

# **Short Life Working Group on Prescription Medicine Dependence and Withdrawal**

## **Consultation Analysis**

**February 2022**

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# 1. Executive summary

In response to a petition submitted to the Scottish Parliament and work undertaken by Public Health England (PHE) to review dependence and withdrawal associated with some prescribed medicines, the Scottish Government established a short life working group (SLWG). The group was asked to look at the scale of the issues in Scotland and the recommendations from the PHE report in the Scottish context, and with consideration of Scottish data. Membership of the SLWG included medical, pharmacy and nursing representation from the professions as well as professional bodies, patients with lived experience, patient organisations, SIGN, Public Health Scotland and academia.

The group sought to identify the scale, distribution and underlying contributors to prescription drug dependence and what might be done to address this in Scotland. The review covered adults (aged 18 and over) and 5 classes of medicines:

- Benzodiazepines (mostly prescribed for anxiety and/or insomnia)
- Z-drugs (sleeping tablets with effects similar to benzodiazepines)
- Gabapentin and pregabalin (together called gabapentinoids and used to treat epilepsy, neuropathic pain and, in the case of pregabalin, anxiety disorders)
- Opioids for chronic non-cancer pain
- Antidepressants (for depression, anxiety disorders and neuropathic pain).

Draft recommendations were provided to the Cabinet Secretary for Health and Sport who has approved their publication by way of public consultation. The consultation paper discussed each of the PHE recommendations in turn, described the current landscape in Scotland, work that had been undertaken during the life of the SLWG and recommendations for further work agreed by the group and patient representatives. The analysis of the results of this consultation form the basis of this report.

A quantitative analysis was conducted on two of the questions within the consultation. These questions asked:

1. Whether the individual agreed with the specific recommendation, and
2. The degree to which they agreed with the recommendation.

Respondents were also provided with a free comment box within which they could express any particular comments they may have in regards to the recommendation or any other topic of interest or concern. A qualitative analysis of the responses to this open ended comments looked for themes, insights and opinions on the respondents views of the consultation recommendations.

## 1.1 Level and strength of agreement with the recommendations within the consultation:

There was a high level of agreement for the recommendations – 34 respondents (87%) agreed with Recommendations 1, 3, 4 and 5, and 33 respondents agreed with (85%) recommendation 2.

Table 1. Table showing the summarised level of agreement respondents recorded for each recommendation.

	Recommendation				
	1	2	3	4	5
Effective	46%	36%	38%	38%	41%
Somewhat effective	28%	33%	41%	38%	36%
Not effective	13%	18%	10%	13%	13%
Not answered	13%	13%	10%	10%	10%

## 1.2 General themes that emerged throughout the consultation:

Although stakeholder responses were characterised by a wide range of topics and opinions in regards to their comments on the individual recommendations, there were certain themes that emerged across responses. These were topics or views that had a continuous thread throughout the various comments, even if within individual recommendation sections there were too few references to identify an emergent theme.

These topics included:

### Value of data

- The value of Data and research, and the particular areas of interest respondents highlighted for further attention and focus.
- The need to consider not only how evidence and data are generated by also how that knowledge is implemented into practice through a process of knowledge mobilisation. Respondents highlighted some current issues with this process for existing data, and the need to alleviate the issue if future work is to be fruitful.

### Need for culture change

- The need for change in work culture/dynamics within the healthcare system. Respondents made reference to the need for greater communication within and between actors in the healthcare system, as well as improved communication and decision making between patients and practitioners.
- Respondents also commented on the topic of patient experience and patient empowerment. These comments focused on the need to centre the patient experience in both data collection and research focus. In addition to the need for patients to be able to make informed decisions through a greater access to relevant information (particularly around the issue of withdrawal), as well as a more collaborative approach to the planning and decision making process of their individual health journey.

## Accessibility of information

- Respondents discussed the need for suitable messaging with regards to guidance/information. Many respondents commented on the need to consider the accessibility of the guidance/data/information that the recommendations would make available. Accessibility in this context often referred to the ability of patients to have the means (either the physical IT resources, or the technical capacity to use said resources) to navigate to the required digital information and to ensure that alternatives were available in order to compensate for any potential disadvantages people may have in accessing this information.

## Better use of resources

- A few respondents commented on the need to better utilise existing resources such as community pharmacies and community pharmacists in order to action the recommendations of the consultation paper.
- Many respondents commented on the issue of resourcing through the consultation. This typically revolved around discussion of the need for greater resources to be made available in order for the recommendations to be successfully implemented. Resourcing in this context could refer to issues such as additional staffing, additional funding, or additional time for people to parse the information available.

The final topics that emerged throughout the consultation were the positive comments and concerns respondents had with regards to the individual recommendations, as well as the consultation as a whole.

In addition, the comments to each individual recommendation were analysed and grouped into emergent themes for each specific recommendation. These themes were often recommendation specific, however due to the nature of the subject matter, themes were often interrelated (e.g. guidance development and adherence), and therefore should be considered within the broader context of the discussion around the recommendation in particular and the consultation as a whole.

## 2. Introduction

### 2.1 Background

In 2017 a Petition was submitted “calling on the Scottish Parliament to urge the Scottish Government to take action to appropriately recognise and effectively support individuals affected and harmed by prescribed drug dependence and withdrawal”.

In January 2018, the UK Public Health Minister, commissioned Public Health England (PHE) “to undertake a review of the scale and distribution of dependence, and the short term discontinuation or longer term withdrawal symptoms associated with prescribed medicines, and the optimal means of reducing it”. The Scottish Government had regular engagement with PHE during the scoping phase, asking them to extend the specifics of the review to Scotland. However, in May 2018 PHE gave notice that whilst Scotland would be afforded observer status in the expert reference group, and have access to findings and learning, the scope of the review would not be extended to report separately on Scotland.

In September 2019, PHE presented its evidence review of “Dependence and withdrawal associated with some prescribed medicines”. The review made five key recommendations. During this period, analysis of the Scottish data was undertaken to provide comparisons and to inform the recommendations. At the end of 2019, Scottish Government set up a Short Life Working Group (SLWG) to consider the PHE recommendations in a Scottish context (See Appendix 1). A Patient Group was established to sit alongside the SLWG with Patient Representatives sitting on the SLWG itself.

The SLWG work covered adults (aged 18 and over) and 5 classes of medicines:

- Benzodiazepines (mostly prescribed for anxiety and/or insomnia)
- Z-drugs (sleeping tablets with effects similar to benzodiazepines)
- Gabapentin and pregabalin (together called gabapentinoids and used to treat epilepsy, neuropathic pain and, in the case of pregabalin, anxiety disorders)
- Opioids for chronic non-cancer pain
- Antidepressants (for depression, anxiety disorders and neuropathic pain).

During 2020, the SLWG and Patient Group met six times, due to the COVID pandemic, most of these meetings took place virtually either by telephone or video conference.

Draft recommendations were provided to the then Cabinet Secretary for Health and Sport who approved their publication by way of public consultation. The consultation paper discussed each of the PHE recommendations in turn, described the current landscape in Scotland, work that had been undertaken during the life of the SLWG and recommendations for further work agreed by the group and patient representatives.

The recommendations from the SLWG to address prescription drug dependence and

withdrawal in Scotland were set out in the consultation document with the aim to gather views from a much wider group of people. The analysis of the results of this consultation form the basis of this report.

## 2.2 Analysis

A quantitative analysis was conducted on two of the questions within the consultation. These questions asked:

1. Whether the individual agreed with the specific recommendation, and
2. The degree to which they agreed with the recommendation.

