hospital (RAID)

Urgent care: A&E, GP OOH, frequent attenders group

Urgent care psychiatric services- (RAID)
What else have we done locally?

2011 audit of primary care attendances:

- Search >15 attendances in 1 year, clean list, talk about patient list as a team, allocate usual Dr and talk to some patients about attendance
- Training offered on how to approach subject.
- 200 discussed/referred for IAPT/Tavi service.
- Good feedback- GPs could see rationale but needed support
- Done through CCLES at that time.
Results

32 practices took part (91%)
21 practices could do data searches. (60%)
Population covered by data search= 151,157
Number attending>15 times a year=1936 (12.8 per 1000)
“Cleaned” lists yielded= 649 (4.2 per 1000)
Number discussed with/referred to IAPT/Tavi/secondary care= 215 (1.4 per 1000)
## Qualitative data

<table>
<thead>
<tr>
<th>Question</th>
<th>Number of practices</th>
<th>Percentage saying yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Useful audit?</td>
<td>32</td>
<td>84%</td>
</tr>
<tr>
<td>Would you do again?</td>
<td>31</td>
<td>58%</td>
</tr>
<tr>
<td>Easy to allocate usual Dr?</td>
<td>31</td>
<td>74%</td>
</tr>
<tr>
<td>Behaviour change in patients?</td>
<td>31</td>
<td>71%</td>
</tr>
<tr>
<td>Behaviour change in Dr?</td>
<td>24</td>
<td>67%</td>
</tr>
</tbody>
</table>
Training offered locally for MUS in primary care

- E-learning module from local provider
- GP workshops- practical “scripts” to use with patients
- Touched on in nurse training package
- Practice meetings with PCPCs
- Joint consultations with PCPCs
- Forum discussions on A&E frequent attenders
- May be part of mandatory GP training next year.
# GP MUS Traffic Lights

<table>
<thead>
<tr>
<th>Color</th>
<th>Description</th>
<th>Management and Support</th>
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</thead>
<tbody>
<tr>
<td>GREEN</td>
<td>Simple presentations eg IBS, tension headaches, gastric upsets</td>
<td>GP management. Simple explanations of stress. Discussion of emotional wellbeing</td>
</tr>
<tr>
<td>AMBER</td>
<td>Long term conditions with added MH need- eg anxiety/COPD, bulimia/diabetes, arthritis/depression</td>
<td>GP management. May need identification and IAPT referral as data shows addressing MH need improves physical health.</td>
</tr>
<tr>
<td>RED</td>
<td>Complex, multi-presentation, multi-OPD</td>
<td>Needs usual Dr approach, containment, long term management and MH help and GP supervision.</td>
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Mechanisms to address change

- CCG/GP contract: training, audits, MH registers
- Clinical audits in acute trust addressing MH issues-in contract- eg IBS/Neuro/Gynae looking at MUS
- Look at your IAPT provision- do they address MUS-at least with LTC patients?
- Mental health trusts- what is their level of interest/expertise or do thresholds get in the way?
- Any spare money to commission a primary care service?
- Even a tiny bit- appoint a GPwSI…..
Ways to implement change!

1. Training: MUS workshops for GP and PNs, reception training managing difficult patients.
2. Pilot audit: pay a few practices to look at frequent attenders
3. Laminate primary care MUS tools sheet for every consultation room.
4. Get PHQ9/GAD7 on EMIS LTC templates
5. Mass audit- pay per practice participating.
6. Frequent attenders group in A&E
7 Commission PCPCS (750K)
8 Commission primary care mental health workers.
Summary

- There are many ways to address MUS in primary and secondary care.
- Some do not need money - they require contract levers etc.
- Culture change is the most important weapon - across primary care and the acute sector AND secondary care MH providers.
- Primary care need help - but capacity and confidence must be addressed as primary care is where most MUS work needs to be.
References

RCGP MUS guidance
http://www.rcgp.org.uk

Commissioning support for London practical tips for MUS management

PCPCS evaluation
http://www.centreformentalhealth.org.uk/complex-needs-report

MUS audit in City and Hackney  (personal data, RCGP 2014 conference abstract)
Frequent attenders group in A&E at Homerton Hospital  (personal data)
Break for networking and coffee
Local Examples
Supporting GPs to manage patients with persistent physical symptoms

Joanne Smithson
Project Manager
Improving Pathways for PPS

Dr Vincent Deary, Joanne Smithson, Dr Michaela Faye.

Faculty of Health and Life Sciences
A quick word on terminology...

