



**All-Party Parliamentary Group
for Prescribed Drug Dependence**

**The Patient Voice: an analysis of personal
accounts of prescribed drug dependence
and withdrawal submitted to petitions in
Scotland and Wales.**

August 2018

To be published 8th October 2018



All-Party Parliamentary Group for Prescribed Drug Dependence

APPG officers:

Chairman: Sir Oliver Letwin MP (Con)

Co-chair: Norman Lamb (Lib Dem)

Co-chair: Luciana Berger MP (Lab)

Co-chair: Paul Flynn MP (Lab)

Co-chair: Baroness Masham of Ilton

Co-chair: Earl of Sandwich

On behalf of the APPG-PDD the report was researched and written by Dr Anne Guy MBACP (Accred), UKCP Reg., Marion Brown BSc., MBA, HG.Dip.P (Scottish Petitioner) and Stevie Lewis BA (Hons), PG DipIM (Welsh Petitioner), with additional support from; Susan Reid MBACP (Accred) PGDip, and Karen Espley, MBA., for response analysis, David Cope, process mapping improvement consultant and Catherine Maryon, MA., for data analysis. This report has been made possible by all those who responded to the two petitions and the Petitions Clerks who published them.

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.

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 analysis³ structured using a 'lean thinking' approach to process improvement⁴. The analysis identifies eight systemic 'failure points':

- (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 being experienced
- (4) People experienced a lack of access to effective management / informed medical oversight of their withdrawal process
- (5) Doctors did not recognise new symptoms as withdrawal and discounted patient experience
- (6) Instead doctors assumed the cause of the new symptoms lay within the individual which led to unnecessary tests and referrals
- (7) There are no dedicated nationwide NHS services to access for help and
- (8) No effective avenues for patient feedback on their experience.

Specific preventative actions are identified including:

- increasing the availability of interventions other than medication
- educating the public about what psychoactive drugs actually do
- amending and updating guidelines and training for doctors to enable:
 - truly informed patient consent and
 - the provision of a service based on current evidence about the prevalence, duration and symptomatology of withdrawal and how it is best managed.

In addition, the British Medical Association (BMA)'s 2015 policy recommendations¹⁵ need to be implemented urgently to create:

- a national helpline for prescribed drug dependence and
- dedicated support services.

The suffering described in the petition responses requires systemic, rather than individual, solutions.

"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)

Introduction

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 petitions call on regional parliaments to “take action to appropriately recognise and effectively support individuals affected and harmed by prescribed drugs associated with dependence and withdrawal”^{1,2}.

The aim of the report is twofold: to consider the question ‘what went wrong?’ in these peoples’ interactions with a healthcare system intended to improve, not worsen, their wellbeing; second, 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 report blends qualitative data in the form of verbatim quotes with quantitative data derived from a formal thematic analysis³ structured using a ‘lean thinking’ approach - a process analysis and improvement philosophy now commonly adopted across private and public sectors, including the NHS⁴. This analysis identifies eight systemic ‘failure points’ which generate significant process ‘waste’, i.e. anything which does not improve or add value to patient care and experience - in human terms this is translating as severe and long lasting harm.

Sample and Methodology

Sample: The 158 patient-experience petition submissions include diverse unstructured personal accounts that have been submitted voluntarily over the past year by individual men and women of all ages and backgrounds who wished to support the respective petitions.

The Welsh petition was restricted to Welsh citizens; the Scottish one was open to anyone who wished to respond. All personal accounts have been formally processed by the respective Petition teams, according to their own official and data protection and privacy rules, prior to formal online publication on their respective webpages^{1,2}, which include all evidence for the petitions to date and which are on-going.

Inclusion criteria: Submissions from individuals or carers giving personal stories.

Exclusion criteria: Known duplicate entries were removed (sent to both Scottish and Welsh petitions), as were any submissions from organisations or other commentators and follow up submissions by the same person.