These were closed questions, with the first question having a limited number of possible responses, and question two utilising a Likert scale from 1-5 to indicate agreement.

Respondents were also provided with a free comment box within which they could express any particular comments they may have in regards to the recommendation or any other topic of interest or concern. A qualitative analysis of the responses to these open ended comments looked for themes, insights and opinions on the respondents views of the consultation recommendations. This method was chosen to gather feedback from individual respondents in regards to any comments they have on the individual recommendations put forward within the consultation document or the broader topic area and environment. Alongside the online consultation two online group discussions took place. Although the format of the questions were different between the online consultation and the group discussions, both revolved around the draft recommendations. The group discussions were distilled into three 'breakout' groups discussing: 1. 'Guidance for medical professionals'; 2. 'Advice and support for patients' and; 3. 'Data and research'. A summary of the responses to the two consultation events can be seen in Appendix 2. The responses from the discussion groups were generally similar to the themes and topics identified in the online consultation. These themes/topics have been incorporated into the analysis of the general themes.

It is important to note that:

- Some responses were from organisations or membership bodies and collated the views of a number of people or organisations (A full list can be seen in Appendix 3).
- The questionnaire asked for comment without specifying exactly what to comment on, as such there were a varying array of topics discussed.
- Since respondents were also asked about their level of agreement with the recommendation in the previous questions, this could influence whether they discussed those aspects within the comment section as they may consider the topic to have already been covered.
- Similarly because a topic wasn't discussed by an individual does not mean that it was not important to them, merely that they did not include it with

that particular response. As such omission does not indicate disinterest or disagreement.

- Responses are not fact but reflect views and opinions.
- Responses are not necessarily representative of public opinion.

This report presents a qualitative summary of the analysis. It focuses on what people said regarding:

- a) Topics relevant to individual recommendations.
- b) Topics relating to the broader topic of prescription dependence and withdrawal and
- c) Topics relating to the consultation itself.

The analysis identified topics, themes and categories that were mentioned frequently. Within these broad groupings, different responses often focused on different aspects or areas of interest. Topics/themes that came up less frequently may also be included in this report if they raised important issues and/or provided valuable insights.

It is important to note that in many cases, the themes and topics presented in this report are interconnected and have a direct impact on each other, or form part of one another (e.g. development of new guidance and implementation of guidance/practice). They should not be regarded as individual or isolated topics.

The analysis in this report therefore represents a range of topics which stakeholders responding to the questionnaire felt were relevant to the recommendations within the consultation or the topic area more broadly.

### 2.2.1 How the responses were analysed

The topics, themes and categories that are identified in this report are those that arose naturally from analysis of the individual responses to the questionnaire. Identifying themes/categories are an attempt to reflect to the reader the broad features of the responses from the stakeholders as a group. The analysis of the questionnaire did not involve assessing the validity of the statements made in respondents' answers to the questions. Instead, this report seeks to reflect the stakeholder's views and opinions as they were presented within their responses.

### 2.2.2 How the analysis is presented in this report

For each recommendation we will present the proportion of agreement shared by the respondents, how respondents scored their level of agreement of the recommendation, and finally a thematic analysis of the main themes that emerged from the open ended request for comments relating to each question.

Responses to the first two questions were analysed and described quantitatively in order to provide an illustration of the views of the respondents with regards to the

specific recommendations. These questions looked to ascertain whether individuals agreed with the particular recommendations, and the level of the agreement/disagreement. For simplicity, responses to the second question were grouped; with “extremely effective”, “very effective” and “effective” being condensed into a single “effective” category, “somewhat effective”, “not effective” and “not answered” remained ungrouped (for a more detailed breakdown of responses please see Appendix 4). These descriptive statistics should be interpreted cautiously, as the sample size was small, and the group may not be representative of the general population. As such the questions are best interpreted as a reflection of the responses of the individual respondents rather than an indication of a more generalised level of agreement/disagreement amongst the Scottish population.

Overall, responses to the open ended comment sections were varied and expansive. There was little clear consensus across the responses on the topics or themes. However, it is likely that this is due – at least in part – to the purposefully open-ended request for comment within the questionnaire. The opportunity to provide comments was intended to gather the breadth and depth of people’s views and ideas. The questionnaire avoided providing people with pre-determined options to choose from, that could artificially ‘restrict’ or ‘limit’ the topics covered in the responses to this section..

Due to the range of themes covered in the responses - reporting by frequency was not deemed appropriate for the analysis of the free text comment sections. (‘Reporting by frequency’ would be to analyse each theme by the number of people/responses that mentioned it. For example, “45% of responses referenced further research into patient experience”). Instead, the report seeks to draw out general themes or categories within the individual responses where possible. It then seeks within those themes/categories to indicate the broad nature of the information provided across all of the responses.

### **3. General overview of emergent themes within the report**

There were certain themes that emerged across responses. These were topics or views that had a continuous thread throughout the various recommendation comments, even if within individual recommendation sections there were too few references to identify an emergent theme. The analysis of the individual recommendations from which these general themes were drawn can be found in Appendix 5.

#### **3.1 Data/research:**

Many respondents throughout the consultation discussed or referenced data collection and usage of prescribing data, as well as drug dependence and withdrawal. The general trend amongst the comments was an agreement in regards to the need for greater data collection and research in the topic, with many respondents suggesting particular benefits of the proposed recommendations, as well as suggesting further topics of investigation (these are listed in the ‘specific recommendations’ section of each recommendation subheading in Appendix 5).

Broadly, respondents discussed:

- The need for greater data collection and utilisation, with a few respondents suggesting a more expansive monitoring scheme to evaluate levels of data and research utilisation across the system.
- That data should be regularly collected, easily accessible, meaningful, timely, robust, linked across the system, and influencing guidance and practice.
- That there are particular areas of interest that some respondents felt were particularly under researched, such as the patient experience, non-pharmaceutical alternatives to certain prescription medications, particular populations of interest such as those from disadvantaged backgrounds, or those with chronic pain etc.
- That resources within the system could be better utilised for data collection or monitoring of specialist services such as substance abuse services, chronic pain services, mental health services, as well as community pharmacies. This could also be seen as another means of improving data linkage, and multi-disciplinary working.

### 3.2 Knowledge mobilisation:

Throughout the consultation many respondents made reference to the need to ensure that both new and existing data and research were incorporated into current practice and guidance.

Several respondents noted that although further research as put forward by the recommendations is laudable and desirable, that new research in of itself would not necessarily lead to improvements, as existing work that could already be beneficially utilised was not being applied currently. A few respondents went further and even suggested that the new research wasn't necessary, as "*enough*" was already known to enact the positive changes they wished to see, however this information was not translating into changes in practice and/or guidance.

Several respondents made recommendations on how to change this dynamic in order to improve knowledge utilisation and mobilisation, focused on practitioner education and work culture as the bottle neck within the process and the potential mechanism of change. Comments typically referenced a perceived unwillingness to adopt new practices due to resistance to change within practitioners/disciplines, or an inability to adopt to new practices due to external constraints e.g. time/resourcing issues, workload, issues with access to data, perceived value of the data (e.g. regularly updated, relevant, responsive) etc.

### 3.3 Need for change in work culture/Doctor-Patient relationship

Several respondents referenced a need for a change in work culture. These comments often referred to the need for greater knowledge mobilisation to tackle issues with a perceived lack of implementation of existing data/guidance (as discussed above), as well as a need for a change in the nature of the relationship

between prescriber and patient, and a general improvement in communication across the healthcare sector.