- Persistent Physical Symptoms (PPS)
- Medically Unexplained Symptoms (MUS)
- Functional Symptoms
- Somatic Symptom Disorder

- A patients’ perspective: like ‘physical’ dislike ‘unexplained’
- ...and is ‘unexplained’ really accurate or useful?
What do we know already?

- 20% of the population have at least one PPS with associated disability
- Our work is focusing on three PPS: Chronic Fatigue Syndrome (CFS), Irritable Bowel Syndrome (IBS) and Fibromyalgia. These three PPS account for at least 15% of GP consultations and up to 30-50% of referrals to specialists
- Both patients and physicians report dissatisfaction with consultations: care can be suboptimal
- Pathways are ill-defined and complex
And the challenge…

Delays and sidetracks in arriving at appropriate treatment and care can be attributed to two main causes:

- A lack of local knowledge of available expertise
- A lack of clinical knowledge and skills in dealing with PPS

Our research seeks to develop a Referral Map and a Resource Pack.
Research Format

- Patient Interviews
- GP recruitment
- Expert Interviews
- Research Panel
- Testing and sharing our findings
Who is the PPS patient?

Our research uncovered a strong moral dimension with clinicians and health professionals holding a wide variety of views as to the nature of the cohort. Taken together with clinician awareness of PPS, this was found to shape levels of compassion patients received and the treatment pathways explored.

Before falling ill, the vast majority of participants in our research had enjoyable, full, often stressful, jobs and careers, juggling multiple interests and commitments. Many vividly describe their ‘crash’ out of the work:

- “I used to work 50 hours a week, then 25, then 10 then I gave up”.
- “I’d been a hard worker and I was having problems and - for a GP to turn around and say to somebody who could work so hard, that there’s nothing wrong with you? It just blew a fuse in my head”
Self efficacy challenge for clinicians

“You feel that helplessness, not in your own skill, but in your own ability to change something that has lots of facets to it, including a subconscious facet” (GP)
We need to talk about symptoms

- One of the key themes emerging from our research was the challenge/difficulty/complexity/ of talking about PPS symptoms.
- At key points along a patient’s pathway the quality of this dialogue can shape treatment trajectory and ultimately patient outcomes.
When ‘great’ communication is critical

- Introducing PPS
- Discussing specific symptoms
- Framing tests
- Broaching the topic that psychosocial factors may impact on symptoms
- So what? Moving on, what next?
Systemic drivers and a comprehensive plan to meet population need
Patient Activation and Self Management?
Preliminary Results

- No clear pathway
- Little support at Institutional/System level
- No GP with special interest
- Reliant on local clinicians who have an interest in these symptoms
Fatigue at 3 months and 12 months: consequences of inactivity

- Reduced tolerance to activity
- Limited repertoire of activities
- Decrease in general fitness
- Loss of muscle strength
- Sleep disruption and sequelae
- Alterations in mood
- Increase in symptoms
- More reduced activity....
What works in Primary Care

- A Practice-wide approach, working with an identified cohort, awareness of distribution across GPs in the practice and role allied health professionals can play
- Consistency of care – seeing one doctor, with scheduled appointments – monthly?
- Hold PPS as a working hypothesis rather than fixed diagnosis, making a positive diagnosis and focusing on symptom management
- Awareness of impact of tests
- Support and training for staff
- Awareness of referral and support options
What works in secondary care?

- Multi-disciplinary teams: trans diagnosis
- The “Durham Wrap”
- Wider use of biopsychosocial approach across disciplines, physiotherapy, rheumatology, neurology, cardiology
- Higher profile for CBT and dealing with medical uncertainty
- Strong links back to GP and Primary Care
Referral routes and services

- Talking Therapies
- Health Trainers/Social Prescribing*
- Community Dietician
- Physiotherapy and exercise
- Pain management
- Medication review
- Fatigue clinic
- Sleep management
- Support groups & patient champions
- Alternative therapies

* Consider severity and illness course
Referral Map: quick question!

- How can we best capture and present what is available locally for clinicians to refer to?
- Ideas, thoughts and suggestions are very welcome!
Thoughts for commissioners

- 20% of the population has a PPS associated with a disability, and cost estimates are £3bn, yet there is no mention of CFS/ME, FM, IBS, MUS or PPS in local JSNAs.

- Current provision is dominated by access and exclusion criteria. Our research found examples of where a Fibromyalgia diagnosis can prevent access to pain clinics, IAPTs and CFS/ME service.

- Commissioning for symptoms or syndromes?

- The role of multi-disciplinary teams e.g. CRESTA (Clinics for Research & Service in Themed Assessments) Fatigue Clinic.
Is IBS at 6 months the same illness as IBS at 3 years?

