What's the Script?

SAMH Research Report
Experiences of Medicines used in Mental Health

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IMPORTANT MESSAGE

If you are concerned about any aspect of your drug treatment, you should speak to your doctor, psychiatrist or pharmacist. Do not stop taking psychiatric drugs without first seeking proper appropriate medical advice. You may also want to contact some of the information providers listed at the end of this publication.

INTRODUCTION

For over 50 years, drugs have been the mainstay of psychiatric treatment and in recent years there has been a substantial increase in the amounts of drugs being prescribed. Many people have found them to be helpful, even life-savers but others have had less positive experiences. Some argue that our treatment system is too dependent on drugs, as opposed to other treatments.

In 2003, SAMH undertook our first large scale study[1] into people's experiences of psychiatric drugs. We surveyed 756 people and found that respondents, in the main, valued psychiatric drugs and saw them as an important part of their treatment. Equally clear though, was that respondents also had serious concerns, both about the extent to which they were involved in the prescription process and about negative or unwanted effects. We were keen to revisit certain aspects of this research to identify, 10 years on, how and whether things have changed.

Since 2003, The Patient Rights (Scotland) Act 2011 has been passed to improve patients' experiences of using health services and to support people to become more involved in their healthcare. Three Quality Ambitions now provide the focus for everything NHSScotland does in its aim to deliver the best quality healthcare; meaning it must be person centred, safe and effective. Therefore, we were particularly keen to identify the extent to which partnerships between patients and those delivering healthcare services are mutually beneficial, with people having greater choice in their treatment and information about their options.

METHODOLOGY

SAMH created an on-line survey to learn more about people's first-hand experiences of psychiatric drugs. The survey ran from April 2012 - August 2012 and received 271 responses. Respondents were free to bypass any question which they did not feel comfortable to answer.

The majority (66.2%) of respondents had been prescribed a psychiatric drug within 12 months prior to completing the survey, 8.2% within the previous 1-2 years, 4.5% within the previous 2-3 years, 5.2% within the previous 3-4 years, and 16.0% longer than 4 years ago. People with a variety of conditions and experiences took part in the survey and nobody was excluded because of the nature or extent of their illness.

Because it was possible for respondents to record more than one answer in response to some of the questions, the data shown may not always add up to 100%. In some sections we have also drawn comparisons between the results of this and our 2003 survey. This is intended to provide an indicative analysis

[1] "All you need to know?" Scottish Survey of People's Experience of Psychiatric Drugs, SAMH 2004

only and comparisons should be treated with caution given the difference in the sample sizes involved.

We wanted to hear people's own views of the drugs they used and the whole process of being given treatment. We hope that the results can be used to identify areas for improvement and also ways that this might be achieved. This type of survey research relies on people volunteering information – and thus our sample is self-selecting. This research needs to be read in conjunction with other methods. No single research method can give a definitive answer to the wide range of issues that we are considering.

SUMMARY

SAMH created an on-line survey to learn more about people's first-hand experiences of psychiatric drugs. The survey ran from April 2012 - August 2012 and received 271 responses. We wanted to hear people's own views of the drugs they used and the whole process of being given treatment.

In over half (53.0%) of cases in our survey, the most recent prescription was made by a psychiatrist. However, many people with mental health problems seeking support are seen by their GP rather than by a psychiatrist; in 46.7% of cases in our survey, the most recent prescription was made by a GP.

The most commonly prescribed drug groups were antidepressants (79.0%) and antipsychotics (37.1%), whilst depressants and stimulants were the drug groups prescribed to the fewest respondents (both 1.9%). The majority of respondents (61.2%) reported that they had not been offered a choice of drugs, with only 33.2% reporting that they had. A further 5.6% were unsure of this. People diagnosed as having Anxiety were the least likely (29.9%) to be offered a choice of drugs, whilst people with Bipolar Disorder were the most likely (42.9%).

Just over half of respondents (52.2%) reported that they had been offered non-drug treatments, 41.8% that they had not and 6% were unsure. People diagnosed with PTSD were the most likely to be offered a choice of non-drug treatments (68.4%), whilst people diagnosed with Schizophrenia were the least likely (33.3%). People with a diagnosis of Anxiety were much more likely to be offered a choice of non-drug treatments (60.8%) than a choice of drugs (29.9%).

The majority (63.3%) of respondents reported that the drug being prescribed was discussed at prescription, 28.5% that it was not and 8.2% were unsure. It is concerning that in more than a quarter of cases there was no discussion of the drug being prescribed between the person receiving the prescription and the person making it.

Almost half reported being either very happy (20.8%) or fairly happy (26.4%) with the information they got about the drug at prescription, with a further 34.0% reporting that they were neither happy nor unhappy. However, 9.8% were very unhappy and 6.8% were fairly unhappy with the information they had received.

2.3% indicted that they were unsure of this. Over half of respondents (51.7%) reported that they were given no written information about the drug provided at prescription. This is of some concern given that a Patient Information Leaflet (PIL) should be included with every prescription.

Just over 20% of respondents reported that they did not feel able to ask questions of the person making the prescription. In some cases this was because the respondent felt too ill to ask questions or enter into dialogue at that time.

The most commonly reported side effects were drowsiness/fatigue (66.0%), weight gain (52.0%) and sexual dysfunction (40%). However, many people experienced multiple side effects and the effects experienced were greatly varied. A large majority of respondents reported finding psychiatric drugs to be either very useful (41.0%) or fairly useful (41.4%) in helping them to manage mental ill-health. However, 17.5% of respondents reported that they did not find psychiatric drugs useful at all.

186 respondents, almost 7 out of 10, reported having had some concerns about the psychiatric drug once they started taking it. The highest proportion of concerns related to antipsychotics at 80.8% and the lowest stimulants and depressants (both at 60.0%). However, these figures should be treated with caution given the low sample sizes and because the figures include cases where more than one drug was prescribed. Of the people who had concerns about a drug after they started taking it, over half (58.6%) discussed their concerns with the person who had prescribed the drug. However, 35.8% did not and a further 5.6% were unsure as to whether they had or not. Over half of the people who had raised concerns felt that they had been listened to, whilst 18.8% did not.

A majority of respondents (65.1%) reported that they had asked to stop taking a psychiatric drug whilst 33.0% reported that they had not. A further 1.9% were unsure of this. There was a fairly even split between those people who felt that, overall, they were treated as an equal partner when deciding which medications were best suited to them (46.3%) and those who did not (42.9%).

Many respondents went on to find out more about the drug they had been prescribed after receiving the initial prescription. The main source of information was the internet, with over three quarters of respondents (78.6%) indicating they either had or would use the internet to get information about psychiatric drugs.

Based on the results of this survey, SAMH believes that there have been some positive developments in psychiatric drug prescribing since our original survey in 2003. For example, more people than before are being offered a choice of non-drug treatments and feel able to ask questions of the person making the prescription. However, it is also clear that more remains to be done to improve the prescribing process and empower people to become active partners in decisions about which treatment options are best suited to them.