A few respondents described the need for greater communication and collaboration between parties involved, this included both prescriber to patient, as well as multi-disciplinary and multi-agency communication. A few respondents also commented on a perceived need for prescribers to “accept” the potential for dependency of certain medications, in order to adequately inform patients of the consequences of their prescribed medications, as well as better support them to tackle the symptoms and process of withdrawal.

Other responses focused on what were perceived as limitations of the current consultation model. A few respondents commented on their scepticism of seeing changes in practice, given the limited time they are allocated to interact with practitioners, and discuss their issues and overall health journey. Respondents pointed to the need for time to discuss information in order for practitioners to accurately assess the patients situation, as well as the time necessary for patients to be given sufficient opportunity to ask questions and make informed choices. These two features were said to require more time than is currently allowed for in the appointment system (less than 10 minute time limits were specifically referenced). Similarly, when discussing telehealth support services, a few respondents expressed concerns that these measures were seen as a means of compensating or potentially replacing these practitioner/patient interactions. These respondents reiterated their belief that interpersonal communication should be the paramount means of accessing information, with telehealth services providing ancillary support.

### 3.4 Community pharmacy

A few respondents expressed their belief that community pharmacies and community pharmacists should be more actively involved in the health care journey of those experiencing prescription medicine dependence and withdrawal.

These respondents commented on the need for greater data linkage with community pharmacies in order for a greater degree of support to be made available. For instance, one respondent noted that community pharmacies do not have access to a patient’s medicine indication or treatment plan, which limited their ability to support patients with “relevant medicine discussions”. Similarly another suggestion was to notify community pharmacists when a patient begins deprescribing in order to enable them to support the patient, this was noted to be potentially helpful during times when their prescriber may not be available.

The "new medication service" (NMS) in England was referenced as a potential model to emulate, the respondent described the system as allowing community pharmacies to provide information and support around that new medication provided such as antidepressants.

### 3.5 Patient experience and patient empowerment

The topic of patient experience was referenced by several respondents. These comments focused on the need to centre the patient experience in both data

collection and research focus. In addition, the need to consult and include patients alongside medical experts in working groups and decision making bodies was also mentioned.

The topic of patient empowerment was also touched upon throughout the consultation comments, with several respondents discussing the need for patients to be able to make informed decisions through a greater access to relevant information (particularly around the issue of withdrawal), as well as a more collaborative approach to the planning and decision making process of their individual health journey.

The topic of patient empowerment also arose in the two online discussion groups that took place alongside the online consultation. Although many of the comments were similar to those referenced above, a few respondents discussed the benefit and need for greater patient advocacy within standard practice. This topic did not have the same emphasis within the online consultation as in the group discussion.

### 3.6 Suitable language for information

Many respondents commented on the need to consider the accessibility of the guidance/data/information that the recommendations would make available. Accessibility in this context often referred to the ability of patients to have the means (either the physical IT resources, or the technical capacity to use said resources) to navigate to the required digital information and to ensure that alternatives were available in order to compensate for any potential disadvantages people may have in accessing this information. The two main groups that were highlighted as requiring particular focus in this regard, were the elderly and those from deprived areas. Respondents highlighted the respective challenges these groups may face, and suggested potential means of compensation for the difficulties e.g. paper based information, interpersonal support etc.

A few respondents made a different, more nuanced comment in regards to the accessibility of the information, which discussed the potential blind spots in regards to messaging around prescription dependence and withdrawal. For instance one respondent commented that many individuals who were dependent on prescription medication, may not look for the information within the “drugs” section of the guidance as they would not consider themselves to be taking “drugs” but rather “medicine”. Similarly there was another comment that highlighted that individuals may not seek help from “addiction” services, as they may not consider themselves ‘addicts’, due to a lack of use of “street drugs”. This raises not only a discussion in regards to the correct messaging to patients in order to facilitate their ability to find and utilise this information (perceived ‘health’ issue vs ‘addiction’ issue), but also how discussion around street and prescription drugs are conducted within medical and governance settings more broadly, and how those decisions may influence the way in which information is conveyed to potential consumers of that information due to a difference in how the respective groups interpret what is being discussed e.g. ‘drugs’ vs ‘medicine’.

Within the online discussion groups, the topic of public health messaging was mentioned by some respondents. Respondents discussed the benefits of public

health messaging with regards to medication and their effects. A few respondents indicated that they believed that public health messaging was helping to better inform patients with regards to potential risks, and facilitating conversations around treatment.

### 3.7 Suitable resourcing

Many respondents commented on the issue of resourcing through the consultation. This typically revolved around discussion of the need for greater resources to be made available in order for the recommendations to be successfully implemented. This additional resourcing included suggestions of additional staffing, additional opening hours for current services, the incorporation of additional services (e.g. community pharmacies), additional funding for research, additional support services for patients (e.g. mental health services), additional resourcing in order to increase data linkage, and additional training for clinicians and staff.

### 3.8 Positives in regards to the recommendations or the consultation

Several respondents commented on the recommendations positively throughout the consultation. Although the specific praise levied towards each recommendation differed depending on the focus of the recommendation (i.e. data, guidance, research etc.), in each recommendation there were several respondents expressing a belief that the actions of the recommendations would lead to desired benefits. A few respondents did however add caveats in regards to perceived potential obstacles that would need to be overcome for the benefits to materialise, most of which have been discussed throughout this analysis (need for additional resources, additional time to parse data etc.).

The points of improvement that could be borne out of the recommendations included (but were not limited to):

- Improved data quality in regards to patient safety and prescribing
- Improved integration across the health care sector
- Support for involvement of patients with lived experience in the development of resources and use of digital solutions.
- Support for facilitating greater shared decision making between patients and practitioners.
- Support for investigation into under researched or underutilised areas of research.
- Support for greater access to information for patients in order to facilitate informed choice.

### 3.9 Concerns regarding the individual recommendations or the consultation

Some respondents throughout their comments to the various recommendations expressed dissatisfaction with the recommendations or indeed with the consultation as a whole.

The points of contention varied amongst the respondents. The most common critique amongst those who expressed scepticism in regards to the recommendations, focused on a perceived lack of efficacy and/or effectiveness of the recommendations, most often attributed to an issue with implementation born out of an inability and/or unwillingness of medical practitioners to adopt what the respondents felt were 'correct' practices, as well as a general lack of shared decision making. In effect, a concern that the recommendations would not be adopted by those needed to make the changes and respondents expressed a belief that the recommendations would not translate to material change unless these issues were rectified.

A few respondents expressed displeasure with the focus of the consultation as a whole, commenting that the consultation and the work of the SLWG had diverged from its intended remit and the focus set out by the original petition. The respondents that referenced this topic commented on a perceived lack of focus on adequate support and non-pharmaceutical alternatives to treatment.

A few respondents expressed issues with the consultation as an evidence gathering instrument. Respondents who commented on this topic, criticised a lack of clarity within certain recommendations, and a need for clearer definitions in order to adequately describe the actions that the recommendations would entail. Despite an open text option being available throughout the questionnaire, these respondents commented that they were unable to provide their opinion or evaluation on particular aspects of the recommendations as they lacked specificity, and so did not allow them to give an informed opinion in regards to what was being discussed and the consequences of the varying interpretations of the recommendations.

## 4. Appendix 1: Original PHE recommendations

### Recommendation 1

“Increasing the availability and use of data on the prescribing of medicines that can cause dependence or withdrawal to support greater transparency and accountability and help ensure practice is consistent and in line with guidance.”