What role is there for support groups, expert patients/patient champions and peer support?

Are we maximising the support and resources available in the voluntary & community sector?

Are we consciously decommissioning services?

There appears to be strong links with work on Long Term Conditions. What knowledge can we transfer?
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My Health Skills [www.myhealthskills.com](http://www.myhealthskills.com)
NAPPS Skills (Northern Association for Persistent Physical Symptoms)
The role of IAPT

Allison Bell
Senior Therapist
Talking Changes
County Durham & Darlington Improving Access to Psychological Therapies (IAPT) Service

Lisa Boyd   Clinical Lead
Allison Bell   Senior Therapist

September 2015
• Background to IAPT and Talking Changes
• Pathfinding process
• 3 years on- pathway and outcomes
• The future of IAPT and LTC/MUS
The ‘Talking Changes’ Service

• A Joint Venture Partnership (TEWV, CDDFT, MHM)

• Partnership Board established

• Hubs and localities

• Clinical delivery in the community

• Approximately 120 staff
Background to IAPT

• Depression/anxiety generate more than half of total disability attributed to mental disorder (Andrews & Hamilton 2000) and consume up to twice GP resource of matched individuals. Managed mainly in primary care.

• Historically very limited access to psychological treatments despite strong evidence base of effectiveness possibly due to static delivery models

• Cost and distress of Common Mental Health problems highlighted and linked to limited access to psychological therapy in Layard report (published 2007)
• Led to 2 IAPT sites (Doncaster and Newham) based on CBT and stepped care models which achieved positive results.

• Goal to deliver evidence based treatments using least intrusive intervention available that will provide health gain-aim to increase capacity and access.

• Funding rolled out nationally in 3 waves commencing 2008. Durham and Darlington 3rd wave site live October 18th 2010
IAPT THREE YEAR REPORT:
THE FIRST MILLION PATIENTS
(DOH November 2012)

IAPT’s successes

• Key successes of the programme in the first three full financial years to March 2012 include:
  • Over 1 million people entering treatment
  • 680,000 people completing treatment
  • Recovery rates consistently in excess of 45% and 65% significantly improved
  • Over 45,000 people moving off sick pay and benefits
  • Nearly 4,000 new practitioners trained
  • A major transformation of Child & Adolescent Mental Health Services initiated.
Why Do We Need to Improve Access

- Long waiting times
- Services tailored around clinicians
- Hospital Sites
- Lack of services
Challenges for IAPT

Be reflective and make changes based upon what we see and what we hear

monitoring of service by area and intervention to see what works best

Consume and contribute to international research to ensure highest quality
Future IAPT Developments and Projects

• Continuing the project to transform mental health services working with children and young people (CYP)

• Being responsive to the needs of diverse and under represented communities

• LTC/MUS
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<tr>
<td>IAPT Service + PBR</td>
<td>Light Blue</td>
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<tr>
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<tr>
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<tr>
<td>IAPT Service + SMI</td>
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<tr>
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<tr>
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<tr>
<td>IAPT Service + CYP + LTC/MUS</td>
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<tr>
<td>IAPT Service + LTC/MUS + CYP + SMI</td>
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**IAPT Projects: Nationally**

![Map of England showing different regions colored according to the services provided by IAPT projects.](image)
IAPT LTC/MUS Pathfinder

- Approximately 15 million people with LTCs; many LTC patients – mixture of multi-morbidity best addressed holistically

- There is a strong link between physical long term conditions and psychological distress/disorder

- LTCs (diabetes, CVD & COPD) 3-4 times prevalence; poorer health outcomes & inc costs
• MUS is often associated with significant psychological distress

• MUS can result in unnecessary and costly referrals, diagnostic tests & operative procedures

• Psychological treatment can improve outcomes and reduce health care consumption

• NICE - with depression and chronic physical health problems.
Figure 1  The overlap between long-term conditions and mental health problems

- Long term conditions: 30% of population of England (approximately 15.4 million people)
- Mental health problems: 20% of population of England (approximately 10.2 million people)

30% of people with a long-term condition have a mental health problem (approximately 4.6 million people)
46% of people with a mental health problem have a long-term condition (approximately 4.6 million people)

Naylor et al 2012 Kings Fund
Figure 3  Proportionate increase in per patient medical costs associated with depression and anxiety relative to people without a mental health problem (based on US claims data for more than 9 million people, Melek and Norris 2008)

Note: direct mental health treatment costs are excluded
Source: Melek and Norris 2008
Talking Changes and LTC/MUS

AIM: Phase 1

• To enhance identification of patients with LTC/MUS

• Trial collaborative care in two economically different patches with two different groups of nurses

• Improve support and supervision processes

• Improve skills and knowledge
Key Objectives of the Pilot

- Develop and pilot new pathway in collaborative care.

