

PE1651/HHHHHHHHH

Petitioner submission of 16 September 2018

Introduction

In my [previous written submission of 12 July 2018](#) under Reference point 3, I explained that written patient experience evidence submitted and published to date for my petition as well as the Welsh petition on Prescription drug dependence and withdrawal - recognition and support was being collated, in association with APPG-PDD.

This information would then be presented as a formal submission reporting patient experience evidence for consideration as part of the Public Health England review on the evidence for dependence on, and withdrawal from, prescribed medicines. The review was launched on 24 January 2018 and is due to report in early 2019.

REPORT by All-Party Parliamentary Group: Prescribed Drug Dependence. Aug 2018

The Patient Voice: an analysis of personal accounts of prescribed drug dependence and withdrawal submitted to petitions in Scotland and Wales. (see refs 1 & 2)

On behalf of the APPG-PDD (Westminster) the [August 2018 report](#) was researched and written by Dr Anne Guy, Marion Brown (Scottish Petitioner) and Stevie Lewis (Welsh Petitioner), with additional support from; Susan Reid, and Karen Espley; for response analysis, David Cope, and Catherine Maryon. This report has been made possible by all those who responded to the two petitions and the Petitions Clerks who published them.

Abstract: This report collates and analyses 158 personal accounts of people impacted by prescribed drug dependence and withdrawal (specifically for antidepressants and benzodiazepines) that were submitted in response **to two petitions lodged with parliamentary Petitions Committees in Scotland¹ and Wales² in 2017.**

The report blends qualitative data in the form of verbatim quotes with quantitative data derived from a formal thematic analysis structured using a 'lean thinking' approach to process improvement. The analysis identifies eight systemic 'failure points' (FPs);

- (1) Prescriptions were offered as an apparent first course of action
- (2) No-one said they were warned about possible side-effects or dependence and associated withdrawal effects so there was no possibility of informed consent
- (3) Treatment was sometimes continued despite drugs not helping and/or severe side effects
- (4) People experienced a lack of access to effective management / informed medical oversight of withdrawal process
- (5) Doctors did not recognise new symptoms as withdrawal and discounted patient experience

¹ Scottish Petition PE01651: <http://www.parliament.scot/GettingInvolved/Petitions/PE01651>

² Welsh Petition PE-05-784: <http://www.senedd.assembly.wales/ieIssueDetails.aspx?Id=19952&Opt=3>

- (6) Locating the problem of new symptoms occurring at withdrawal with the individual, not the drug, leads to unnecessary action
- (7) There are no dedicated nationwide NHS services to access for help and
- (8) No effective avenues for patient feedback on their experience

The aim of the report is a) to consider the question 'what went wrong?' in these peoples' interactions with a healthcare system intended to improve, not worsen, their wellbeing;
and b) to enable their collective voice to be heard as evidence in the consideration of the scale, harms and response needed for prescribed drug dependence in the UK.

The analysis of the submissions is represented in systems analysis Flow Chart Maps A: 'Prescription and Outcomes' and Map B: 'Withdrawal and Outcomes' with an additional page of 'Overall Impact' patient quotes. All quotes can be referred back to the original full patient petition submission via the respective reference lettering/number given (W=Welsh).

The systems 'Failure Points' identified (see maps A and B appended) are reflected in the recent (June 2018) RCGP submission³ - which evidences the GP guidance incl. flowchart.

FP1: GPs are encouraged to 'treat' symptoms of stress (anxiety, depression, insomnia etc.) – and antidepressants are an 'advised' treatment (especially when other options scarce).

FP2: The guidance (NICE GG90)⁴ for GPs :

Advise patients that antidepressants 'may take a while to become effective', 'keep on taking', 'may need to adjust dose and/or try another', 'are not addictive')

FP3: GPs are guided about 'relapse prevention' (NICE CG90) ... ('keep on taking'...)

FP4: NICE Guidance for GPs about tapering and ending antidepressant treatment is unrealistic for patients, too swift, and withdrawal effects attributed (by doctors) to 'relapse'.

FP5: Patients are not believed. Withdrawal symptoms (many of which are of a physical nature) are not recognised: instead the doctors are misdiagnosing as 'medically unexplained'.

FP6: Problem located with patient 'medically unexplained symptoms' (MUS) – and suggested that person's 'underlying condition' and/or unreasonable 'anxiety' is the problem.

FP7: There is no support – as withdrawal is not recognised

FP8: There is no way that patients can 'feed back' what is happening to them – and if they attempt to do so they are disbelieved and seen as 'difficult' patients.

Suggested preventative actions are identified including; increasing the availability of alternative responses to medication; educating the public about what psychoactive drugs actually do; amending and updating guidelines and training for doctors to enable truly informed consent, the provision of a service based on more current evidence about the prevalence, duration and symptomatology of withdrawal and how it is best managed.

³ http://www.parliament.scot/S5_PublicPetitionsCommittee/Submissions%202018/PE1651_SSSSSSSS.pdf

⁴ <https://www.nice.org.uk/guidance/cg90/chapter/1-Guidance>

To alleviate the suffering of those currently experiencing withdrawal the BMA's 2015 key policy recommendations⁵ need to be implemented urgently; to create a national helpline for prescribed drug dependence and to create dedicated support services. The suffering described in the petition responses requires systemic rather than individual solutions.

Links with Petition PE1517

I note that the Committee's report on PE1517 - Polypropylene Mesh Medical Devices states--

*“ The Committee has heard too often, in respect of this and other petitions, about the difficulties that patients face in being believed when they tell clinicians what they are experiencing” **“The Committee recommends that the Scottish Government undertakes an exercise to understand why this is such a common concern and what steps can be taken to ensure that patient voices are listened to and heard”***⁶

It is my belief that there are similarities between this petition and my petition. Many of the submissions received on my petition highlight that despite the symptoms people were experiencing as a result of taking prescribed drugs, people felt they had not been believed by their clinician.

Ultimately this (APPG-PDD) report summarises the experience of only 158 people who submitted their accounts to these two petitions but who might be said to represent all those:

- who have not yet tried to come off their medications,
- do not realise there is an alternative narrative to the one they are hearing from their doctors,
- are too ill to tell their story or
- have not survived to tell it.

“I hope you make change, not only for the thousands of us that are suffering now, but for the hundreds of thousands that are currently on prescriptions, ignorant and unaware. This issue is as big as the current opioid crisis and the time for change has come” (W5)

⁵ <https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/prescribed-drugs-dependence-and-withdrawal>

⁶ <https://digitalpublications.parliament.scot/Committees/Report/PPC/2018/8/21/PE1517---Polypropylene-Mesh-Medical-Devices>