EXPERIENCE AT PRESCRIPTION

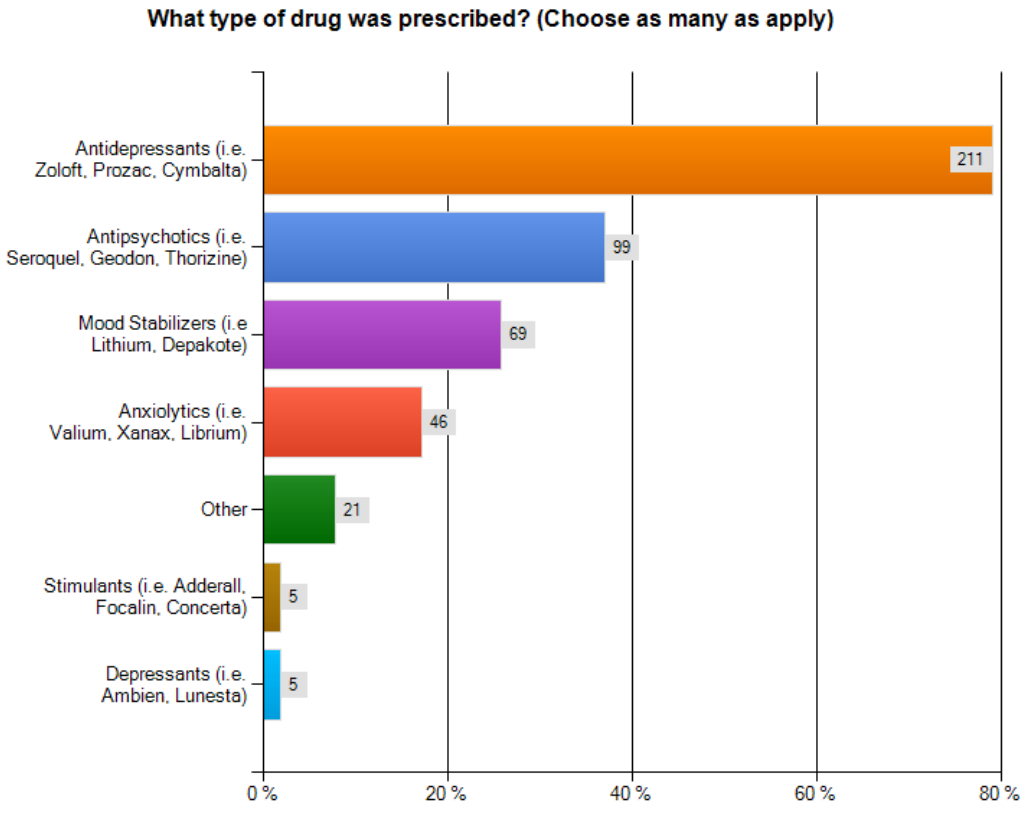
Person issuing prescription

Psychiatric drugs are usually prescribed by either psychiatrists or GPs. In over half (53.0%) of cases in our survey, the most recent prescription was made by a psychiatrist. However, many people with mental health problems seeking support are seen by their GP rather than by a psychiatrist; in 46.7% of cases in our survey, the most recent prescription was made by a GP. In 2003, 72.5% of respondents received their prescription from a psychiatrist and 26.6% from GPs, suggesting that GPs are now more likely to prescribe psychiatric drugs.

Prescribed by	Number	%
GP	126	46.7
Psychiatrist	143	53.0
Other	1	0.4

Type of drug prescribed

Respondents were asked what type of drug/s had been prescribed, by selecting as many as applied from a range of options.



The most commonly prescribed drug groups were antidepressants (79.0%) and antipsychotics (37.1%), whilst depressants and stimulants were the drug groups prescribed to the fewest respondents (both 1.9%). This is a marked increase in

antidepressant prescribing when compared to the results of our 2003 survey,[2] in which only 49% of respondents reported being prescribed antidepressants. Despite previous targets[3] to reduce the amount of antidepressants being prescribed in Scotland, a total of 4.66 million antidepressant items were dispensed during 2010/11. This was an increase of 350,372 from the previous financial year. It is also estimated that 11.3% of the Scottish population aged between 15 and over make daily use of antidepressant drugs.[4]

However, work with NHS Boards on antidepressant prescribing demonstrates that GPs in Scotland are more likely to be working to clinical practice and guidelines than elsewhere.[5] The gap in prescribing rates between Scotland and England also appears to be reducing.[6] As such, the high numbers of people taking antidepressants may reflect the prevalence of mental health problems more generally: one in four of us will experience a mental health problem in any given year.[7]

Choice of drugs

Respondents were asked whether they had been offered a choice of drugs, with the majority (61.2%) reporting that they had not and only 33.2% reporting that they had. A further 5.6% were unsure as to whether they had been offered a choice or not.

[2] "All you need to know?" Scottish Survey of People's Experience of Psychiatric Drugs, SAMH 2004

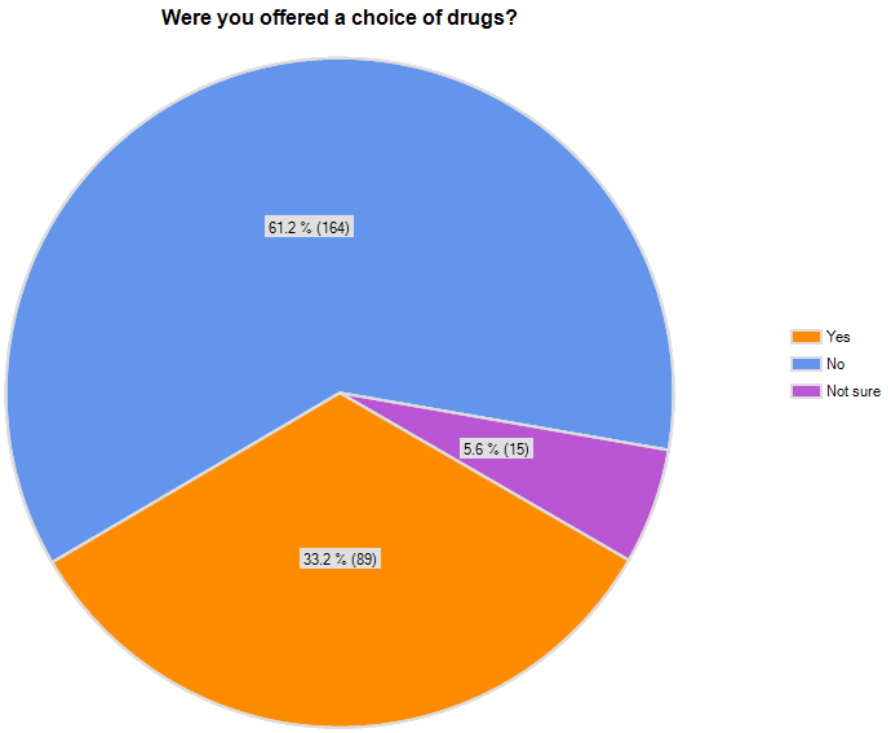
[3] HEAT Target: Reduce the annual rate of increase of defined daily dose per capita of antidepressants to zero by 2009/10 and put in place the required support framework to achieve a 10% reduction in future years (2009/10)

[4] Publication Summary Prescribing & Medicines: Medicines used in Mental Health Financial years 2001/02 – 2010/11, Information Services Division , September 2011

[5] "Factors associated with duration of new antidepressant treatment: analysis of a large primary care database" British Journal of General Practice 2012; DOI: 10.3399/bjgp12X625166

[6] Mental Health Strategy for Scotland: 2012-2015, Scottish Government, 2012

[7] Office for National Statistics (ONS) (2001). Psychiatric Morbidity Among Adults Living in Private Households. London: ONS



Some respondents described having a good working knowledge of psychiatric drugs, sometimes having learned what works best for them through a long period of trial and error. This had enabled them to have a greater sense of choice and control when making decisions about a particular drug. However, some people felt that their options had become more limited through time as they gradually exhausted the options available to them, or as the drugs themselves became less effective:

"I'm a pharmacist so my psychiatrist is quite understanding about letting me use my knowledge and views to manage medication."

"I research medication thoroughly and I'm interested in the history/mechanism of action of the medications I take; as a result whenever a medication needs to be changed the decision is a mutual one between my psychiatrist and me."

"Have been on a few over the years but through time they became ineffective therefore my choice was limited."

