PE01651/UUUUUUUU
Petitioner submission of 12 July 2018

This submission is to respond directly to the evidence requested by the Petitions Committee, following their last consideration of PE01651 on 26 April 2018, from: BMA Scotland, the Scottish Government and the Royal College of GPs Scotland.

1. **BMA Scottish GP Committee 28 May 2018 1651/HHHHHHHH**

This submission describes what would be 'normally' discussed and 'mutually decided' with patients about the prescribing of medication, and GPs 'following clinical guidance'. Unfortunately, as has been clearly shown in evidence submitted for this petition, prescribing doctors are working under significant time (and other) pressures, the prescribing guidance is in question, and there is a gulf between 'ideal' and what happens in real life. The tone of this BMA submission is noticeably quite debasing about the experiences of patients, and this is the attitude of doctors that patients do indeed experience – and which has contributed to the situation in which we now find ourselves. As indicated in the final paragraph, the medical profession really has no idea of 'the scale of the problem' - and patients and doctors are in desperate need of help and support.

2. **BMA Scottish Council 28 May 2018 1651/IIIIIIII**

This submission is in the main supportive of our petition, as would be expected from our previous and ongoing work in collaboration with the BMA Board of Science. The reference to the 'BMA gathering feedback' is interesting – as this feedback was actually collected and collated by Fiona French, who kindly designed a survey (using questions posed by BMA Board of Science) for the purpose. We and BMA shared and distributed the survey and Fiona French returned the outcome results to BMA Board of Science.

3. **Scottish Government 29 May 1651/JJJJJJJJ**

It is encouraging that the Scottish Government does have a representative observer on the Public Health England (PHE) 2018-2019 review group, and it is certainly to be hoped that a Scottish focused review will be undertaken in parallel with the current PHE review.
The written patient experience evidence submitted and published to date for the Scottish and Welsh petitions (prescribed drug dependence) is currently being collated, in association with APPG-PDD, in order to provide a formal submission reporting patient experience evidence for consideration as part of the PHE review. The PHE deadline for evidence submission is beginning August 2018. Reference to this initiative can be found in the minutes of the APPG-PDD meeting of 6 June 2018, points 2.3 and 2.4.
http://prescribeddrug.org/minutes/
We will update on this prior to the next committee consideration of this petition.

4. **RCGP submission 7 June 2018 1651/SSSSSSSS**

It is extremely disappointing that in seeking the views of practising GPs across Scotland the Petition Committee chose to ask just two questions, and only of the Royal College of General Practitioners (RCGP). The response is predictably unsurprising, based very largely on 'policy' and Scottish Government publications. There is no indication whatever that any of the patient experience (or indeed other) evidence submitted and published since the launch of our petition, over a year ago, has been read or considered in this response.

Meanwhile the Petitions Committee has received a number of submissions from Dr Des Spence, Professor David Healy, Dr Terry Lynch and Dr Peter Gordon which offer a range of

well-informed experiential perspectives. The Committee has also received evidence from individuals who have built up extensive experience of supporting people, over years, to safely withdraw from prescribed benzodiazepines and antidepressants (such as Baylissa Frederick, Gwen Olsen, and the founder of Surviving Antidepressants), as well as from a range others including Professor Cosci, Dr Lucassen, Dr McKelvie and Irving Kirsch.

The 2014 SAMH survey of Scottish GPs includes actual GP comments/quotes and has been mentioned in our petitioner submission of 13 April 2018: https://www.samh.org.uk/documents/A_SAMH_Survey_of_general_practitioners_in_Scotland.pdf . SAMH's patient survey 'What's the Script', referenced in the SAMH submission of 4 August 2017, is very relevant here: https://www.samh.org.uk/documents/what_s_the_script_final_%281%29.pdf .
Given this context, the 2014 RCPsychiatrists briefing paper cited in the RCGP Scotland submission illustrates the deeply worrying trend of RCPsych and RCGP actively downplaying the (then clearly) emerging concerns about antidepressants especially. Since our last submission, a more accessible version of the now widely circulated and well-received April 2018 Psychiatric Times article by Josef Witt-Doerring et al 'Online Communities for Psychiatric Drug Withdrawal: What Can We Learn' has become available: http://www.psychiatrictimes.com/article/online-communities-drug-withdrawal-what-can-we-learn

We (Beverley Thorpe, Fiona French, Alyne Duthie, Janette Robb, myself and others) have previously provided written submissions, in considerable detail and with many research references, about suicidality and suicide risk (also associated with PE01627) and about the lack of accurate guidance for prescribers leading to serious issues around 'informed consent'. RCGP Scotland now states "The efficacy of antidepressants is not disputed and indeed is well supported by evidence" citing the now immensely controversial Feb 2018 Lancet paper by Cipriani et al. (mentioned in our 13 April and other recent submissions) which of course looks only at short term prescribing of antidepressants.