- Train pilot group of CM’s & PN’s in collaborative care for depression, anxiety for LTC/MUS and role of these problems in repeat admissions.

- Community Matrons train local IAPT workers in awareness of LTC/MUS.

- Evaluate implementation and impact using MDS and service utilisation.
Collaborative Care pathway

Screen LTC using PHQ2-GAD2
Com Matron-PN

Positive-Full PHQ9 and GAD7/Depression assessment
Scores mild-moderate

Positive CMH problem integrate depression CC into follow up and discuss in supervision with IAPT

Commence psycho-education/guided self help following structured protocol
Brief interventions for Depression and Anxiety, complete MDS
Face to face-telephone-email

Improvement Continue and review
Non improvement/scores increase/supervision decision
Pass to IAPT stepped care for follow up and treatment of psychological care
IAPT decision to step up Step2b or Step3
Phase 2

- Build on lessons learned in Year 1 and modify the existing collaborative model from findings to date

- Increase existing pilot sites

- Roll out more training to CM’s, PN’s.

- Disseminate knowledge & skills service wide and primary care

- Modify supervision process

- Establish links with acute liaison
What have we achieved so far ......

Training:

• So far specialist staff trained by Talking Changes in delivering Wellbeing workbooks = 52

• So far staff have received awareness training on LTC/MUS = all from DDES and Darlington CCG and district nurses
Collaborative Care

What is it?

Healthcare professionals should ensure collaborative care is provided to all people with moderate to severe depression/anxiety and a chronic physical health problem with associated functional impairment, whose symptoms are not responding to initial interventions. (NICE 2011).
Collaborative Care - Key Features

- Proactive follow-up of patients through brief scheduled protocol led contact

- Engaging patient with psychological and pharmacological treatments

- Monitoring patient progress (tool PHQ9, GAD7, QOL)

- Taking action when treatment is unsuccessful; Stepping Up
• Enhanced communication between multi-professionals

• Delivering psychological support

• Regular planned feedback to Talking Changes

• Regular planned supervision

• Telephone support for unexpected change.
Benefits of the Collaborative Care Model

**Action**
- Due to enhanced communication and decision making by multi-professionals
- Earlier case identification
- Regular measurement against benchmarks

**Benefit to patient**
- Improved care for patient
- Quicker access to pathway for patient
- Quicker opportunity to revise treatment plan for
Action

• Reduced referrals to intensive psychological services
• Continued support and intervention by identified health professional
• Involvement in care

Benefit to patient

• Right level of intervention for patient at the right time
• Improved chance of engagement from patient
• Increased patient satisfaction and engagement
Other Benefits

• Close links with Teesside University

• Specifically trained staff.

• Two way staff support and education

• Health Service Benefits.

• Improved pathway interface with Liaison Services
Outcomes so far for people with LTC/MUS…..

In the last 12 months; 2045 referrals.
• 28% are still receiving treatment.
• 46% went on to complete treatment.
• 43% recovered,
• 23% reliably improved
• 28% showed no change
• 6% reliably deteriorated.

Official report from Surrey University not released
OutcomesMeasured

• Reduce Depression and Anxiety (MDS)
• Increase self efficacy (CGI, Client Global Impression Scale)
• Reduce use of health services & costs (CSRI, Client service receipt inventory)
• Reduce A&E and acute ward admissions (CSRI)
• Increase Q.O.L. (EQ5D)
• Prevent relapse to previous levels (6 monthly evaluation)
• Patient satisfaction (PEQ)
Evidence

• Gilbody et al(2006), meta analysis found
  – CC effective to improve short term outcomes in
depression, with emerging evidence of long term
benefits
  – CC potential to reduce global burden of illness
associated with depression
• Meta regression
  – Better concordance with medication regimens
  – Better outcomes with planned regular
supervision
  – Better outcomes when at least 1 staff member
has MH background
Barriers and Challenges to Integrating Care

Quality

• Resource stretched- specialised LTC pathway within IAPT versus loss of collaborative care model.