### Recommendation 2

“Enhanced clinical guidance and the likelihood that it will be followed”

### Recommendation 3

“Improving information for patients and carers on prescribed medicines and other treatments and increasing informed choice and shared decision making between clinicians and patients”

### Recommendation 4

“Improving the support available from the healthcare system for patients experiencing dependence on or withdrawal from prescribed medicines”

### Recommendation 5

“Further research on the prevention and treatment of dependence on and withdrawal from prescribed medicines”

## 5. Appendix 2: Summary of online group discussion events

The Scottish Government held two online events as part of its consultation. These took place on 18/05/2021 and 19/05/2021. These events took the format of a summary of the work of the Short Life Working Group and the draft recommendations followed by 3 concurrent breakout groups that discussed specifics of the recommendations. The groups were:

1. Guidance for medical professionals
2. Advice and support for patients
3. Data and research

Summary of the main topics discussed within the two consultation events:

**Resourcing:** Primarily the need for additional resourcing in order for necessary changes to be achievable

**IT/Digital solutions:** Discussions focused around the role of digital/IT solutions, and their appropriateness in different situations, or with different groups. Concerns were raised around digital exclusion.

**Joined up working:** Multiple mentions of the need and benefit of greater joined up working amongst different actors within the healthcare sector.

**Public health messaging:** Discussions took place in regards to the benefit of public health messaging, and the potential form it should take.

**Support services/support in general:** Discussions focused on the need for greater support for patients generally, and an increase in the utilisation of support services in particular.

**Patient empowerment:** Patient empowerment was discussed through the lens of person centred care and patient advocacy.

**Data:** members discussed the importance of data and the types and level of data they were interested in.

## 6. Appendix 3: list of organisations who responded to consultation

Patient Group SLWG.
NHS Lanarkshire Mental Health & Learning Disabilities Drug & Therapeutics Committee
Managed Clinical Network for Chronic Pain in Greater Glasgow and Clyde
Scottish Pain Pharmacists Network (recently formed)
SAS
NHS Fife Pharmacy Service
NHS Greater Glasgow & Clyde Alcohol & Drug Recovery Services
The All-Party Parliamentary Group for Prescribed Drug Dependence
NHS Ayrshire and Arran
NHSGGC Pharmacy Services
Voices of Experience (VOX)
Royal Pharmaceutical Society
Scottish Specialist Pharmacists in Substance Misuse (SPiSMs)
NHS Grampian
SAMH (Scottish Association for Mental Health)
Secretary, Scottish Parliament Cross Party Group on Chronic Pain
National Pharmacy Association
RCPsychiS
Healthcare Improvement Scotland
Community Pharmacy Patient Safety Group

**7. Appendix 4: Detailed breakdown of quantitative analysis**

	Recommendations									
	1		2		3		4		5	
Yes	34	87%	33	85%	34	87%	34	87%	34	87%
No	4	10%	5	13%	4	10%	3	8%	4	10%
Not Answered	1	3%	1	3%	1	3%	2	5%	1	3%
	<b>39</b>		<b>39</b>		<b>39</b>		<b>39</b>		<b>39</b>	
Extremely effective	2	5%	1	3%	1	3%	1	3%	0	0%
Very effective	4	10%	5	13%	7	18%	5	13%	5	13%
Effective	12	31%	8	21%	7	18%	9	23%	11	28%
Somewhat effective	11	28%	13	33%	16	41%	15	38%	14	36%
Not effective	5	13%	7	18%	4	10%	5	13%	5	13%
Not Answered	5	13%	5	13%	4	10%	4	10%	4	10%
	<b>39</b>		<b>39</b>		<b>39</b>		<b>39</b>		<b>39</b>	
Effective	18	46%	14	36%	15	38%	15	38%	16	41%
Somewhat effective	11	28%	13	33%	16	41%	15	38%	14	36%
Not effective	5	13%	7	18%	4	10%	5	13%	5	13%
Not Answered	5	13%	5	13%	4	10%	4	10%	4	10%
	<b>39</b>		<b>39</b>		<b>39</b>		<b>39</b>		<b>39</b>	

## **8. Appendix 5: Thematic analysis of individual recommendation responses**

### **Recommendation 1**

“Make data available for all prescribers, health and social care partnerships and patients to allow monitoring of data and improvement in practice.”

87% (34) of the respondents recorded that they agreed with the recommendation. 10% (4) of the respondents recorded that they did not agree with the recommendation. 3% (1) did not answer the question.

46% (18) of the respondents felt that the recommendation would be effective. 28% (11) felt that the recommendation would be somewhat effective. 13%(5) felt that the recommendation would not be effective and 13% (5) did not answer the question.

Data:

The majority of the comments focused on data availability, as well as the utilisation and shaping of practice as a result of data. In addition, challenges in regards to the implementation of the recommendation were mentioned, as were specific suggestions around the type of data that should be collected and/or utilised. The various aspects of the data theme that were mentioned are described below:

Knowledge mobilisation:

Some respondents referenced the need to not only improve data collection, but work needed to ensure that it becomes embedded in practice:

“The data collated and prescribing patterns would be helpful but that then must be interpreted and acted upon by practitioners”

A few respondents also referenced aspects of the data that would need to be considered and changed in order to allow for data to be better adopted and implemented. These include aspects such as the regularity and level (national, regional, local etc) of the available data:

“data should be regular (quarterly) and comparable at different levels of analysis (local, national)”

As well as the practitioner’s workload:

“It will be effective to have the information to track any improvement or identify any areas for improvement. However, it will only be effective if prescribers (be that Drs or pharmacists) are given the time to analyse the data and act upon it, on top of their existing workloads.”

“Would need to ensure time and resources is allocated to review and understand data”

## Value of data:

Several respondents made reference to the value of improved data collection practices. Comments in this topic focused primarily on the ability of data to improve service provision and guidance:

“With increased availability of accurate data, any changes in prescribing data can be used to review new guidance (recommendation 2) and the impact this has on prescribing practices ongoing.”

“Making data available will identify the scale of the issue and allow services to plan and evaluate any interventions implemented to tackle this.”

“If data is available to all those in contact with patient's, this will help integrate care across teams, and better understand where practice can be improved.”

Comments also referenced the opportunity provided by improved data collection practices to provide insight into topics that individual respondents perceived to be under investigated:

“We firmly believe that robust data collection will allow progress in improving prescribing. Collection of data around chronic pain as a condition has always been difficult and has restricted progress and understanding of the condition.”

Or as a means of better identifying individuals who would benefit from support:

“Understanding the nature of the issue and identifying those individuals at risk can best be served through information gathering and data.”

In addition a few respondents referenced how greater data availability would help individual patients better understand their situation and allow them to make more informed choices:

“.....This data will also be useful to individual patients in understanding their situation.”

## Data linkage:

Two respondents referenced the benefits of increased data linkage in this area:

“Important to consider data linkage, specifically where patient specific and how this can be accessible to all clinicians participating in patient care irrespective of sector or health board boundaries (e.g. Unscheduled care/community pharmacy/ temporary residents in other HB areas) Significant role of data linking in supporting population health, the individual healthcare interaction and prescribing of medicines.”

“The lack of unified data across healthcare is extremely dangerous and accounts for countless hours of meds rec and enquiries which should be completely unnecessary.”

Specific recommendation about type of data:

Many respondents made suggestions as to the type of data that should be collected and/or be a particular point of focus. These included:

- Prescribing data from specialist services such as substance use services and specialist pain clinics.
- Geographical mapping of prescribing rates of drugs in post mortem toxicology for people dying from drug deaths.
- Greater understanding of patients' experiences.
- Potential links between suicidal ideation and antidepressant use.
- Long term drug use and withdrawal.
- Collection of data around chronic pain.
- Data on the clinical reasons for prescribing to be made available for improved data monitoring.
- More data relating to outcomes of treatment, including recovery.
- That data should be broken down by protected characteristics, as well as age, gender, ethnicity and Scottish Index of Multiple Deprivation.
- Identifying the value of treatment support provided by health and social care professionals delivering NHS services.