Others had a limited experience of taking psychiatric drugs and felt happy to leave the choice of drugs to the health professional. Some later regretted this decision:

"I (wrongly) presumed my GP knew best, so trusted their prescription pad and didn't think to question their choices of drugs."

A number of respondents didn't feel they were given any choice and were very unhappy about this. Others felt that they had some degree of choice but that this was limited:

"It was a case of 'Oh, depressed again are we? Here's the script'."

"Was told this was what I had to take ... lots of pressure to take them."

"My psychiatrist, when I once tried to negotiate the way a change in meds would happen, told me that "he was the doctor and he would decide what happens"".

"Psychiatrist only showed one which she thinks might be most suitable. No discussion about different options."

Of those respondents who were offered a choice of drugs, many identified good practice:

"My GP has always been very supportive of my long term depression and my need to manage it and stay in control. He's always happily spent time discussing options and side effects."

"My psychiatrist is very good at including me in making decisions about my care and… we have looked at and tried alternatives."

People diagnosed as having Anxiety were the least likely (29.9%) to be offered a choice of drugs, whilst people with Bipolar Disorder were the most likely (42.9%). People who received their prescription from a psychiatrist were also slightly more likely (36.6%) to be offered a choice of drugs when compared to people who received their prescription from a GP (28.8%).

Were you offered a choice of drugs? – Diagnosis

Diagnosis*	Yes	%	No	%	Not Sure	%
Depression	51	31.1	104	63.4	9	5.5
Anxiety	29	29.9	62	63.9	6	6.2
Schizophrenia	7	33.3	9	42.9	5	23.8
Bipolar Disorder	30	42.9	36	51.4	4	5.7
Personality Disorder	13	41.9	16	51.6	2	6.5
PTSD	8	42.1	9	47.4	2	10.5

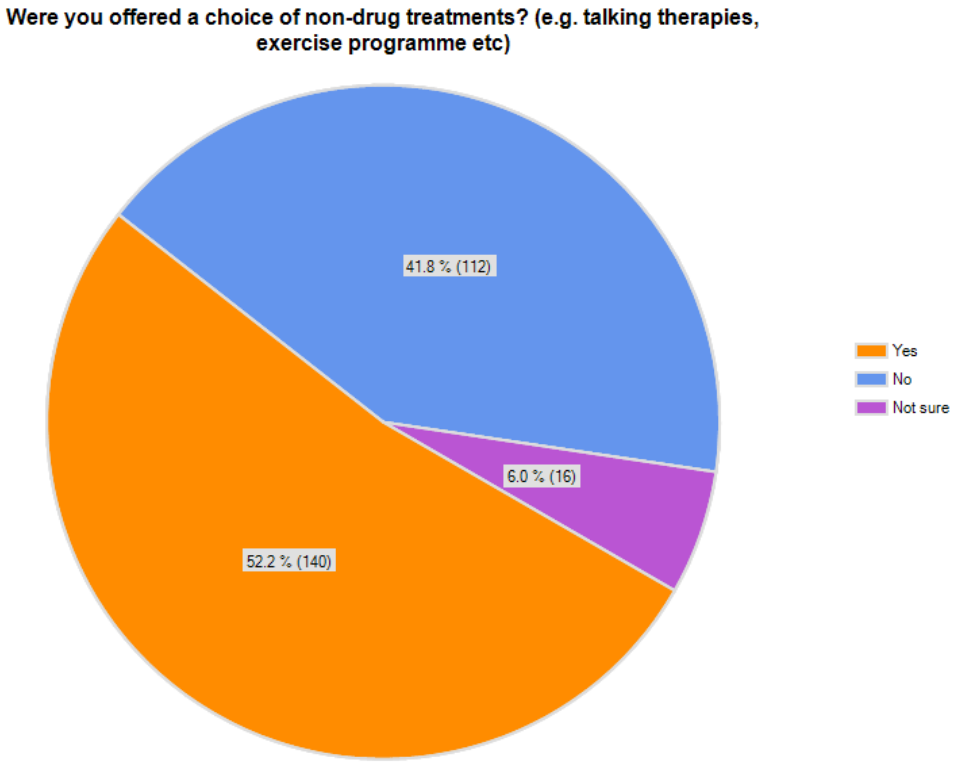
* It was possible to record more than one diagnosis.

Were you offered a choice of drugs? – Prescriber

Prescribed by	Yes	%	No	%	Not sure	%
GP	36	28.8	84	67.2	5	4.0
Psychiatrist	52	36.6	80	56.3	10	7.0

Choice of non-drug treatments

Respondents were asked if they had been offered non-drug treatments with just over half (52.2%) reporting that they had, 41.8% that they had not and 6% being unsure. Some of the non-drug treatments mentioned included counselling and talking therapies (e.g. cognitive behavioral therapy and psychotherapy), internet based support, anxiety strategies, stress management courses, relaxation groups/exercises, confidence building courses, and workplace occupational health. In 2003, only 26.6% of respondents reported that they had been offered non-drug treatments, indicating that there has been a notable improvement in this regard.



A number of respondents reported that they had faced long waiting times to access non-drug treatments, or had instead opted to pay for these privately. Others were only offered non-drug treatments after pro-actively seeking them out. Some felt that they would have taken up the offer of particular non-drug treatments had they been offered or made available to them:

"After initial diagnosis of depression, I was told there was a lengthy waiting list for CBT (Cognitive Behavioral Therapy)*. I paid for this privately. If exercise programme had been offered I would have used it."*

"Only when I expressly asked my GP about it on about my third visit… they didn't volunteer the information. On my first visit, we did discuss local options for therapy (which would have been paid for by me) but the ones I contacted were too expensive or had temporarily closed their waiting lists."

People diagnosed with PTSD were the most likely to be offered a choice of non-drug treatments (68.4%), whilst people diagnosed with Schizophrenia were the least likely (33.3%). People with a diagnosis of Anxiety were much more likely to be offered a choice of non-drug treatments (60.8%) than a choice of drugs (29.9%). Overall, people with every diagnosis were more likely to be offered a choice of non-drug treatments than a choice of drugs, although the figure remained the same for people with a diagnosis of Schizophrenia. People who received their prescription from a GP were also more likely to be offered a choice of non-drug treatments when compared to people receiving their prescription from a psychiatrist, although the differential was very slight.

Were you offered a choice of non-drug treatments? – Diagnosis

Diagnosis*	Yes	%	No	%	Not Sure	%
Depression	97	59.5	58	35.6	8	4.9
Anxiety	59	60.8	34	35.1	4	4.1
Schizophrenia	7	33.3	10	47.6	4	4.1
Bipolar Disorder	28	39.4	38	53.5	5	7.0
Personality Disorder	19	61.3	10	32.3	2	6.5
PTSD	13	68.4	6	31.6	0	0.0

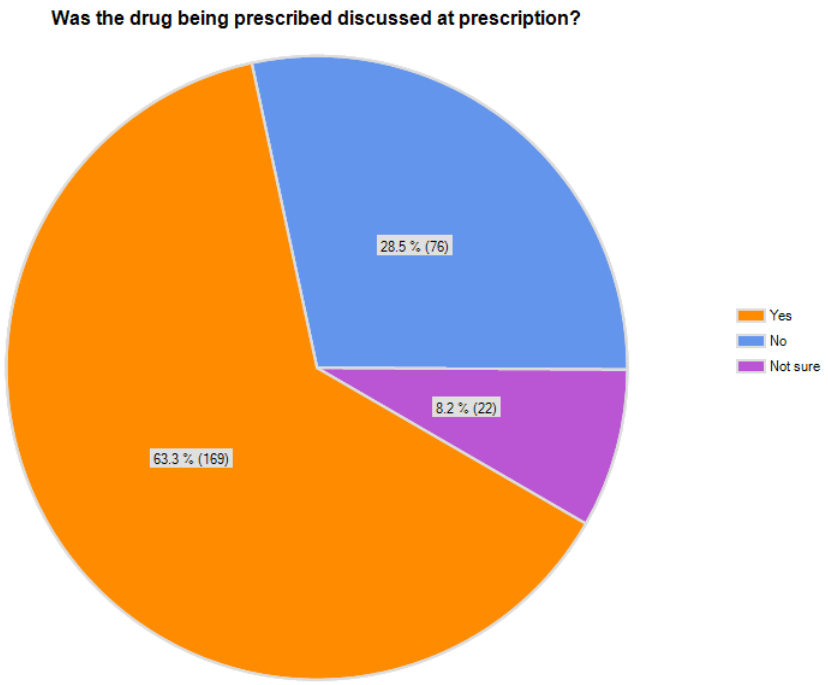
* It was possible to record more than one diagnosis.