Patient/ Health Professional Factors

• Patient insight
• Referrer insight
• Condition and Engagement.
Cost/ Resource Factors

- Difficult to continue to deliver Collaborative Care (CC) without funding.
- Engagement with Primary care staff has been difficult due to their workload and capacity with subsequent impact upon (CC) with practice nurses

Time

- Without correct resource, home visits = caseload numbers = IAPT figures impacted.
Accepting Change

In 2007 the World Organization of Family Doctors and the World Federation for Mental Health joined the Breaking through Barriers Campaign, 501 GP’s & 252 adults with depression

• 78% of GPs agreed that a mind body connection existed.

• 85% of GPs agreed that understanding the connection between mind and body helped them in their diagnosis.

• 93% of GPs agreed that this understanding helped them in their management.

• 84% of GPs agreed that there was a need for GPs to be educated on the mind and body connection.

(WFMH, 2010).
Current LTC/ MUS Care Pathway

Referral received where physical health problem indicated.

Patient is booked in for telephone screening. ALL patients must have risk assessment, MDS and Telephone screening completed.

Is physical health problem is causing problem to day to day functioning?

Yes

Discuss with patient the progression model and assign to TSGH if suitable to patient. Use workbooks for physical health conditions.

No

Process as per progression model

If patient declines TGSH, allocate to step 2b LTC guided self help waiting list.
The future- How to change the existing paradigm?

- A need for more integration of mental health services within primary care within providers of chronic disease management, and closer working relationships with other health care professionals

- Clinical commissioning groups should prioritise integrated approaches in their strategies –
• Targeting extra funding can build on existing provision rather than set up something new- build on current foundation.

• Joint funding with physical health commissioners

• Funding for specialised service- this is not just an addition to usual role. The local commissioners have not at this point agreed to fund LTC/MUS separately. There is a need for a national steer.
• Be persistent in engaging GPs, provide training for GPs and be flexible

• Retaining existing staff with specialist skills to maintain and expand the fast track to specialist staff to be able to deliver steps 2 and 3.

• Build clear pathways with step 4 provision.
That’s all folks!

Thank You
Commissioning for patients with functional neurological disorders

Claire Braid
Network Delivery Lead
Dr Philippa Bolton
What is the purpose of this document?

This document aims to provide guidance on commissioning a stepped care model for the management of functional neurological disorders, including examples of good practice, resources to support local organisations and sources of further information.

What are functional neurological disorders?

Functional neurological disorders (FND) are symptoms such as blackouts and paralysis that are genuine but not due to a neurological disease. The term ‘functional symptoms’ includes dissociative (non-epileptic) attacks, functional limb weakness/movement disorder, sensory, visual, speech and cognitive symptoms (Healthcare Improvement Scotland).
What can be done to treat people with these symptoms?

Functional neurological disorders can be effectively treated with psychoeducation, physiotherapy, psychology and medication to treat co-morbidities. However, across the North East and North Cumbria there is limited or no access to treatment for patients with functional neurological disorders. Patients are often severely affected by their condition, faring worse than patients with other neurological disorders across a range of psychosocial domains often resulting in the development of significant levels of psychiatric comorbidity.

The lack of service provision for patients with functional neurological disorders can lead to frequent GP attendances, frequent secondary care referrals, A&E attendances, unnecessary investigations and unnecessary social care support being put in place (e.g. carers).

Prompt diagnosis and treatment can mitigate this to a large extent, so improving access to effective treatment is therefore a priority for these patients.

The document produced by Health Improvement Scotland explains one approach to treating this common problem, using a stepped care model. This model will be explained in more depth later.
Is it a big problem?

Yes. Scotland is a world leader in functional neurology and, in 2003, conducted comprehensive research to estimate the size, cost and extent of the problem. The Scottish Neurological Symptoms Study found:

- **31% of people attending neurology outpatient clinics had functional symptoms.** As a whole, this is the largest single group accessing neurological services.

- **27% of people attending with functional symptoms were not working for health reasons.** This impacts on the wider economy, including an increase in benefits claims.

- **At least 5,000 people per year are estimated to be diagnosed with a functional neurological disorder.**

- The cost to the health economy in Scotland for people with functional symptoms is estimated at
  - £1.3 million per year for outpatients
  - £6.01 million for inpatients
  - £4.01 million for primary care

Scottish studies suggest a 50% decrease in health service utilisation may be possible if patients receive appropriate treatment.
But what about England?

There are no similar studies for England, but the Department of Health estimates that:

- ‘medically unexplained symptoms’ cost the economy £18 billion every year
- £3.1 billion of this is NHS cost
- a further £5.2 billion in lost productivity, and
- £9.3 billion attributed to a reduced quality of life.