Whilst responders to the Welsh petition were invited to respond to four questions about their experience⁵ these only represent 7.6% of the 158 submissions analysed. The vast majority therefore, i.e. those responding to the Scottish petition, had a completely free hand in deciding what information to provide about their experience, and this needs to be born in mind when considering the results of the captured themes. On the one hand this means that not everyone's experience is captured on every issue (captured as 'not said'), but on the other, the remarkable similarities of experience are perhaps more notable.

Methodology: Patient interactions take place within a defined healthcare system which one might reasonably assume has been designed to offer a valuable or helpful service to those patients. In order to understand what common problems are being encountered and to locate them in that system the researchers conducted a formal thematic analysis³ of the 158 personal accounts adopting concepts from 'lean thinking' as the lens to structure findings.

'Lean thinking' is a process analysis and improvement philosophy which originated in the automotive industry that is now commonly adopted across private and public sectors, including the NHS⁴. In this approach processes or 'Patient Journeys' are mapped and considered in terms of what *value* is created and what outcomes or activity (resulting from failure points) might be defined as *non-value* added for customers, or in this case, patients.

Importantly this kind of analysis locates problems with the system in which they are generated rather than with individuals either working in or being impacted by the system – this is an essential step in moving towards understanding what actions might be taken to prevent problems occurring and to design and implement appropriate measures to ensure the overall system is delivering the desired outcomes, rather than blaming rogue doctors or complaining patients.

Method

All petition submissions were read in order to define inclusion and exclusion criteria, identify an initial view of the common themes of a patient journey together with a range of possible values for each theme. A thematic data capture tool was created and adjusted following an initial pilot across a random sample of submissions.

Patient accounts were then analysed using the resultant thematic framework³ and in addition, verbatim that encapsulated both a particular issue the responder encountered and the overall impact on their life identified. Results from the data capture were summarised, reviewed and overlaid on a framework of two patient journey maps - A) initial prescription and outcomes and B) withdrawal and outcomes.

Researchers were recruited from a range of backgrounds including psychotherapy, nursing (ex) and process improvement. Only one researcher had personal experience of prescribed drug dependence and withdrawal and analysed 6% of the sample.

The populated journey maps were then reviewed to identify systemic 'failure points' i.e. where the process generated 'non-value' added outcomes. These points were analysed to identify what preventative actions could be taken for the benefit of both the customers of that process and those running it.

Relevant verbatim was selected in order to describe the human impact of these system failures from the patient view. These excerpts were included in Patient Experience Maps A & B and in an overall rich picture summary of the impact on people's lives, C.

Limitations: As 92% of the patient accounts analysed were submitted completely free form there were gaps in the data where petitioners had simply not commented on a particular aspect of experience – these are shown in the data tables as 'not said'.

It should also be noted that both the number and severity of drug or withdrawal effects are under represented in this analysis, as many of the very harrowing accounts did not always give the details required to capture the number of effects using phrases like 'myriad', or 'too many to count'. As one researcher, an ex-nurse, summarised 'the data capture does not truly describe the full horror of what these people have gone through'.

Results

The results of the analysis are presented as two Patient Journey Maps and a rich picture summary:

A: Initial Prescription and Outcomes Map

B: Withdrawal and Outcomes Map

C: Overall impact on patient lives of the experience of prescribed drug dependence and withdrawal.

The identified process failure points are expanded upon and some possible preventative actions noted.

Notes on reading Patient Journey Maps:

- they are best viewed in full screen or printed on A3
- readers are advised to follow the process flow from left to right, returning to read the verbatim excerpts located at the top of the page as they reach the relevant failure point (yellow diamonds).
- all verbatim excerpts are unedited transcripts from personal submissions using the lettering system allocated by the petitions clerks.