Were you offered a choice of non-drug treatments? – Prescriber

Prescribed by	Yes	%	No	%	Not sure	%
GP	68	54.8	52	41.9	4	3.2
Psychiatrist	71	49.7	60	42.0	12	8.4

Discussion of drug being prescribed

We asked people whether the drug being prescribed was discussed at prescription. The majority (63.3%) of respondents reported that it was discussed, 28.5% that it was not and 8.2% were unsure. It is concerning that in more than a quarter of cases there was no discussion of the drug being prescribed between the person receiving the prescription and the person making it.



Many respondents commented that while there was some discussion, this was limited or they had little input. Some reported that only certain aspects of the drug were discussed. A number of respondents also felt that discussion was discouraged:

"A little, but not much. I was expected to just take his word for it and discussion wasn't really welcome."

"…certainly the doctor talked, but I had no informed input."

However, there were also examples of good practice and positive experiences:

"Discussion is positively encouraged."

"Effects and treatment fully explained to me."

We also asked, more specifically, whether the possible side effects of the drug being prescribed were discussed. In response, 51.5% of respondents reported that they were, 41.8% that they were not and 6.7% were unsure. Many people commented that only certain side effects were discussed (i.e. the most severe) while others felt that discussions were limited or rushed, sometimes due to time constraints:

"Sexual dysfunction isn't (ahem) raised and is (ahem) hard to bring up yourself."

"Doctors NEVER discuss side-effects - they don't have time to discuss anything anymore."

Information at prescription

We asked people how happy they were, overall, with the information they got about the drug at prescription. Almost half reported being either very happy (20.8%) or fairly happy (26.4%), with a further 34.0% reporting that they were neither happy nor unhappy. However, 9.8% were very unhappy and 6.8% were fairly unhappy with the information they had received. 2.3% indicted that they were unsure of this.

A number of respondents commented that they were unable to absorb the information provided at the time of prescription as they were not well enough to do so. This highlights the importance of ensuring that people can access information on an ongoing basis, at a time that is right for them. Others, in hindsight, felt that they would have benefited from more information had this been provided. Some respondents regretted not asking more questions at the time of prescription, although it was not always felt by them that there was time to do so. A few people also had concerns about the quality/accuracy of the information they were given:

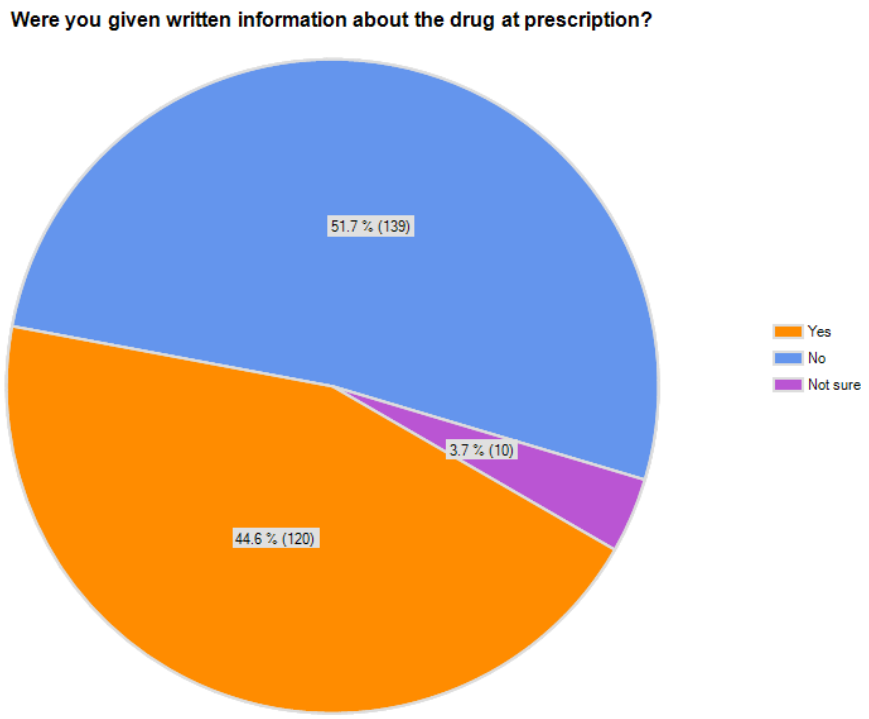
"I hadn't considered it an issue at the time but looking back I can see that information would have been helpful and informative."

"I should have asked questions."

"Usually, there is never enough time for the Dr to discuss it properly (they are always looking at their watches and you need to bear in mind that you are just one case number among thousands)."

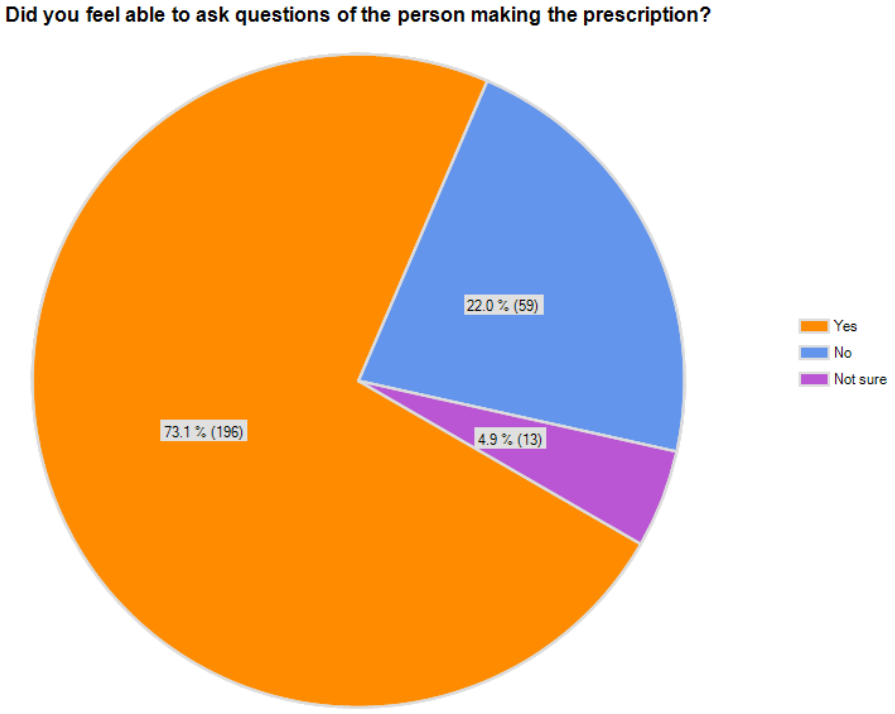
"On further research I have discovered that most of the usual information is either erroneous or does not apply to one self..."