Deprivation:

Two respondents referenced the need to consider deprivation and how it relates to the recommendations and the topic more broadly.

“We would also suggest that delivering this recommendation would require further steps, including in relation to reaching out to deprived communities...”

Positive comments around the recommendation:

Several respondents made positive comments in regards to the recommendation and the potential benefit the proposed actions may have to the benefits of greater understanding of the topic:

“This would be very helpful; the WHO has described prescribed medication dependence as the biggest growth area of addiction in the world, not because it is increasing, but because we are only just recently starting to recognise it.”

As well as the benefits for service improvement and patient care:

“Presentation of hard facts makes it more difficult for prescribers to deny there are issues. It helps collaboration and discussion on how to improve services and patient care. It is most effective, when like STU it can be brought down to practice level and I would encourage bringing down to prescriber level where possible.”

“I feel that it can only be a good thing, that way everyone who needs to know about the history or current use of medicines for their patient will have the most up to date information available to all.”

“This should enable a more integrated and efficient system, which should contribute to increased patient safety and patient outcomes.”

“Improving access to data that quickly and easily identifies patients that require review is a positive step.”

Concerns relating to the recommendation:

A few respondents referenced issues relating to the recommendation. These primarily revolved around a perceived lack of clarity with the definitions utilised within the recommendation and therefore they felt unable to comment on its proposed effectiveness. However others felt that the recommended action itself would be ineffective:

Lack of clarity of recommendation:

Some respondents referenced issues relating to a lack of clarity in the recommendation. Comments referenced a need for greater precision in regards to its definitions, for instance by specifying the type of data the recommendation is discussing:

“To evaluate more effectively the impact of this action it would need to clearer what data was going to be gathered, how it was going to be analysed and why. Also, it is not explained how this data would differ to that already available to prescribers and how it would lead to improvement in practice...”

“I think this is quite vague. It has the potential to be very effective in theory for all stakeholders, but that depends largely on how well this data is shared across various interfaces and between different geographical areas/sectors or care, for example. If done well this will have huge benefits but if the systems and procedures are not fit for purpose it could be detrimental to patient care.”

Ineffectiveness:

A few respondents made specific references to their view that the recommendation would be ineffective in the long term.

“Unlikely to improve matters much whilst we still have many doctors refusing to accept that certain medications are addictive or dependence- forming.”

“None of the actions described above are focused on prescribed drug dependence and / or supporting withdrawal specifically. It doesn't sound like anything will change.”

“...More and more data has some relevance at some points - but this consultation is overladen with it, potential years of paperwork, to the exclusion of practical aid to help current sufferers.”

## **Recommendation 2:**

“Develop or renew Quality Prescribing Guides for all classes of drugs covered by the SLWG: z- Drugs, benzodiazepines, gabapentinoids, opioids, antidepressants.”

85% (33) of the respondents recorded that they agreed with the recommendation. 13% (5) of the respondents recorded that they did not agree with the recommendation. 3% (1) did not answer the question.

36% (14) of the respondents felt that the recommendation would be effective. 33% (13) felt that the recommendation would be somewhat effective. 18%(7) felt that the recommendation would not be effective and 13% (5) did not answer the question.

Guidance:

Several respondents referenced the value clear guidance can provide in improving service provision:

“Quality Prescribing Guidelines should be encouraged. These provide a standardised approach and ensure consistent and equitable approached to treatment provision. Essential that any new/developed prescribing guides are used in practice- need to be accessible/ practical/ useful.”

“Clear guidance and direction for clinicians and the wider supporting groups are essential to provide consistent practice and messages around the management of conditions where the medicines may be dependence forming or harmful with longer term use.”

“Guidelines provide quality evidence-based documents on the benefits and risks and clinicians rely on them to make informed decisions so this development would be welcomed.”

“Clear and practical guidance will be required to support clinicians undertake appropriate interventions. These issues are not new and in addition to appropriate guidance some support and education of clinicians will be required.”

“Prescribing guides have to be communicated and shared effectively, I think COVID has shown us that the dissemination of information is an issue - Blink is not a reliable source of dissemination. I think that we also need to be mindful of duplication of work and effort - development of guidance should be centralised and information obtained from specialist areas as requested.”

Adherence:

Several respondents referenced the need to ensure that even if guidance is correctly and clearly presented, that particular effort is needed to ensure that the new information is followed and adhered to:

“Enhancing clinical guidance in practice should be positive however, many do not follow or re-educate themselves on revisions and improvements to clinical guidance and literature, this is where it will fall short in resolving any of the consulting issues.”

“Our group felt that clinical guidelines in this area are important, but are aware that even when guidelines are made very accessible (which is not always the case), there are challenges in translating the guidelines in to clinical practice. This has an impact on the effectiveness of guidelines.”

A few of the respondents referenced full adherence to guidelines being an issue in the past.

“The problem here is in theory its good, but ensuring the guides are implemented is key to effectiveness, something that has been an issue in the past.”

Local buy in:

Two respondents referenced the need for local buy in for the recommendation to be successful:

“Implementation of recommendations always requires local buy in which can be difficult to achieve but what I like about Quality Prescribing Guides is they are evidence based and give practical resources to help implementation.”

“Useful tools but needs buy in at all Board levels to be embedded into practice.”

Evidence based:

Two respondents referenced the need for the guidance to be evidence based and nationally focused:

“Needs to be national and embedded in formulae. Driven by the data to address areas where improvements are not seen. Resource required to tackle historic prescribing.”

“It is vital that guidance and treatment are evidence-based, therefore updating or creating guidance for these drug-classes will be very useful in standardising care across Scotland in line with current evidence.”

Regularly updated:

A few respondents referenced the need for the guidance to be regularly updated in order to be effective:

“It should be reviewed periodically, as things change quite often, so this will enable everything to be kept up to date. It may make decision making by clinical staff easier, if the information is the same everywhere, with easy access to all. Hopefully it will reduce the possibility of patient dependence.”

“important that all prescribers are following the same guidelines to provide consistency of service to patients. Will aid prescribers in keeping up to date with the latest evidence. Can provide data on the danger of over prescribing these drugs inappropriately.”

Joined up approach:

A few respondents referenced the need to ensure that the recommendation takes place alongside and in partnership with other strategies.

“Updated practical guidance on how to address high prescribing in these areas would be useful-Not just a guide in isolation - needs to be part of an implementation strategy and joined up approach. - It would be good if it could link in with the substance misuse strategy.-Same with all guidance - it is useful, but depends on the quality, the buy-in and the source.”

“Given the nature of the medication, it would be useful to have clear guidelines so that prescribing issues such as titration and dose reduction is clear, logical and shared by all members of the MDT.”

“Important to engage with pharmacies at all levels of patient journey.”

Specific recommendations around guidance:

- To include the MHRA reminder within guidance, as “*this is the highest level advice*” for co-prescribing benzodiazepines and opioids informing practice.
- To indicate in published clinical guidance, that the guidance was based on patient feedback and resulted from the advocacy of harmed patients.
- That working groups developing guidelines should have input from professionals with experience in the field of substance use/addiction alongside patients with lived experience, patient groups and advocacy groups.
- To foster “*App development*” for ease of use in clinical settings.