The RCGP cited Pottie et al 2018 'Deprescribing Benzodiazepine…' paper has been read with alarm and even horror – the advised confidently published 'tapering' schedules being far faster than has been found to be safe – at very great cost to many lives including those of several people who have submitted evidence for our petition.
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The RCGP cited Johnson et al 2012 BGJP research paper illustrates just what is happening (being that people have great difficulty withdrawing safely from long-term antidepressants and this is being misdiagnosed as 'relapse'), as does the 'Depression Management' flow chart which is attached to the RCGP Scotland submission of 7 June 2018.

Since our last petitioner submission (13 April 2018) we have watched the evidence session for the new petition PE01690 by Emma Shorter on behalf of ME Action in Scotland, as well as the 21 June 2018 Westminster Hall debate about ME brought by Carol Monaghan MP. There are striking parallels - where ME patients relate similar harrowing experiences of suffering severe and debilitating 'medically unexplained' symptoms and of being disparaged and disbelieved by doctors and others.

We have been trying to spread awareness and raise alarm at what the evidence submitted for our own petition is revealing and, for the purpose of a visual summary, have had the attached infographic 'Patient Journey' representation designed. This can be perused

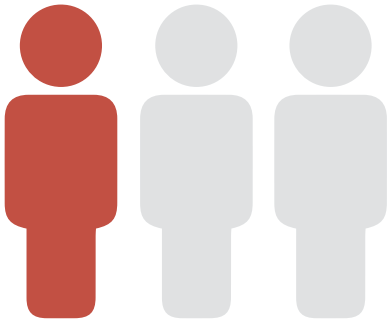
alongside the flow chart provided by RCGP with their 7 June 2018 submission – where the flowchart demonstrates what GPs are being ‘recommended’ to do as ‘Depression Management’ - and where the Patient Journey infographic demonstrates what is actually happening, to a significant proportion (BMA suggests a ‘substantive minority’) of people, as a direct consequence of the guidance for GPs: i.e. ‘a substantive minority ‘ of patients are being made very ill and eventually disabled by medicines ‘taken as prescribed’ whilst prescribing doctors are ‘following guidance’. This is deeply troubling.

A PATIENT'S JOURNEY

Consequences of Antidepressants/Benzodiazepines

LIFE CRISIS AND/OR TRAUMA FEELING OVERWHELMED

Insomnia, anxiety, panic, anger, depressed, not coping



VISIT EFFECTIVE THERAPIST

TELL STORY - FEEL HEARD & VALIDATED

Psychoeducation, understanding

Breathing, Guided Imagery

Trauma recognised/healing

PATIENT RETURNS TO LIFE - NEEDS MET

VISIT GP

Started on antidepressants (AD) or benzodiazepines (BZ)

GP advises: Stay on ADs for **AT LEAST SIX MONTHS**

Patient wishes to stop

GP advises rapid taper

Withdrawal symptoms

Doctor misdiagnoses relapse, puts patient back on ADs/BZs

No response or adverse effects = dosage increased or other drugs added

Patient unable to stop, seeks help elsewhere

SLOW TAPER

Patient may or may not get off the drugs

Withdrawal problems

Protracted syndrome

Multiple physical symptoms

Patient seeks medical advice

GP blames underlying condition

Patient undergoes extensive and costly tests

GP/Specialist diagnoses Medically Unexplained Symptoms (MUS)