Over half of respondents (51.7%) reported that they were given no written information about the drug provided at prescription. This is of some concern given that a Patient Information Leaflet (PIL) should be included with every prescription. While our findings may demonstrate inadequacies in prescribing practice they may also be due to some survey respondents not being aware of a PIL.



Asking questions of the person making the prescription

Respondents were asked whether they felt able to ask questions of the person making the prescription. Just over 20% of people reported that they did not. In some cases this was because the respondent felt too ill to ask questions or enter into dialogue at that time.



Many people described having either a good or bad relationship with their GP/ Psychiatrist and saw this is being instrumental to their ability to ask questions. Some people choose not ask questions as they were happy to trust in the expertise of the person making the prescription, others feared that questions might be perceived as a challenge to this expertise. Again, time restraints were identified by some as limiting their ability to ask questions. Some respondents felt that their questions were not appreciated or found that they were not answered satisfactorily. However, many people also reported having positive experiences and felt their questions were properly addressed:

"I did ask questions, but got very short and uninformative answers. The psychiatrist said he didn't have time to provide me with detailed information."

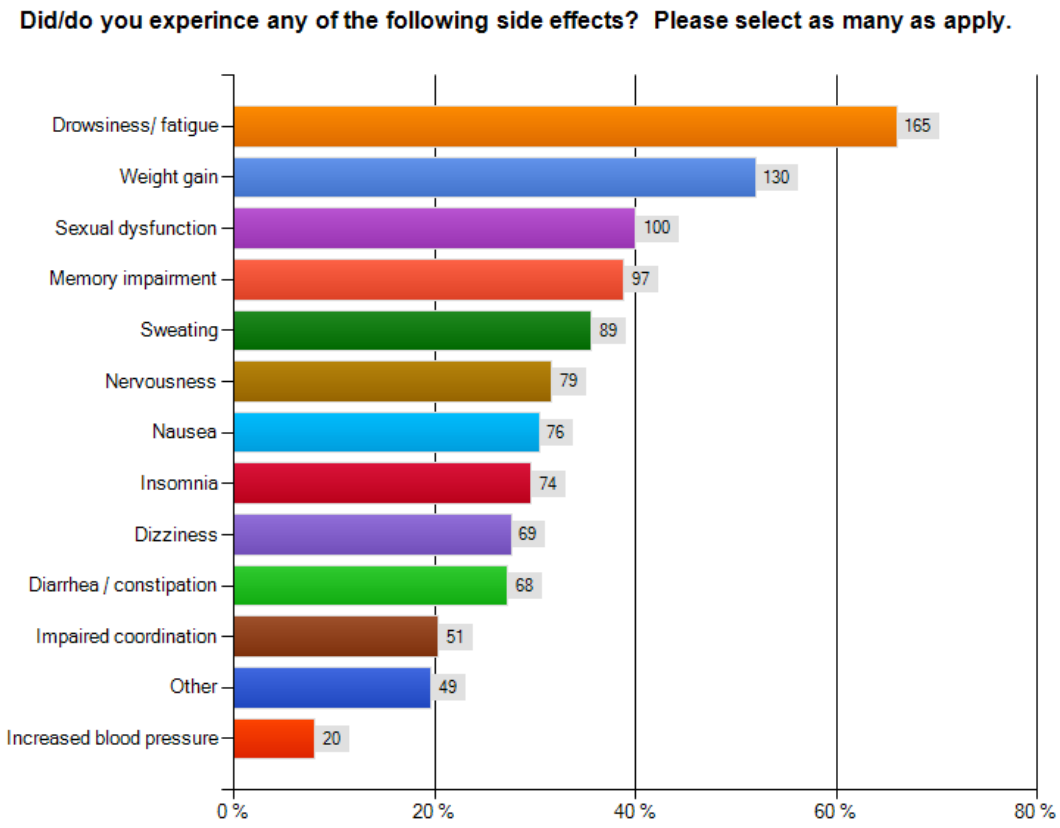
"Able to ask questions, yes, but I have feeling that GP is in charge and you shouldn't be questioning too much!"

"My GP is always willing to answer any questions. He reassured me as I was very anxious about treatment…"

TAKING A PSYCHIATRIC DRUG

Experienced side effects

We asked respondents what side effects, if any, they had experienced after taking psychiatric drugs. The most commonly reported side effects were drowsiness/fatigue (66.0%), weight gain (52.0%) and sexual dysfunction (40%). However, many people experienced multiple side effects and the effects experienced were greatly varied.



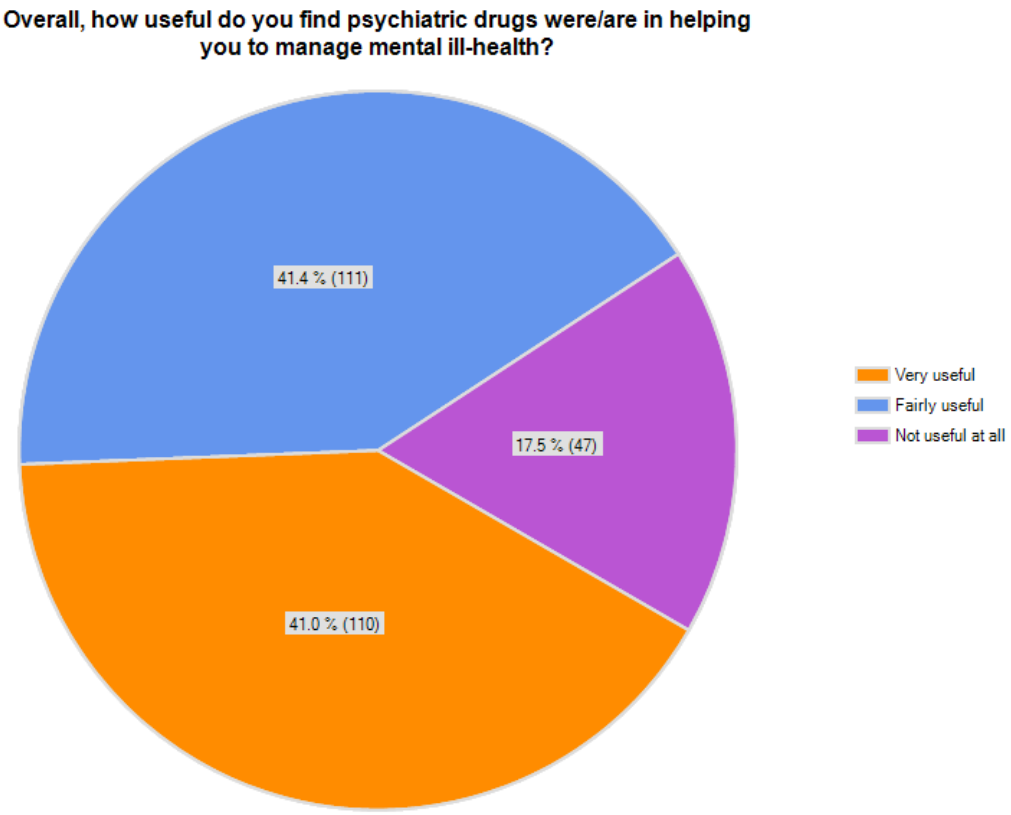
Of respondents, 19.6% also reported experiencing side effects which were not listed within the survey. This included: depression, suicidal thoughts, shaking, loss of appetite, dry mouth, involuntary tics, emotional numbness, headaches, vivid dreams, feelings of agitation/anger, muscle pain, imbalance/falling, sleep paralysis, disorientation, disassociation and heartbeat irregularities.

Some people commented that they had been prescribed many psychiatric drugs and so had difficulty identifying which side effects were related to which drugs. Similarly, some people were unsure as to whether the difficulties they were experiencing were due to psychiatric drugs or other factors:

"I've been on so many different psych meds that it's difficult to remember which ones did what."