Failure Points associated with Patient Journey Map A – Prescription and Outcomes

FP1: Prescription offered as an apparent first course of action – lack of alternatives offered

Whilst up to three GP initial responses per patient account were noted, being offered talking therapy was only mentioned by 5% (8) responders, despite 35% (56) of responders volunteering an account of a stressful or traumatic triggering life event as the cause of the experiences which led them to visit their doctor, 63% of which were primarily psychological.

Possible preventative actions include:

- Understanding and addressing the causes behind the lack of availability of alternative responses other than medication (an increased range of talking therapies and social prescribing) e.g. review the National Institute for Health and Care Excellence (NICE) guideline development process reliance on a medical model of evidence which it has been argued is inappropriate for interventions based on dialogue⁶
- Educate the public about what psychoactive drugs actually do (i.e. they do not cure an underlying disease process or chemical imbalance⁷)
- Amend guidelines and training for doctors to include the provision of access to evidence summaries on when medications have been found to be helpful and in what ways, alongside the Number Needed to Treat (NNT) figures so that patients may evaluate the risks of drug interventions alongside others offered (e.g. the NNT for anti-depressants is 8, i.e. for one person to benefit 7 will be exposed to possible harms; for antipsychotics it is 6⁸).

FP2: No warning is given about possible dependence and associated withdrawal effects so there is no possibility of informed consent

46% of responders report not being warned about side effects (as NICE guidelines⁹ recommend they should be) with a similar 47% of responders saying they were not warned about possible dependence & withdrawal effects. No-one said they were warned about either.

Possible additional preventative actions include:

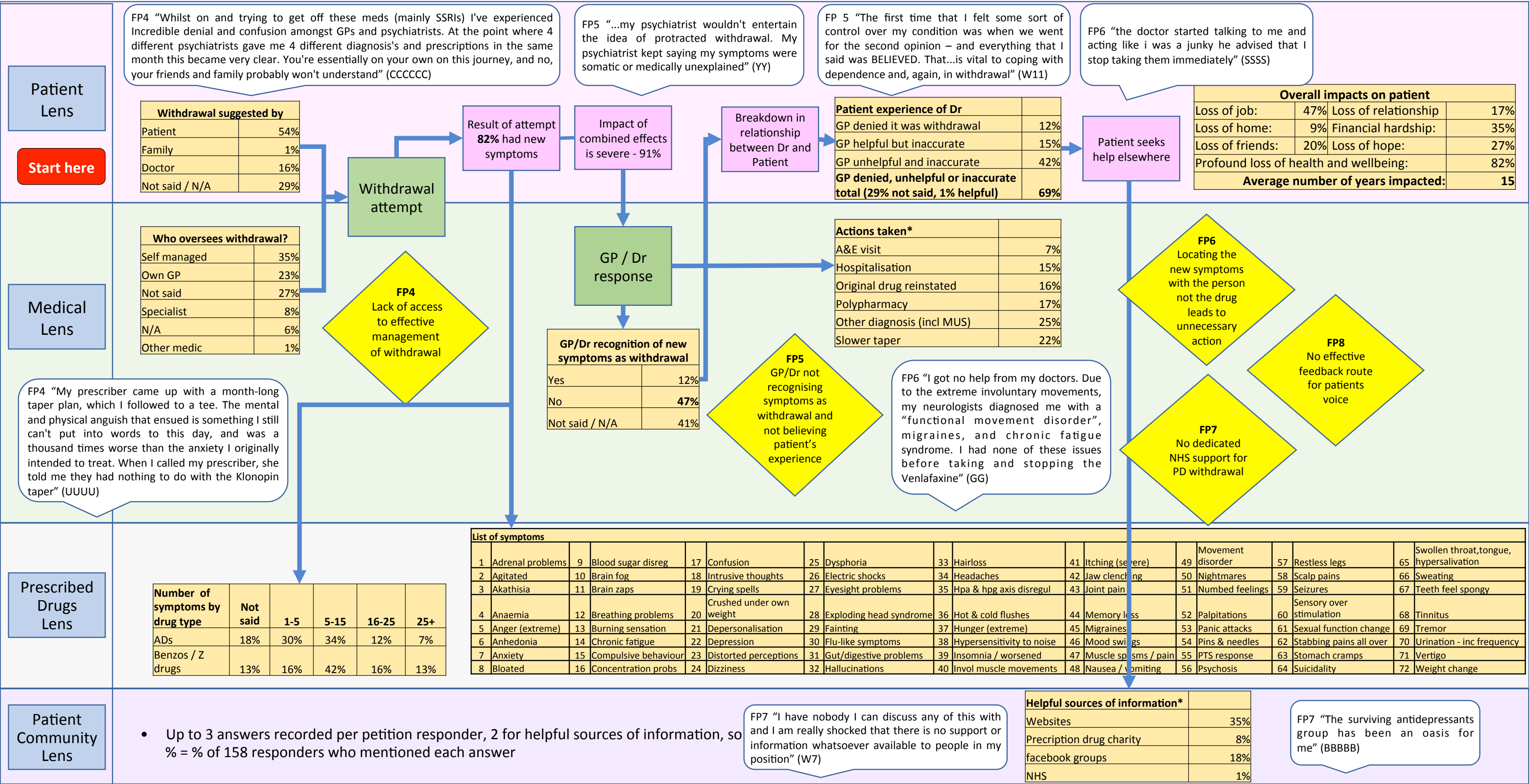
- Update NICE guidelines covering the prescription of psychoactive drugs to include the requirement to warn the patient about possible issues of dependence and associated withdrawal effects (in addition to side-effects)
- Implement a method of ensuring warnings are given to enable patients to give informed consent to treatment.