Locally, data collected in the Durham Medically Unexplained Physical Symptoms (MUPS) service indicated that 85% of people with a diagnosis of non-epileptic attack disorder were unemployed.
The solution – a stepped care approach

STEP 1: Good initial diagnosis and explanation of functional symptoms by neurologist (or Consultant in another specialty as appropriate)

STEP 2: Brief intervention delivered by a trained nurse or therapist, based within specialism (group based or 1:1)

STEP 3: Longer term intervention delivered by specialist

STEP 4: Highly complex patients requiring inpatient treatment or MDT working. This would be a very small group of patients
So, how does this ‘stepped care model’ work?

**Step 1:**
**Improving initial diagnosis and management** within neurology. **One in ten patients will be cured** of the disorder if this step is done well. Optimal explanation of symptoms by neurologists has been shown to help patients and reduce health care utilisation. Many patients wait years for an accurate diagnosis, and this leads to psychosocial comorbidities that is not only an adverse outcome for the patient, it also makes later treatment more complex and costly.

**Example from practice: Using a ‘computer analogy’ for explaining a functional diagnosis in neurology**

“This looks like a software sort of problem. The hardware is intact - we know there is nothing degenerating or nasty, but the programme is not responding. With a computer you can just switch it off and back on to rectify the problem, but with people it isn’t quite as simple. Some computer systems seem more prone to crashes, in the same way that some people are more prone to getting these sorts of problems. If there are lots of rogue programs in the background using computer processing power it can cause crashes, and similarly, if there are things in the background using brain processing power, such as stress issues, functional problems are more likely, so addressing these background factors can help. There are helpful techniques to try and get things working again.”
Step 2:
Four-session group or 1:1 CBT based psycho-education delivered by a specialist nurse or physiotherapist, within neurology. This is a cost effective intervention that can be delivered in a timely fashion to most patients immediately after diagnosis. Evidence suggests that early additional psychoeducation from a trained nurse/physiotherapist following diagnosis significantly improves patient long term outcomes. Many patients would not need more than this. There could also be a role for IAPT within this step.

Example of a ‘Step 2’ intervention - nursing

For patients with disorders such as non epileptic attack disorder, 5 sessions of psychoeducation could be delivered in a group setting. This is currently provided in the Medically Unexplained Physical Symptoms Service in Durham and Darlington. Peer support and shared experience is reviewed very positively by patients and it is often the first step to the route to psychosocial recovery. It helps destigmatise the condition and make patients feel they are not alone.

It is also a more cost effective way of delivering treatment. One support worker and one band 6 nurse run the groups, which are 5 sessions and have approximately 5 patients per group, at an estimated cost of £25 per patient for the total intervention.
Glenn Nielsen, a physiotherapist at the National Hospital for Neurology and Neurosurgery, works in a functional neurological disorders service providing treatment for patients with functional motor disorders. In 8 sessions of physiotherapy over a 5-days, approximately two thirds of patients reported themselves to be ‘better’ or ‘much better’ and the effect is sustained at 12-month follow up. Nielsen has developed a consensus document on approaches to treatment for people with functional motor disorders.
Step 3:
For those patients who need it, this would involve 2 options:

- **support worker intervention** to rehabilitate those patients who have lost independence and to help them to engage in meaningful and purposeful activities, designed to improve self esteem, symptoms and upskill patients. This can also be a necessary first step to stabilise the patient so that they can then engage in psychology. If this is not done, then expensive psychology time can be wasted stabilising patients which can be done in a more cost effective manner by support workers.
- **1:1 psychology** and / or longer term physiotherapy for more complex patients. This step is **time limited**. Following this intervention, the patient would leave the pathway then be referred back to their GP for continued management.

Example of support worker-led rehabilitation

Mrs T

Mrs T developed seizures 5 years ago and was diagnosed with non epileptic attack disorder 1 year ago. In the four years before diagnosis she had lost all independence, receiving 24 hour care from family members.

Following treatment from the psycho-education group and work with her support worker, Mrs T and her family understand the condition better and Mrs T is now able to go out by herself and use public transport, has joined a craft group, can take her children out alone and is aiming to get back to work in the next 2 months. Mrs T can be seen talking about her progress on the functional conditions video.
Examples of psychological interventions (including and excluding physiotherapy)

Ms P, 35 year old single mother, presented with a stroke like episode. This was diagnosed as functional. She was left with severe gait disturbance. She worked with psychology, who identified previous trauma which contributed to the condition. She was subsequently treated using eye movement desensitisation therapy and between this and physiotherapy involvement her walking returned to normal over a series of 12 sessions.

Mr H had a 10 year history of health anxiety which had resulted in severe functional abdominal pain and multiple A and E admissions. He was treated using antidepressants and 18 sessions of CBT which resulted in Mr H going back to work.
Why should we commission this model?