Functional Somatic Syndromes

Treated with CBT/Graded exercise

Potentially given ADs

Patient disabled with no understanding and little support

Concept: Marion Brown, 2018. Design by: Miranda, **miranda-design.co.uk**

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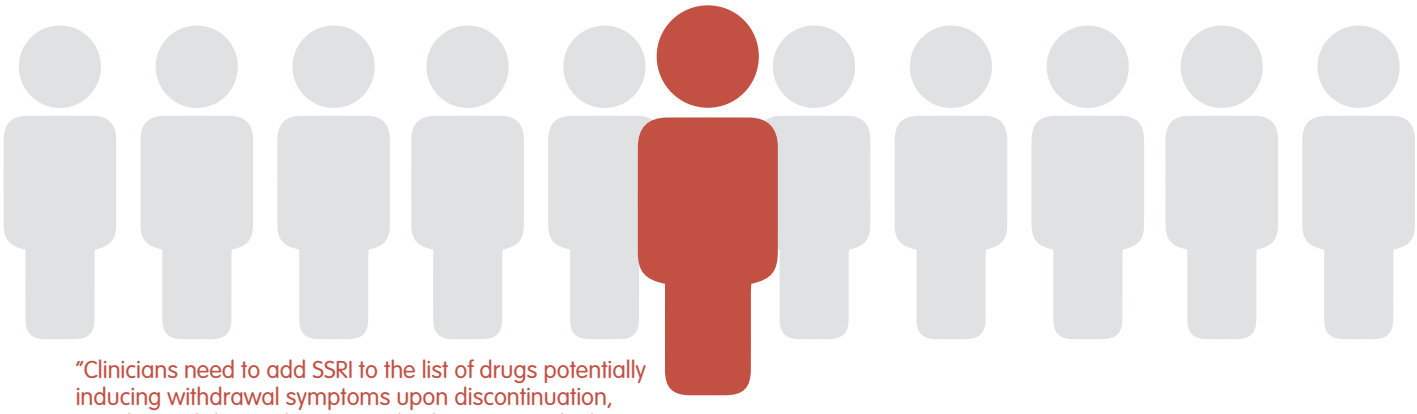
Consequences of Antidepressants/Benzodiazepines



"Clinicians need to add SSRI to the list of drugs potentially inducing withdrawal symptoms upon discontinuation, together with benzodiazepines, barbiturates and other psychotropic drugs" **(Fava G. A. et al 2015)**

SIGNS AND SYMPTOMS OF WITHDRAWAL FROM SSRI

(www.karger.com/Article/FullText/370338)

SYSTEM INVOLVED	SYMPTOMS
General	Flu-like symptoms, fatigue, weakness, tiredness, headache, tachycardia, dyspnea
Balance	Gait instability, ataxia, dizziness, light headedness, vertigo
Sensory	Paraesthesias, electric-shock sensations, myalgias, neuralgias, tinnitus, altered taste, pruritus
Visual	Visual changes, blurred vision
Neuromotor	Tremor, myoclonus, ataxia, muscle rigidity, jerkiness, muscle aches, facial numbness
Vasomotor	Sweating, flushing, chills
Sleep	Insomnia, vivid dreams, nightmares, hypersomnia, lethargy
Gastrointestinal	Nausea, vomiting, diarrhea, anorexia, abdominal pain
Affective	Anxiety, agitation, tension, panic, depression, intensification of suicidal ideation, irritability, impulsiveness, aggression, anger, bouts of crying, mood swings, derealization and depersonalization
Psychotic	Visual and auditory hallucinations
Cognitive	Confusion, decreased concentration, amnesia
Sexual	Genital hypersensitivity, premature ejaculation

What is MUS?

"Medically Unexplained Symptoms (MUS) refers to persistent bodily complaints for which adequate examination does not reveal sufficiently explanatory structural or other specified pathology. MUS are common, with a spectrum of severity, and patients are found in all areas of the healthcare system.

Patients with MUS are more likely to attribute their illness to physical causes rather than lifestyle factors. This can include symptoms such as pain in different parts of the body, functional disturbance of organ systems and complaints of fatigue or exhaustion."

FUNCTIONAL SOMATIC SYNDROMES

SYMPTOMS (COMBINATION OF)	SYNDROME
Bloating, constipation, loose stools, abdominal pain	Irritable Bowel Syndrome
Fatigue (particularly post-exertional and long recovery) pain, sensitivity to smell	Chronic Fatigue Syndrome, Myalgic Encephalomyelitis
Headache, vomiting, dizziness	Post Concussion Syndrome
Pelvic pain, painful sex, painful periods	Chronic pelvic pain
Pain and tender joints, fatigue	Fibromyalgia/Chronic widespread pain
Chest pain, palpitations, shortness of breath	Non cardiac chest pain
Shortness of breath	Hyperventilation
Jaw pain, teeth grinding	Temporo-mandibular Joint Dysfunction
Reaction to smells, light	Multiple Chemical Sensitivity

Source: Joint Commissioning Panel for mental health, Guidance MUS, Feb 2017, www.jcpmh.info

NOTE THE CLEAR SIMILARITIES IN THE SYMPTOMS OF WITHDRAWAL AND 'UNEXPLAINED' SYMPTOMS

Concept: Marion Brown, 2018. Design by: Miranda, **miranda-design.co.uk**