FP3: Treatment is sometimes continued despite drugs not helping and/or severe side effects

36% of responders volunteered the fact that the drug they were prescribed did not help with their initial problem.

Possible additional preventative actions include:

- Implement a selective use protocol based on NNT data. This would attempt to identify those not responding positively to the drug in order to switch them to non-medication interventions as quickly as possible. Patients would be informed of the timeline for assessing benefits, evaluating side effects, ending treatment and alternative treatment paths if benefits not realised or side effects significant⁸.



Failure Points associated with Patient Journey Map B – Withdrawal and Outcomes

FP4: Lack of access to effective management / informed medical oversight of withdrawal process

The fact that 82% of responders said they had new symptoms appear after attempting to come off their medication and that 35% of responders said they attempted to manage their own withdrawal would strongly point to a lack of access to effective medical oversight of the withdrawal process.

Just 32% said they were under the supervision of a medical professional – however, 86% of those managing their own withdrawal said they had new symptoms arise, compared to 98% of those being managed by a medic.

Possible additional preventative actions:

Guidelines and training need to be created or amended to:

- Rectify the current bias towards drug therapy initiation without adequate planning for its ending
- Include up to date, accurate tapering information (that was predominantly accessed via the patient community online)
- Warn patients about possible withdrawal effects & dependence and the need for slow tapering, at both initial prescription and at medication reviews

FP5: GPs do not recognise new symptoms as withdrawal and discount patient experience of them as unrelated to original issue

47% of responders volunteered information indicating their doctor did not recognise new symptoms as withdrawal effects, with 12% of responders explicitly saying their doctor denied what they were experiencing was withdrawal.

In terms of their overall experience of their doctor a total of 69% of responders said their doctor either denied withdrawal, was unhelpful or gave inaccurate information.

1% said their doctor was helpful and accurate.

When these patients raised the possibility of their symptoms being withdrawal effects and were not believed it undermined their relationship with their doctor and 51% volunteered that they had turned elsewhere for support. Many were effectively pushed out of the mainstream healthcare system that they increasingly have come to distrust and see as the cause of their problems.