Usefulness in managing mental ill-health

We asked respondents how useful they found psychiatric drugs were in helping them to manage mental ill-health. A large majority reported finding them to be either very useful (41.0%) or fairly useful (41.4%). However, 17.5% of respondents reported that they did not find psychiatric drugs useful at all.



Many people described psychiatric drugs as being invaluable in helping them to manage mental ill-health, enabling them to lead a better quality of life and in some cases prevent suicide:

"I would be dead without it. I have severe mental health problems and however imperfect the medication, when it works on balance it makes life tolerable - without it suicide would be a certainty."

"They literally saved my life."

"Enables me to continue to work full-time."

"I went a week without medication once and I couldn't cope without it - I very nearly had a breakdown and my parents were worried that I'd be sectioned."

A number of respondents were clear that, whilst psychiatric drugs were useful in managing the symptoms of mental ill-health they did not directly address the cause:

"Controlled use of psychiatric drugs with right support can suppress symptoms allowing you to tackle root cause, but right care plan is as important, if not more so than the drug."

"They were a sticking plaster - not dealing with root cause"

"They balanced the missing chemicals BUT they only treat the symptoms."

Some people reported that the medication they had been prescribed was only partially effective as it was unable to address all of the symptoms they were experiencing. Others felt that the drugs they had been prescribed became less effective through time, or that the prolonged use of psychiatric drugs had hampered their recovery:

"I have a dissociative disorder and medication helps regulate some of the symptoms like anxiety and depression but doesn't take the dissociation away..."

"Initially raised mood but then felt a worsening of symptoms."

"… if I had only been prescribed them short term their overall effect would have been positive, but the fact I ended up taking them for nearly 20 years meant the overall impact was negative."

Others were unsure about the overall usefulness of the drug, or described having mixed experiences with different types of psychiatric medications. For some, the fact that they had been prescribed a psychiatric drug had been useful in getting others to acknowledge the extent of the difficulties they were facing:

"I'm not actually sure if they help me chemically or not…it is almost like a rite of passage you have to go through so that people believe there's something seriously wrong and you're not just a bit under the weather."

Several people commented that psychiatric drugs were useful to help them manage mental ill-health when they were used in conjunction with other supports or activities:

"With a combination of meds / therapy and supports I seem to have the right balance for me."

Of those respondents who didn't find psychiatric drugs to be useful, a number reported that the drug had in fact worsened their condition. Despite this, some had continued to use the drug concerned in order to avoid withdrawal symptoms. Others described self-medicating with illegal drugs to manage mental ill-health when prescribed drugs proved to be ineffective. Some people had found that they were better able to manage mental ill-health without any medication at all:

“The pills made me feel worse; instead of making me feel more capable, more able to cope with my life, the pills gave me more to deal with and compromised me further.”

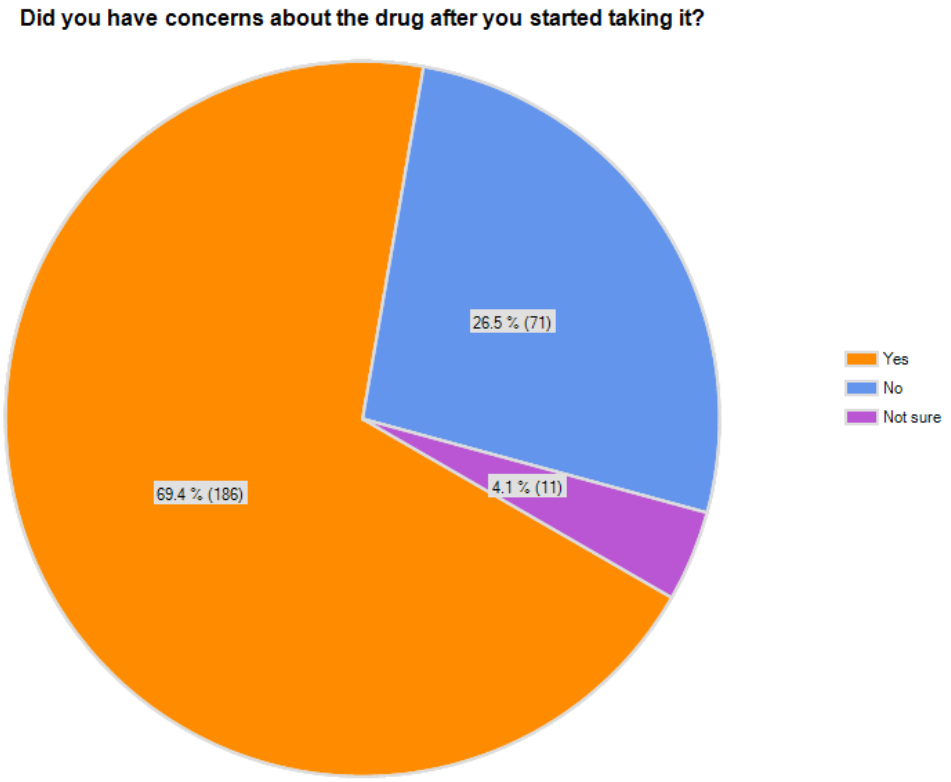
“I was put on so many different meds I didn't have a clue where I was and felt a lot worse than I had been when I initially asked for help. I only started to recover once I stopped ALL meds and used alternative therapies instead.”

“… I find them less effective during CRISES. Then I tend to fall back on heroin which seems to help my symptoms....”

EXPERIENCE AFTER PRESCRIPTION

Raising concerns after prescription

Respondents were asked if they had had any concerns about the drug after they started taking it. 186 respondents, almost 7 out of 10, reported having had some concerns about the psychiatric drug once they started taking it.



The highest proportion of concerns related to Antipsychotics at 80.8% and the lowest Stimulants and Depressants (both at 60.0%). However, these figures should be treated with caution given the low sample sizes and because the figures include cases where more than one drug was prescribed.

Did you have concerns about the drug after you started taking it?

Drug group prescribed*	Yes	%	No	%	Not sure	%
Antidepressants	144	68.6	60	28.6	6	2.9
Stimulants	3	60.0	1	20.0	1	20.0
Antipsychotics	80	80.8	17	17.2	2	2.0
Mood stabilizers	50	72.5	17	24.6	2	2.9
Anxiolytics	30	68.2	11	25.0	3	6.8
Depressants	3	60.0	1	20.0.	1	20.0

*includes cases where more than one drug was prescribed

The vast majority of concerns related to both potential and experienced side effects. Other concerns related to the duration of use, dosage, the addictive property of the drug/s concerned, and the drug/s not having the desired effect:

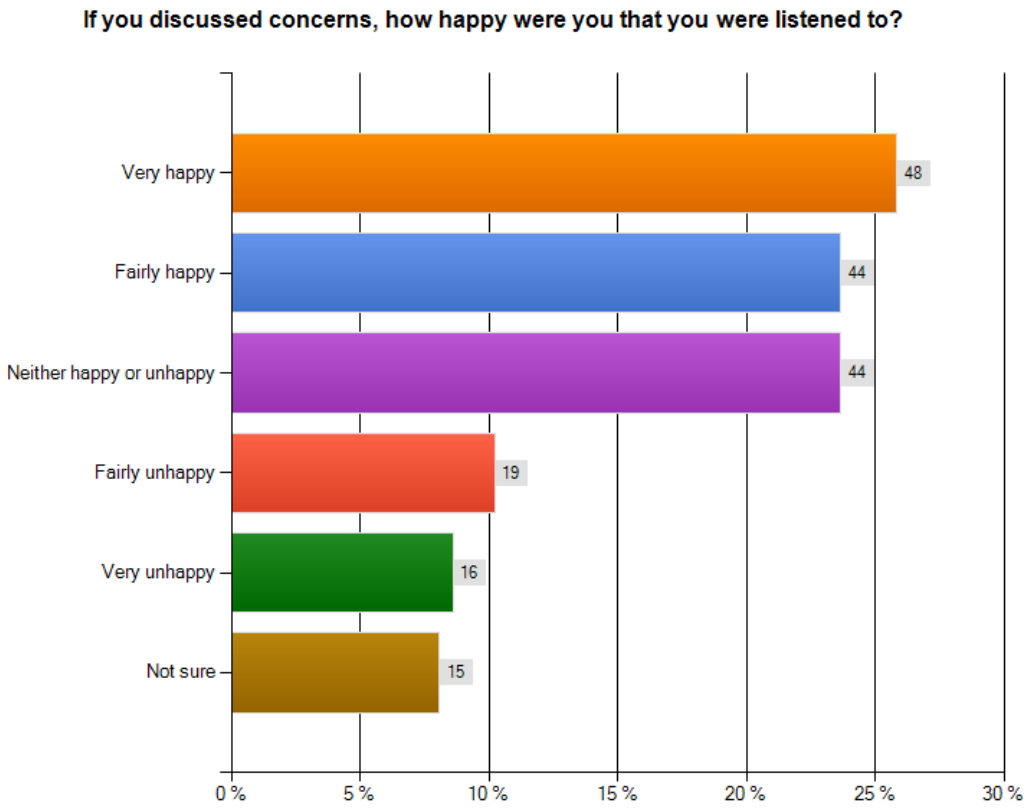
"Yes, but only after about 3 or 4 months, when the night sweats, broken sleep and vivid nightmares began."

"Was concerned about possible side effects."

"I've only been taking this new drug for a week and I was anxious after having previous bad reactions… I will have to double the dose in a week and I am wondering how it will affect my ability to function and how long the side effects will last."

Discussing concerns after prescription

Of the people who had concerns about a drug after they started taking it, over half (58.6%) discussed their concerns with the person who had prescribed the drug. However, 35.8% did not and a further 5.6% were unsure as to whether they had or not. Of the people who had raised concerns, 25.8% felt very happy that they had been listened to but 8.6% reported feeling very unhappy about this.



Many respondents described good experiences and praised the efforts of health professionals who took time to ensure that they were happy with their medication and address their concerns:

"GP is fantastic!"

"I have a great relationship with my GP service; I have had same doctors through out my life."

"Was listened to by Psych and we discussed what was the best way forward."

"The person making the prescription pointed out possible problems now and in the future and we discussed them."

"GP always more than happy to assist with any worries, questions and problems."

However, others reported less positive experiences. This had led some people to consult with a different health professional:

"… I felt my concerns were considered to be unimportant and I felt undervalued as an intelligent individual with sensitivities like everyone else."

"Saw a different GP as lost all trust in the previous one."

“The psychiatrist's attitude was patronising, i.e. that I should trust his judgment as the expert.”

Others felt that specific concerns about side effects had not been taken seriously:

“He was not at all interested in my weight gain concerns.”

“It seems that I should be happy about my illness being "cured" and that is a bigger thing than the weight issues. Being so gross has made my self esteem plummet and I do not like to be seen outside of my home.”

“Sometimes there is just a shrug of the shoulders. I'm sure if they had had the side-effects, they would have had a very different attitude.”

Some reported that they had been treated in a dismissive manner by their GP or psychiatrist. Again, time constraints were highlighted by some as contributing to this situation:

“They (concerns) *were pretty much ignored, in a "you have to take this" kind of way.”*

“My psychiatrist dismissed my worries. I discussed various side effects and felt dismissed on the whole as they 'were keeping me well'.”

“I have tried to discuss side effects with my psychiatrist but there isn't sufficient time in appointments....”

“When you are 'mentally ill' you are not really listened to by psychiatrists, except for when you conform, take the drugs and agree with what they say. If you are 'non-compliant' then you are in trouble.”

Stopping taking a drug

Further to being asked about discussing concerns, respondents were specifically asked if they had ever asked to stop taking a psychiatric drug. The majority (65.1%) reported that they had whilst 33.0% reported that they had not. A further 1.9% were unsure of this.

After having asked to stop taking a drug, many respondents reported having a positive experience of negotiated reduction or withdrawal. This was more likely to occur where people had a good and consistent relationship with the person making the prescription:

“I always come off them gradually with support from my GP.”

“Meet regularly with GP and have increased and lowered dose as I have felt needed.”

“I think that over 5 years we have learned to trust each other when it comes to discussing medication.”

However, some people felt that they had not been adequately supported in their attempts to stop taking a drug:

“I was told that stopping would have to be monitored; it then wasn't monitored (by anyone but me and my family).”

Others who had asked to stop taking a drug reported that while they had continued taking the drug they felt that their doctor had discussed the options with them and listened to their concerns:

“GP and Psychiatrist always spend time discussing pros and cons with me, difficult to be subjective when you are the patient. Sometimes I stopped and other times after discussing options I have continued to take drug.”

“I was asked to give the drug longer to take effect and if in the given time it wasn't helping then it could be evaluated and changed for another.”

In some cases, although people had continued taking a drug (having asked to stop) their drug type, or dosage, had been changed:

“…I have had my dosage lowered, and now I am taking the pills every second day, rather than daily. My new doctor was very informative and supportive.”

“I was told no and given a lower dose.”

Others reported that they had stopped taking a drug without their psychiatrist/doctor’s agreement:

“I was ignored, but did it anyway.”

“I didn't ask - I just stopped everything cold turkey. I knew myself well enough to understand the drugs were making me much worse.”

Some respondents indicated that it was made very clear that stopping taking a drug was not an option:

“Was not allowed to stop taken medication”

“Told not to stop.”

In some cases people were encouraged to resign themselves to life-long drug use:

"They did advise me to take it the rest of my life but after I insisted over 13 months the doses were reduced until I was off them."

A number of respondents who did stop taking a drug reported that their symptoms had become worse as a result, sometimes causing them to resume use of the drug. Many people also described experiencing severe withdrawal symptoms:

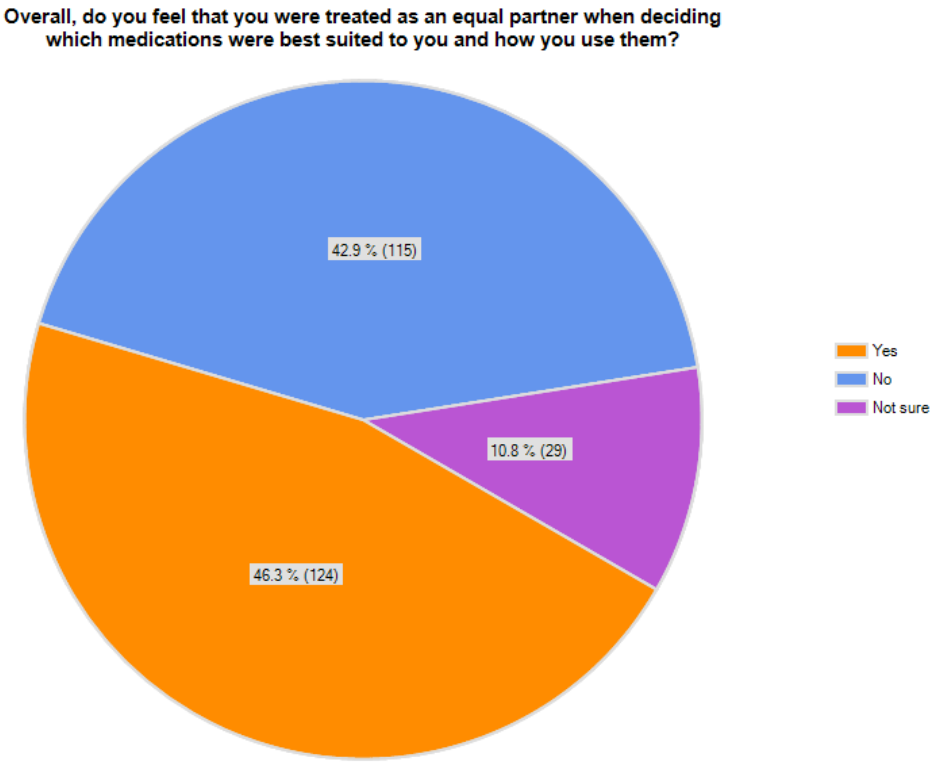
"Bad withdrawals when I stopped taking it myself."