Commissioners may like to consider the stepped care model for the following reasons:

- A stepped care approach such as this will aim to treat according to levels of need, thus ensuring that the **right treatment** gets to the **right patient**.

- The **greatest number** of patients can be treated in the most **timely** and **cost effective** way.

- It can be **based within neurology**, with links to liaison psychiatry and IAPT as required for patients with psychiatric co-morbidity, or for those who require CBT as a psychological intervention.

- It is a model that can be **transferred to other conditions**, outwith neurology, as demonstrated in the ‘MUS Commissioning Guide for London’. 
What are the components that make this model work?

**Education**

Education of key professions involved in this stepped care model is a necessary starting point for implementation. To help with this, Health Education North East and the Northern England Clinical Networks have developed a functional disorders awareness video.

CCGs should support ongoing education and access to learning resources for all health professionals. Functional conditions manifest in all areas of medicine and well meaning but inappropriate management (diagnostic labels, repeated tests, unnecessary prescriptions and equipment provision) is both costly and can cause harm.

This should be supplemented with high quality patient information material in a variety of formats. This level of management will be appropriate for all patients with functional neurological symptoms and may be all that is necessary for patients with mild to moderate disability, and no accompanying major psychiatric disorder.
Good education leads to good diagnosis

By making a positive diagnosis, clinicians can avoid harm and cost from multiple referrals and investigations, and also offer a therapeutic route to improvement. **It will free up neurology outpatient clinic slots** as currently, (in the case of non epileptic attack disorder), these patients take up to 8 years to diagnose.

CCGs need to consider investing in tools to reduce time to diagnosis, such as video EEG (current wait for this in Newcastle 18 months). For example, in Glasgow, suspected non epileptic attack disorder patients get a 30 minute video EEG the day after being seen in clinic by neurology.
Physiotherapy

For patients with functional motor disorders physiotherapy is a vital part of treatment, both in providing diagnostic support, brief intervention and complex treatment in conjunction with psychology. Currently there is no dedicated physiotherapy service for patients in this area, and CCGs need to consider how physiotherapists working with both inpatients and in the community can be upskilled to treat patients with functional neurological disorders as part of this pathway.
Psychology and psychiatry provision

Psychology provision is needed for the complex end of the patient spectrum, with provision required for about a third of patients, although psychologists also need to provide supervision to other team members. Ideally this would be provided by psychology within neurology, but in areas where there are no dedicated neurological services, liaison psychiatry or IAPT could be commissioned to provide it, in the context of having access to allied health professionals such as physiotherapy as required.

Liaison psychiatry can link into neurology services to help diagnose and manage co-morbid mental health conditions and patients with more challenging and complex needs (Step 4), such as those who are frequent A&E attenders, those with complex psychiatric comorbidity and levels of risk to self or others.
Multi-disciplinary team working

Key to this model is multidisciplinary team working. Other professionals such as occupational therapy, speech and language therapy, and the pain team may need to also be linked to the model to ensure a consistent and holistic approach. This would also support the increase of skills and knowledge to work with these patients within these professional groups.

Ms L

Ms L presented with a functional tremor. Following 1:1 psycho-education with a psychiatrist, and the addition of antidepressants, her mood started to improve and she started to work out ways to reduce her tremor. She worked with a physiotherapist to learn progressive muscular relaxation, which further improved the situation, and finally an OT worked with her to put in aids to promote a relaxed grip and adapt tasks so she had a more relaxed posture, which again reduced her tremor. Her tremor is significantly improved.
Recovery

Recovery with support worker intervention. Many patients have lost independence and confidence through having a functional neurological disorder. They do not necessarily need complex psychology but need support for psychosocial rehabilitation to learn to do tasks such as getting on a bus again. This can link to vocational rehabilitation programmes such as volunteering and the Shaw Trust, which helps patients with disabilities back to work. It is a key step that can really improve patient’s quality of life, improve functioning, and prevent relapse. It is also a step which can be necessary in order to stabilise the patient before accessing psychological therapy.

Severe and complex inpatient provision

For the few patients who have the most severe and complex needs, specialist inpatient services may need to be developed, like the Yorkshire Centre of Psychological Medicine in Leeds. Walkergate Park neuropsychiatric service may be the most appropriate place to develop this, with training and closer joint working with mainstream neurosciences.
Are there any local services that treat these conditions?