- To find consensus on wider guidance e.g. from PHE and NICE relating to the same topic. Similarly one respondent suggested that actors should consider whether it would be beneficial to consolidate guidance from multiple sources (e.g. SIGN, NICE, the GMC etc) or create a single platform where all these sources can be accessed.
- To develop protocols for reducing opioids post-surgery on hospital discharge.
- That guides should include detailed information on: when and how to refuse inappropriate medication.
- To provide guidance for “*common drugs of abuse and potential red flags to look for...*” in order to support “*positive prescribing journeys*”.
- For guidelines to be interlinked, so that the risks of prescribing multiple classes are highlighted.
- To take into account the complexity and challenges of treating people with “*combined street/non-prescribed drug use and prescription medicine dependence*”, and “*combined street/non-prescribed pain drug use and prescription medicine dependence*”.
- To adopt PHE recommendation 2.9 around the training of new clinicians and ensuring that curricula include education and training to adequately address issues related to dependence on and withdrawal from prescribed medicines, at undergraduate, foundation and postgraduate levels.
- To utilise multidisciplinary working to achieve the best outcomes for the patient. Suggestion included notifying community pharmacists when a patient begins deprescribing to enable them to support the patient, particularly at times when their prescriber may not be available.
- Ensure guidelines are applicable to all healthcare settings where these medications will be prescribed or used and that they are followed while taking into account variations in demographic requirements and healthcare provider.
- To recognise that some clinical specialty areas will require justifiably higher prescribing of these medications than others.
- To ensure that clinical guidelines is flexible in order for it to be applicable to patients with a history of substance use, particularly where illicit substances are being used.
- To ensure the impact of poly drug use should be taken into consideration when developing the guidelines.
- To ensure access to alternate quality non-pharmacological options is consistent and available across Scotland.

- To improve the monitoring of adherence to current and future guidelines.
- To expand the network of psychological wellbeing services at a local level so that people can access support for their mental health without the need for a referral or waiting lists.
- To implement a mental health triage system in every community in Scotland, the role of which would be to quickly assess someone's mental health to connect them to the appropriate support.
- To have greater engagement with community pharmacists.
- To ensure prescribing plans are available to the patient and their community pharmacy, with an indication/reason for the prescription and whether it is a trial.
- That the patient should be provided with the clinical guidelines for the treatment or condition they are being treated for, whether that is depression, pain or anxiety.
- That clinical prescribing guideline should contain an exit strategy including how to stop and if a taper is required.
- To have a statutory requirements for opioid safety counselling from the prescriber and pharmacy.

Positive comments around the recommendation:

A few respondents made positive comments around the recommendation and its aims:

“Guidance gives a measuring stick to best practice. Prescribers can be held responsible and accountable to agreed guidance. The challenge to guidance being followed is there is so much of it, but it would give patients some protection and leverage when they do not experience best practice.”

“Really important. I think it could prevent unavoidable dependency and deaths”

“Clinical guidelines for the use of the 5 categories of medicines described by the SLWG is a positive step.”

### **Recommendation 3**

“Work with NHS Inform and NHS 24 to develop online guides and resources to support patients suffering from withdrawal from the 5 classes of medication covered by the review.

Develop decision aids for the medicines covered by the SLWG. Patients with lived experience to be involved in their development.

Make resources available in easy to use forms that maximise availability, including through the polypharmacy app.”

87% (34) of the respondents recorded that they agreed with the recommendation. 10% (4) of the respondents recorded that they did not agree with the recommendation. 3% (1) did not answer the question.

38% (15) of the respondents felt that the recommendation would be effective. 38% (15) felt that the recommendation would be somewhat effective. 13%(5) felt that the recommendation would not be effective and 10% (4) did not answer the question.

Concerns around the recommendation:

Many respondents made reference to having concerns in regards to the efficacy and/or effectiveness of either the recommendation itself, or the changes that would be required in order for the recommendation to be a success.

Online resources:

Some respondents expressed concern that the focus on online resources would be insufficient to meet the needs of those requiring support:

“Simply put 'on-line guides' for those at risk of dependency and/or withdrawal will fall short of doing anything other than educating those that are currently unaffected. It's naive to believe that those suffering for whatever reason whether it be drug dependency caused by addiction, mental health conditions, neuropathic pain disorders or similar will have the capacity to search on-line and read a guide while also taking in the information and then putting it into practice.”

“There are two different parts to this recommendation. I think improving information is laudable, but not likely to be very effective, while I think that a co-operative approach to decision making is empowering.”

“Transition to alternatives needs to be factored into this programme of management so that non pharmacological alternatives can be considered as a reality. Online guides and resources will have a role but investment into specialist staff and clinics will be crucial to achieving success in Scotland.”

Stretched capacity:

While one respondent felt that little would change as this was already being utilised to the best of their ability:

“to be honest, I think most of us in primary care are already doing this as much as we can.”

Lack of research:

Another respondent believed that the issue around the recommendation lay in part with the lack of data on specific drugs:

“In respect of certain drugs, this guidance on Realistic Medicine and patient engagement in the prescribing decisions can be very important, but this is strictly in areas where medicine specific performance for patients is fully understood in respect of 'risk to benefit'. In the case of antidepressants, the risk benefit ratio is not remotely understood or evaluated.....Until these numbers are accurately known, the balance of 'risk versus benefit' cannot possibly be understood - and even less explained to a patient who has to consider the arguments on whether or not to start taking antidepressants.”

Need for cultural change:

Many respondents made reference to the need to change certain aspects of current behaviours and interactions in order for the recommendation to be successful. Some respondents referenced a need for change in the relationship between patients and prescribers:

“How are you going to tackle the fact that many doctors are still reluctant to discuss side effects/withdrawal symptoms with patients.”

“Some clinicians (specifically psychiatrists) I have worked with on my own mental health issues have been reluctant to engage in shared decision making.”

“I think development of the above resources is to be welcomed but should be backed up with additional resources and training for clinicians to help implement and include tools to encourage engagement and development of services in collaboration with third sector agencies.”

A few respondents referenced the difficulties of achieving the desired outcomes of the recommendation with the current model of patient and practitioner interactions. In particular the limited face to face time that is available to discuss potential support was referenced as well as other corresponding issues and concerns:

“The current standard 10-minute appointment time for GPs creates barriers for people with mental health problems. Some respondents in our research acknowledged that mental health problems themselves can make engaging with health professionals more difficult.”

“Are you really sure. I struggle to see the consultant and the last appointment I had with the consultant lasted 8 minutes.”

“Timing matters :Timing is of importance for example when being prescribed with a new medication the patient is often not in the best frame of mind (e.g. feeling depressed/anxious or in pain), for this reason it may be best for the clinician to get in touch again in a few days to talk about it again/give another opportunity to ask questions.”

#### Resourcing:

One respondent referenced the need for additional resources for the recommendation to be successful:

“I think development of the above resources is to be welcomed but should be backed up with additional resources and training for clinicians to help implement and include tools to encourage engagement and development of services in collaboration with third sector agencies.”

#### Clarity:

One respondent raised the issue of clarity in regards to definitions:

“If this recommendation pertains to withdrawal from the 5 classes of ‘prescribed’ medication only, this needs to be made clear.”

#### Wrong approach:

One respondent disagreed with the approach of the recommendation altogether, as they were concerned it would take precedent over interaction with their prescriber:

“Patients should not routinely have to go to nhs inform to find out about the medication they have been prescribed or for support on withdrawal symptoms. This information should be discussed and provided to them at point of prescribing for example if they are prescribing a medication that causes withdrawal symptoms on ceasing this should be explained to the patient at point of prescribing. It is not appropriate to provide this info retrospectively especially when withdrawal symptoms are expected.”