The originating petitioners both highlighted in their submissions that *“affected patients are finding themselves with vague diagnoses e.g. ‘medically unexplained symptoms’ or ‘functional/somatic system disorders’, which are essentially psychiatric diagnoses attributing various debilitating and disabling physical symptoms to patients’ own anxiety, beliefs, etc. This has the effect of discounting, disempowering and demoralising these patients still further”*^{1,2,10}.

Failure Points associated with Patient Journey Map B – Withdrawal and Outcomes

FP5 continued: Possible additional preventative actions:

- GP education about withdrawal needs updating. In its response¹¹ to the Scottish petition, the Royal College of General Practitioners (RCGP) included a process flow which relies on a 15 year old study of relapse prevention which itself acknowledges that:
“Unavoidably, the design of the trials included in this review necessitated that some patients were withdrawn from active treatment. Therefore, the possibility is raised that the risk of relapse or recurrence might be increased by a direct quasi-pharmacological response to the withdrawal of medication per se rather than the relapse or recurrence being solely due to the underlying disorder”¹².
- Guidelines and training need to be created or amended to reflect more recent evidence that suggests antidepressant withdrawal has a far higher incidence and longer duration than current guidelines acknowledge which gives “added credence to concerns that many doctors are misdiagnosing withdrawal e.g. as relapse or treatment failure”¹³.

FP6: Assuming the cause of new symptoms occurring at withdrawal lies within the individual and not with the drug led to unnecessary tests and referrals

- 25% of responders were given an additional diagnosis following withdrawal
- 17% said they ended up on multiple drugs
- 15% said they were hospitalised
- 7% said they went to A&E at least once

In Lean thinking terms the consequence of all the previous failure points has led to either rework or over-processing⁴ where unnecessary steps are performed that do not add value – in many cases these steps have done further damage (e.g. poly-pharmacy).

For some of the responders all consultations, no matter what the problem, are now being seen through the lens of having a root cause in anxiety/depression because of their history with these medications, sometimes when that wasn’t even the reason for being prescribed the drug in the first place: “On the day he retired, my long term GP...phoned me to say that he had simply forgotten the neck injury reason for my prescription and just thought I always had anxiety.” (NNN)

Possible additional preventative actions:

- If withdrawal was managed and recognised this time and effort would largely be saved. In the meantime, A&E staff could be trained to recognise it and signpost patients to appropriate dedicated services once created.

Failure Points associated with Patient Journey Map B – Withdrawal and Outcomes

FP7: There are no dedicated nationwide NHS services to access for help (one Prescribed Medication Support Service exists in North Wales)

Overall 51% of responders said they had found alternative sources of information to those provided by their doctors (which are detailed on map B).

Possible preventative actions:

For these respondents there remains a clear lack of support for withdrawal. There is an urgent need to identify existing patients (e.g. by reviewing those given diagnoses such as ‘medically unexplained symptoms’) and to reach out to them to provide appropriate dedicated services.

This is in line with the 2015 BMA report¹⁴ based on a call for evidence on ways to improve the prevention and management of prescribed drug dependence. The three key policy recommendations were:

1. the creation of a national helpline for prescribed drug dependence;
2. an increase in provision of specialist (dedicated) support services;
3. revised guidance for doctors on safe prescribing, management and withdrawal of prescription drugs¹⁵

FP8: No avenue for patient feedback on their experience

The final failure point is that there currently appears to be no effective review of performance for this system as a whole, involving collection of feedback from its customers (patients) thereby allowing the patient voice to be heard. This is logically connected to failure point 5 as the evidence from these responders is currently systemically not acknowledged, and so patients find themselves caught in a loop whereby the system designed to help them not only fails to do so but in many cases repeatedly compounds the problem.