Service provision is patchy and inequitable. None of these have physiotherapy input:

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Durham and Darlington</td>
<td>The Medically Unexplained Physical Symptoms (MUPS) service. This service is commissioned to treat all patients with MUPS from secondary care which includes functional neurology.</td>
</tr>
<tr>
<td>North Durham</td>
<td>Dissociative Seizures Services. This provides psychological treatment to patients with dissociative (non-epileptic) seizures.</td>
</tr>
<tr>
<td>Middlesbrough</td>
<td>Neuropsychology service within neurology. There is one neuropsychologist working into this service with a three-year waiting list.</td>
</tr>
<tr>
<td>Sunderland</td>
<td>No dedicated service although IAPT provide a Persistent Physical Symptoms service, and see people with non-epileptic attack disorder.</td>
</tr>
</tbody>
</table>
Is this model only for neurological conditions?

No! Functional conditions are very common in most specialities, for example, gastroenterology, respiratory and rheumatology. The underlying principles can be applied to all patients with functional symptoms, with group based therapy provided in a specialty-specific context. Local examples of this are the pilot service within gynaecology for women with chronic pelvic pain in Durham and Darlington, and the Chronic Pain Service run by Northumbria Healthcare NHS Foundation Trust:

Gynaecology Service (Durham and Darlington)

‘Step 1’ is two sessions of psycho-education delivered jointly by gynaecology and psychiatry / psychology. Patients are then offered an 8-session group intervention with a nurse and support worker (Step 2). At the end of this, they are reassessed and either discharged or offered further, more complex treatment (Step 3) such as IAPT, liaison psychology / psychiatry, support worker.

Chronic Pain Service (Northumbria)

‘Step 1’ is a half-hour face to face or telephone assessment with a Consultant or Extended Scope Practitioner. This includes a discussion about the biopsychosocial nature of persistent pain. ‘Step 2’ is ‘education and assessment’, delivered as a 90-minute group session, run twice a month, for up to 8 patients. It is facilitated by a physiotherapist and a clinical psychologist. Following this, patients are invited to attend a range of group-based interventions, or less intensive drop-in sessions. Individual psychology and physiotherapy sessions are available if necessary.

Longer term support is offered through a monthly self-management group. Any patients who require more complex interventions are referred back to their GP.
What next?

There is currently a dearth of economic data relating to functional disorders services. A health needs analysis needs to be completed to establish the level of need and service provision that would be required. Scottish Data suggests that patients with neurological symptoms alone cost the Scottish healthcare system £11.3 million a year, and in England, patients with medically unexplained symptoms in general cost the health service an estimated £3bn a year, with costs to the wider economy amounting to £18bn a year.

Commissioners would need to identify the best geographical location for this type of service, and decide whether these services be aligned solely with existing neurology services (in Sunderland, Middlesbrough and Newcastle) or whether there needs to be service provision in district general hospital settings, either as stand alone services or based within liaison psychiatry.

Commissioning for early diagnosis, treatment and management for patients with functional neurological disorders in the North East should aim to provide cost effective, patient focused services where none exist currently. The ideal is that every patient with these disorders in the North East can have access to timely treatment and experience minimal disruption to their lives, with a reduction in cost to the health service and wider economy as well as an increase in patient quality of life.
Resources and Contacts

Symptoms and patient support websites
www.neurosymptoms.org
www.fndhope.org
http://www.nonepilepticattacks.info

Resources for professionals and useful documents
http://www.fnforum.org/

www.myhealthskills.com (Northern Association for Persistent Physical Symptoms group)

British Medical Journal learning module (requires login)

Healthcare Improvement Scotland neurological symptoms report

Scottish Neurological Symptoms report

London Commissioning Model for MUS

Investing in emotional and psychological wellbeing for patients with long term conditions, (section on ‘medically unexplained symptoms’)

Publications from Sheffield Neurology Psychotherapy Service

Northern England Strategic Clinical Networks:
www.nescn.nhs.uk

For more information contact the Northern England Clinical Networks team at: england.nescn@nhs.net
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August 2015
Workshop and networking:
Where do we go from here and how Clinical Networks can support you

Dr Philippa Bolton
High intensity work
Specialist psychotherapy, liaison, acute trust clinics

Moderate intensity work
Physiotherapy, OT IAPT

Low intensity work:
Social prescribing, Patient groups, guided self help, IAPT

Primary care management:
GP and patient education and resources.
What currently exists as far as we know....

**Primary care:**
Darlington GP’s frequent attenders group
Oxford Terrace practice Gateshead

**Low intensity**
Ways to wellness, Colour your life. IAPT Durham and Sunderland

**Moderate intensity**
IAPT Durham

**High intensity**
Summary and conclusion