#### Positive aspects of the recommendation:

Many respondents commented in a positive way in regards to the recommendations in general:

“This will be very useful and I think the most important part of this recommendation is involving patients (whether past or current) in its development.”

“All of methods of educating the public and increasing patients knowledge and expectations of these medicines will be helpful in supporting conversations.”

“Great idea to use the app to allow any resources to be easily accessed and not lost amongst other resources and documents.”

With particular focus of the comments being on the usefulness of the proposed recommendations:

“Patients still very resistant. however, I think an online advertising campaign would help to raise awareness, to see if patients themselves can come forward for review.”

“Information regarding polypharmacy risks and advice for patients on NHS Inform would be a helpful resource for staff and patients.”

“The availability of information on either medication or services supports an improved patient/ clinician experience with realistic expectations and better outcomes. People don't see 'treatment' as being addictive/dependence-producing, and clear and upfront information would be very desirable, as part of informing on the risks of these meds.”

“Decision aids, particularly developed in conjunction with patients who have lived experiences of this would be very beneficial to patients being treated particularly if it is emphasised these have been developed by their fellow patients, it could help to encourage/foster concordance. The more readily available (e.g. by app) the information is, the easier it will be to use/apply in practice.”

Access:

Many respondents referenced the need for the accessibility of information to be taken into consideration as well as the means of accessing it when enacting this recommendation. Particular focus was placed on those who would be less likely to access online resources, either due to a lack of access to the necessary IT equipment, or due to a lack of the necessary skill set to find and utilise the digitally published material:

“While this is a useful baseline resource, many patients may not access it. The first point of call will likely be to consult their GP or pharmacist. Certain patient groups, e.g. the elderly, ethnic minorities will likely be excluded from this source of help. The resources would need to be publicised. This is often a very difficult situation for patients and consideration must be given to providing specific services and support, rather than simply online and telephone support.”

“Information in alternate formats should be made available to ensure that digital poverty does not create inequalities in informed decision making. Awareness of these tools for patients and clinicians and ease of use will influence effectiveness....”

“The resources would be welcomed but thought should be given to how to make these resources available to all. Many, especially from deprived areas, do not have the skills or equipment to access IT based resources.”

“Online resources help those with IT skills but more resources are needed for the older patients with limited internet access. - Access to info across platforms within the NHS and beyond is also a good thing - so that there is consistency in the approach in the clinical environment.”

“Accessibility to these apps and people’s literacy skills need to be taken into account, with alternative resources made available.”

Two comments raised the issue of patients not seeking or accessing the online material, as they may not be aware that it is directed toward them:

“Really challenging to direct patients to these resources especially if they feel they are not addicted and require the it knowledge and capability to access.”

“Most people taking prescribed medications would not look at a 'drugs' section as they believe they're taking medicines....”

Primary care/Community pharmacy:

A few respondents commented on the potential benefits of utilising community pharmacies and primary care services more effectively:

“Decision aids and withdrawal information for patients and prescribers provide support for patients to commence and sustain withdrawal from prescription medicines. The community pharmacy team, under the supervision of a pharmacist, have the opportunity to provide significant wellbeing interventions, answer patient queries and provide additional information or reinforcement messages of what to expect as a patient commences medicine withdrawal by reducing dose.”

“There is also an opportunity to use primary care settings to set up what may be, for some, effective group interventions. These could educate patients on their prescriptions and benefits/harms.”

Specific recommendations:

- Patients must be made aware of the withdrawal support pathways.
- To create a guide for withdrawal from these medications to allow any treatment withdrawal to be planned in anticipation of any difficulties which may occur.
- To ensure patients with lived experience of “*combined street/non-prescribed drug use and prescription medicine dependence*” are involved in the development of these decision aids.

- To ensure the language used is not “*borrowed*” from the recreational drug use guides mentioned. The respondent goes on to recommend that there is a separate section for prescribed medicine benefits and harms including the potential for dependence and withdrawal.
- That decision aids should include clear elements about patient information, engagement, informed consent to treatment and the likely benefits and goals of treatment.
- To ensure the correct emphasis is given between balancing the value of treatments, with the need for appropriate review and the provision of support to help patients come off treatment safely minimising any withdrawal/discontinuation effects.
- To develop an opioid toolkit similar to the "NSAID" toolkit.
- To approach prescribed drug harm differently from recreational drug harm.

#### **Recommendation 4**

“Work with NHS Inform and NHS24 to explore out of-hours helpline to assist patients suffering from dependence and withdrawal from prescribed medicines.”

87% (34) of the respondents recorded that they agreed with the recommendation. 8% (3) of the respondents recorded that they did not agree with the recommendation. 5% (2) did not answer the question.

38% (15) of the respondents felt that the recommendation would be effective. 38% (15) felt that the recommendation would be somewhat effective. 13%(5) felt that the recommendation would not be effective and 10% (4) did not answer the question.

Lack of knowledge/awareness:

A few respondents referenced a lack of knowledge in regards to available interventions or programmes:

“Many patients I have approached to reduce their opioids ( I have dealt mainly with co-codamol and tramadol) have been utterly closed to non-drug approaches. This is not due to a lack of resources out there but a lack of insight and knowledge.”

“Needs to be more specialised advice.”

Unmet need:

Many respondents made reference to a theme that can be described as a current unmet need within the system, this was either due to issues perceived issues with resourcing, or the perceived inappropriateness of available support and services.

#### Resourcing:

A few respondents referenced the current shortage of resources as a limiting factor in providing of appropriate support:

“There was a feeling that due to GP's not having alternative mental health type support to offer (combined with long waiting times for talking therapies) that the quick and easy answer is often prescribing medicine/adding additional medicines. There needs to be a shift to transform the way in which we can offer alternative support at the time it is needed.”

“There is not the resource in primary care at present to support patients appropriately and this leads to substance misuse services plugging the gaps for patients that its often not entirely appropriate for.”

Similarly several respondents referenced the need for increased resourcing moving forward in order for the recommendations to be successful:

“Scheduled care provision is an unmet need and would require additional investment to support patients.”

“The NHS must provide a more substantial and effective service for patients and not be confined to the working week 9-5. I would think especially weekends must require more services to help these patients.”

“Staff increase on a large scale is needed for chronic pain clinics.”

“This may prove helpful but investment will be needed if the cause of the problem is to be addressed properly.”

#### Inappropriate current service:

Several respondents made negative reference to current service provision with regards to telecare in general and helplines in particular:

“Calls to the line must be answered. Current lines are absolutely useless...due to limited hours and i have never had anyone answer my call in crisis which has just made me feel much worse. If no one answers the calls and the line is understaffed it should not be created.”

“Patients' experience of NHS 24 111 is that the call handlers (and indeed prescribers) have absolutely 'no idea' when it comes to the terrible issues encountered with prescribed drug dependence and withdrawal.”

“Digital therapies and online support simply aren't enough and more needs to be in place to enable those withdrawing to do so safely and with conclusion.

Out-of-hours helplines are beneficial as many suffering from side effects may be unable to leave the house or travel, but a level of compassion needs to be applied by those training for this role in order to do it justice.”

Out of hours:

Many respondents commented on the importance of out of hours service provision. Specific reference was made to the out of hours period being a particular period of vulnerability to those looking to utilise the services:

“Out of hours is a key time where patients may feel unsupported or at greatest risk of relapse or overdose, anything that can be done to increase availability of some services at this time is to be welcomed, again collaborating with third sector where appropriate.”

“Everything possible should be done to prevent issues culminating out of hours. This should be a safety net only, not a main strategy.”