This seems to echo the experience of other patient groups who have become experts by experience and resorted to taking legal action against the NHS (e.g. women who have suffered issues with Transvaginal Meshes). The Scottish Parliament has commented in its 2018 report on this issue in response to Petition PE1517, that

*“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. In particular, on this petition, the Committee emphasises its alarm at the apparent disregard of patients’ evidence of the devastating and debilitating impact that mesh has had on their lives. **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**” [emphasis added]¹⁶.*

C: Overall impact on patients

“I was once a qualified primary schoolteacher... now I am suffering intolerable symptoms through Benzo Withdrawal Syndrome. I can't do anything with my 8yr-old. My partner goes out to work and leaves me bedridden with plates of food ...” (CCCC)

“I don't believe I will ever again be the productive, happy, sociable person I used to be because of one 10 minute appointment where a GP decided it was appropriate to prescribe me SSRIs with no warning of possible side effects.” (W7)

“They took away my meds
They hung me out to dry
My world began to crumble
And all I did was cry
The paramedics came around
They rushed me to A & E
They said, carry on as normal
It's only anxiety
My body shook n shuddered
My mood was mean and low
I pushed away my loved ones
I wanted to die, just go” (VVVV)

“I am unable to work and housebound. Withdrawal is the single most gruelling and challenging experience of my life and I know that I am far from alone. I understand what is happening to me, many don't and are frightened by it” (W6)

“I was an avid gym-goer, dedicated to my fitness. I have never suffered physical illness in my life, prior to Citalopram. Now I have been so crippled with debilitating symptoms ..” (DDDDD)

“I was fully functioning working full time as accountant several staff under me, driving socialising dating - fully normal life. All taken away from me, driving included” (YYY)

Overall impacts on patient			
Loss of job:	47%	Loss of relationship	17%
Loss of home:	9%	Financial hardship:	35%
Loss of friends:	20%	Loss of hope:	27%
Profound loss of health and wellbeing:			82%
Average number of years impacted:			15

“As a consequence of all of this my wife's health has deteriorated rapidly over the years. She has gone from a normal functioning person, working and studying to being completely incapacitated. She has always taken care of her self through diet and exercise and does not drink or smoke, but yet a legally prescribed pill has left her this way” (AAAAAA)

“Words cannot describe the utter hell , torment and terror that I have lived thru and continue to battle thru every single day and not one ounce of help, empathy or sympathy from any doctor” (YYYYYY)

“Before I was put in this situation I was a 'normal' person doing things like most people are doing, have always supported myself, working full time. I have lost all savings, small investment and close to losing my home” (YYYYYYY)

“I continue to fight to get my life back , I could write a novel on the amount of suffering I have endured thanks to SSRI use. It has effected every part of my life , I can't work , I am not able to be active and even worse I can't get help because the prescribers are in the dark about the true harms of the drugs they prescribe” (XXXX)

“I regressed from an amateur international athlete to a very ill, depressed and withdrawn individual. At low points I considered suicide” (XXX)

Conclusion

This report has attempted to describe and analyse the collective experience of those people who responded to two regional petitions on prescription drug dependence and withdrawal. The implications of this collective picture can be considered from three key standpoints – the individual, the systemic and the social.

On an individual level it is clear that, at the very least, a proportion of patients' needs are not being met in anything like a satisfactory way and that they are struggling to move the discussion beyond their own psychological contribution to their experiences. The personal suffering currently being experienced is evident in every one of the personal accounts submitted. Doctors following current guidelines are also likely to be frustrated at the lack of effectiveness of what is recommended in terms of knowledge and options available to them.

Systemically a paradigm shift is needed from one that locates the problems being experienced at withdrawal in the individual (particularly in their psychology) to the effect of the drugs being prescribed, and beyond the drugs to the larger system which then supports patients in either adapting to those effects if beneficial, or withdrawing from them and trying alternative interventions if not. Processes need to be reviewed and redesigned in the light of this to prevent more patients being harmed, marginalised and thrown back on their own resources or those of other experts by experience.

Finally from a social standpoint there are great losses in both human and financial terms that could be significantly reduced by changing how this issue is dealt with.