“Out of hours is a time when a lot of patients with addiction issues struggle to access help and support, with many turning to their community pharmacist for help and advice. To help facilitate this, shared patient records would be essential which would give all healthcare professionals dealing with the patients care up to date information on their current health status, including mental health status, and medication regardless of the prescriber.”

A few respondents commented on the desirability of improving in hours care in order to lessen the need to utilise out of hours services:

“If we can improve in hours care it is to be hoped there would be less risk in out of hours however important to recognise OOH is often a crisis time and it would be good to offer that support.”

Need for support:

Some respondents commented on the benefits and need for support for those experiencing withdrawal:

“This is important in providing consistent/ accessible support for individuals. In the end, these symptoms may be inevitable for some people, whatever the reduction regime, and support is good; but only if it does support the process of withdrawal, rather than producing roadblocks.”

“It is important that if the support that is required is because of declining mental health that the referral pathways ensure fast and appropriate access to a service that can provide specific mental health support.”

“Improved access to harm reduction information and support is important.”

Although the ways in which support was envisioned by respondents appears to have a varied focus:

“Helpline would be good to talk through any social issues that may be route cause of addiction similar to breathing space.”

“I agree with the recommendation heading but the ways forward entirely miss the need to provide local in-person services tailored to withdrawal support.”

#### Negative experiences of support:

A few respondents expressed negative experiences of the support they received, or felt that the recommendation was not sufficient:

“What is suggested is not good enough. People who are withdrawing from prescription dependence can have severe withdrawal symptoms. Talking to someone on the phone does not deal with physical issues of withdrawal symptoms.”

#### Positive comments relating to the recommendation:

Some respondents made positive comments in regards to the recommendation and expressed the belief that the actions described would lead to positive change and support:

“Having worked in deprived areas with a lot of addiction issues this I believe would benefit massively and reduce accidental overdose/misuse of medicines over weekends in particular”

“Can only be a good thing, giving extra information to the call centre staff, and in turn helping the patients who call in”

“This work would be welcomed if it resulted in timely access to help and support for patients at these times from an appropriate healthcare practitioner.”

#### Community pharmacy

A few respondents commented on the need to make better use of community pharmacies and pharmacists in order to support those going through withdrawal and/or seeking support:

“Community Pharmacies are the heart of medicines supply and open without need for appointment 6/7 days a week. They should be resourced and trained to provide support to patients managing withdrawal symptoms.”

#### Specific recommendations:

- To ensure there is support that is targeted at dependence on prescribed medicines as opposed to “*addiction services*”. The respondents reasons that members of the public generally associate “*addiction services*” with illicit drug

use, and therefore may not believe the services are relevant to them, or may find their use unappealing.

- To ensure staff training includes supporting people with “*combined street/non-prescribed drug use and prescription medicine dependence.*”
- To involve “*addiction specialists*” in the development/delivery of training to NHS 24 staff.
- To ensure a “*robust process*” for rapid onward referral to an appropriate healthcare practitioner for patients who are deemed to be requiring further assistance at that time.
- The use of pharmacist independent prescribers should be considered as a potential solution to addressing withdrawal out of hours. However it is noted by the respondent that this would require shared notes and robust governance.
- To improve monitoring and reviewing after prescriptions have been administered.
- To take steps to embed community pharmacies as part of an integrated model in primary care.
- To ensure any proposed helpline is advertised effectively and suitably

### **Recommendation 5**

“Further research on the prevention and treatment of dependence on, and withdrawal from, prescribed medicines.”

87% (34) of the respondents recorded that they agreed with the recommendation. 10% (4) of the respondents recorded that they did not agree with the recommendation. 3% (1) did not answer the question.

41% (16) of the respondents felt that the recommendation would be effective. 36% (14) felt that the recommendation would be somewhat effective. 13%(5) felt that the recommendation would not be effective and 10% (4) did not answer the question.

Knowledge mobilisation:

Several respondents made reference to the need to utilise research into current practice. However whether that was new or existing research differed depending on the respondent.

A few respondents discussed this through the implementation of new research into existing practice:

“Further research will always be a positive recommendation especially if it teaches us more on how to resolve negative responses to medications. However, a barrier to any research itself will be the re-education of general practitioners. Many stick firmly to outdated notions of conditions and will prescribe according to their set-beliefs rather than updated research.”

“As with the first recommendation the research would then need to be implemented into practice but we do need to explore alternate solutions for managing drug dependence of all types as the current national methodology is flawed.”

Whereas others placed an emphasis on utilising and embedding what is already known:

“This should again be viewed in context. From what I have seen, there is much information already available with respect to factors that can bring about inappropriate use of medications. It is not being adequately acted on.”

“In the longer term research will help to support policy and practice but there is already a considerable wealth of knowledge and international example of the potential harms associated with prescribed medicines and their use.”

“There are hundreds of good resources out there the NHS needs to stop reinventing the wheel and get on with the job.”

Patient experience:

A few respondents suggested conducting more research on the patient experience:

“Evidence based research including those with lived experience is vital to inform strategic direction in Scotland to reduce harm, keep people safe & reduce DRDs.”

Positives comments about the recommendation:

Several respondents commented positively in regards to the actions put forward in the recommendation:

“Having better evidence from robust high quality research studies would enable informed decisions to be made at a government, health board, clinician and patient level.”

“Research is the best way forward and the best way to increase the quality of care. There should be as much research done as possible and this is done through recommendations.”

“Research will be essential to fully understand the causes of these issues and evaluate the solutions.”

“We agree that there is a need for further research on the prevention and treatment of dependence and withdrawal from prescribed medicines.”

Specific research topics:

- To ensure there is a better understanding of the incidence, duration, nature and severity of withdrawal from antidepressants, including long-term and enduring side effects.
- To commission/conduct more research to see what works and how to implement the findings.
- To enable “*short responsive research pieces*” that may be required as well as more in depth analysis and support from research bodies.
- To research “practical” alternatives to prescribing any of dependence-forming medications. And - if prescribed at all - how to support safe withdrawal of the medication(s).
- To commission/conduct more research on prescription medication.
- To research lack of service provision and its effect on people with chronic pain.
- To investigate service provision for people who have prescription dependence and the lack of service provision for mainstream addiction services.
- To make use of the Scottish Pain Research Network.
- To find ways of encouraging new researchers/clinicians to get involved with development of small research groups.
- To conduct more international comparisons of models of service provision.
- To research evidence based options for supporting patients to withdraw from medications.
- To include research to explore/describe dependence on and withdrawal from street/non-prescribed drugs in population experiencing dependence/withdrawal from prescribed medication.
- To shift perspective on patients as recipients of care and move towards research which views patients as equal respondents.
- To consider other non-medicine based support and how this can have a positive effect on supporting withdrawal and reducing dependence.
- To establish better data collection in regards to number of patients experiencing withdrawal symptoms.

- To conduct/commission more research on the incidence of long term harms such as endocrine suppression, metabolic syndrome and research on whether all necessary physical monitoring is happening.
- To reevaluate the extent to which realistic medicine principles are being adhered to in communication and engagement with patients to mitigate future dependency.

## **9. Appendix 6: Glossary**

DRD: drug related deaths

GMC: General Medical Council.

GP: general practitioners

IT: information technology

NICE: National Institute for Health and Care Excellence

NHS: National Health Service

NMS: New Medication Service

NSAID: Non-steroidal anti-inflammatory drugs

MDT: multi-disciplinary team

MHRA: The Medicines and Healthcare products Regulatory Agency

OOH: out of hours

PHE: Public Health England

SIGN: Scottish Intercollegiate Guidelines Network

SLWG: short life working group.

STU: Scottish Therapeutics Utility

WHO: World health organisation



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