Ultimately this 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)

References

- ¹ Scottish Petition PE01651 <http://www.parliament.scot/GettingInvolved/Petitions/PE01651>
- ² Welsh Petition reference P-05-784 <http://www.senedd.assembly.wales/ielIssueDetails.aspx?IId=19952&Opt=3> Personal Narratives: <http://www.senedd.assembly.wales/documents/s74825/Personal%20Experiences.pdf>
- ³ Braun, V., & Clarke, V., 2006, Using thematic analysis in psychology, *Qualitative Research in Psychology* 2006;3 77-101, Edward Arnold Ltd
- ⁴ NHS England, 2007, Going Lean in the NHS, *NHS Institute for Innovation and Improvement*, [Viewed July 2018] Available online: <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Going-Lean-in-the-NHS.pdf>
- ⁵ Welsh Petition reference P-05-784, 2018, Invitation to Submit Views [Viewed August 2018] Available online: <http://www.senedd.assembly.wales/documents/s72461/February%202018%20-%20Invitation%20to%20submit%20views.pdf>
- ⁶ Guy A, Loewenthal, D., Thomas, R. and Stephenson, S., 2012, Scrutinising NICE: The impact of the National Institute for Health and Clinical Excellence Guidelines on the provision of counselling and psychotherapy in primary care in the UK', *Psychodynamic Practice*, 18.1.
- ⁷ Moncrieff, J., 2009, A Straight Talking Introduction to Psychiatric Drugs, *PCCS*, Ross-on-Wye
- ⁸ Whitaker, R., 2018, Randomised Controlled Trials of Psychiatric Drugs Tell of Harm Done, *Mad in America* [viewed 24th July 18] Available Online: <https://www.madinamerica.com/2018/06/rcts-of-psychiatric-drugs-tell-of-harm-done/>
- ⁹ NICE, 2009, Treatment and management of depression in adults (CG90). National Collaborating Centre for Mental Health, Published by *The British Psychological Society* 2010 [Online]. Retrieved from <https://www.nice.org.uk/guidance/cg90/chapter/1-Guidance#care-of-all-people-with-depression>
- ¹⁰ NHS, 2018, Medically Unexplained Symptoms [Viewed August 2018] Available online" <https://www.nhs.uk/conditions/medically-unexplained-symptoms/>
- ¹¹ RCGP, 2018, Submission to Scottish Petition PE01651, Available Online: http://www.parliament.scot/S5_PublicPetitionsCommittee/Submissions%202018/PE1651_SSSSSSSS.pdf

References contd...

- ¹²Geddes, JR., Carney, S.M., Davies, C., et al, 2003, Relapse prevention with antidepressant drug treatment in depressive disorders: a systematic review. *Lancet*, 361, 653-661: p660
- ¹³Davies, J., & Read, J., 2018, A Systematic Review into the Incidence, Severity and Duration of Antidepressant Withdrawal Effects: Are Guidelines Evidence-Based?, *Addictive Behaviours* (forthcoming) p12
- ¹⁴ BMA, 2015, Prescribed drugs associated with dependence and withdrawal – building a consensus for action , Available online: http://bmaopac.hosted.exlibrisgroup.com/exlibris/aleph/a23_1/apache_media/H6IB5G1BL8SX1KJ7VY4MCRCXVG6EV7.pdf
- ¹⁵ BMA, 2016, Supporting individuals affected by prescribed drugs associated with dependence and withdrawal, Website page available: <https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/prescribed-drugs-dependence-and-withdrawal>
- ¹⁶The Scottish Parliament Petitions Committee, 2018, PE1517 - Polypropylene Mesh Medical Devices Available online: <https://sp-bpr-en-prod-cdnep.azureedge.net/published/PPC/2018/8/21/PE1517---Polypropylene-Mesh-Medical-Devices/PE1517%20-%20Polypropylene%20Mesh%20Medical%20Devices.pdf>