"Total relapse."

"My health was good for a while, but then I required to restart the drug."

Joint decision making

We asked respondents whether, overall, they felt treated as an equal partner when deciding which medications were best suited to them and how they used them. In response, there was a fairly even split between those people who felt this to be the case (46.3%) and those who did not (42.9%).



Many people choose to trust in the expertise of their GP/Psychiatrist, or reported being too unwell to genuinely participate:

"I'm no expert on which drugs are best. Had to go along with what was prescribed. At times I was too I'll to even discuss them."

"I trust my psychiatrist so I would trust their professional opinion."

Some people felt very strongly that they had not been treated as an equal partner and were clearly upset by this. At times, people reported feeling that hadn't been recognised as individuals:

"I wasn't even treated as a patient, I was treated as an irritation."

"I was just a number."

Others were equally clear that they had been treated as an equal partner and that their views and wishes had been fully respected:

"Absolutely - I was given full control in whether to take medication or not."

"Yes! Very much a discussion. If I think I need an increase or decrease in anti-depressant, it happens."

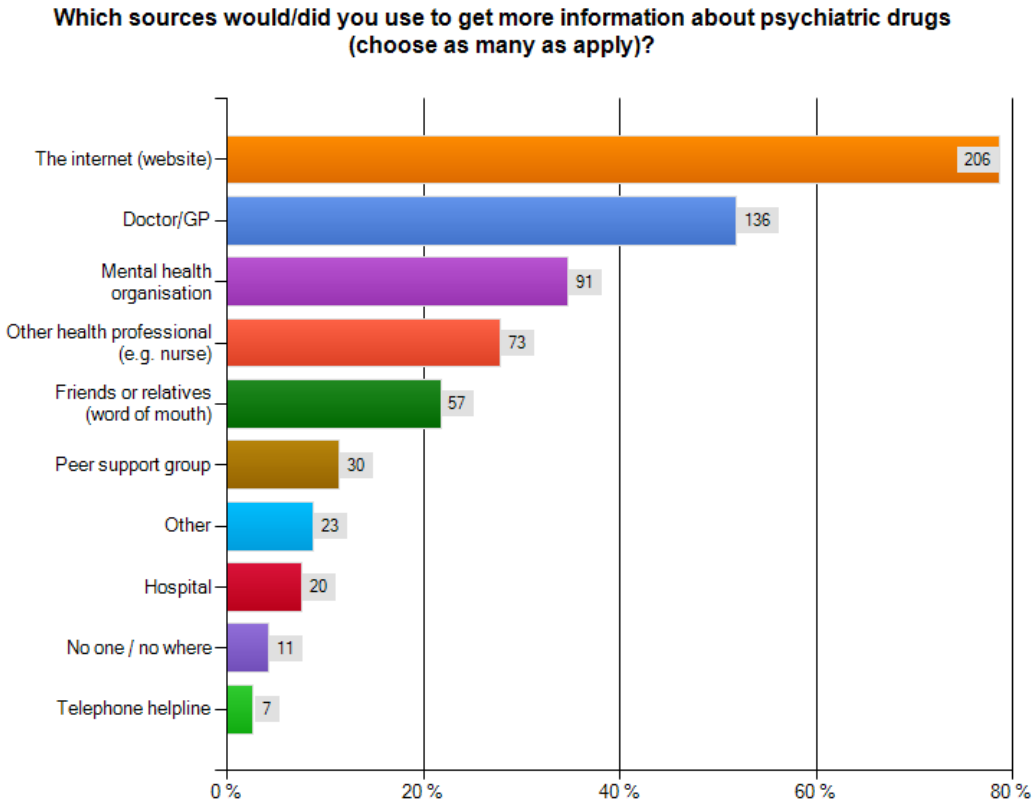
Several respondents reported having mixed experiences, with some reporting more positive experiences in recent years:

"Absolutely in the case of my GP. As far as the psychiatrist is concerned: absolutely not!"

"Again, only in recent years."

Seeking information

Many respondents went on to find out more about the drug they had been prescribed after receiving the initial prescription. The main source of information was the internet, with over three quarters of respondents (78.6%) indicating they either had or would use the internet to get information about psychiatric drugs. Several respondents commented that they had found internet forums, research websites and on-line support groups to be particularly useful. However, others cautioned that on-line information could be unreliable unless it was provided by a trusted source. Telephone helplines were the least popular information source, chosen by only 2.7% of respondents. A significant minority of respondents (4.2%) indicted that they would not seek information from any source.



Of respondents, 8.8% had/would use a source of information other than those listed in the survey. This included: books, peers (i.e. in hospital as opposed to a structured peer support group), academic studies, colleagues, The British National Formulary (BNF), and Pharmacists.

"It was only after reading and becoming interested in research into medication that I fully understood and felt very empowered by enabling myself to make a fully informed choice."

"Pharmacist (due to lack of MAOI card we ended up e-mailing manufacturer & getting their diet info prior to starting. Patient info leaflet once started). Looked up myself in BNF."

AREAS FOR IMPROVEMENT

Respondent's suggestions for improvement

Psychiatric drug prescribing can only be improved by consulting and listening to people who have personal experience of the prescription process and psychiatric drug use. We therefore asked people what, if anything, they thought needed to be improved about psychiatric drug prescribing. This question generated a considerable response and some of the individual responses we received are highlighted below, grouped into the most commonly occurring themes.

More discussion/information about the drug being prescribed and alternative drug options, with greater overall transparency in the prescribing process:

"They (patients) *need to be made aware of how the drugs work, what they do and of any potential side effects. They should be given this info in writing and be given a little time to familiarise themselves with it all before making the decision along with the doctor."*

"Information about the range of drugs available and details as to why the GP has selected a particular drug."

"It would not be going too far to ask for a clear information sheet to be made available at the time, so people are not sent away more anxious, worried and confused..."

"I would like to see prescriber providing a patient with an accurate as possible time frame for how long the medication will be taken and at what dosage…"

"Better record keeping regarding prescribing & reasons for changes in medication & dosage levels. Patients should be given their own record cards to do so & these could be shared between the different care professionals."

People should be empowered to participate in the prescribing process in so far as they are able, and be afforded greater time and opportunities to be heard:

"Being listened to as you know yourself better and not everyone fits a text book box."

"Patient needs to feel they can have their say and have the ability to say no if they have concerns about drugs"

"More time needs to be spent talking with the patient to establish IF medication will work best."

"Neither GP's nor Psychiatrists have time to discuss anything in any detail..."

Greater provision and promotion of non-drug treatment options:

"…Alternative treatments seem to be overlooked. Counselling, therapy and exercise should be promoted a lot more…"

"Other options should be explored before tablets are prescribed..."

"The referral to CBT and a MH (mental health) *employment programme (both via GP) helped so much more than pills."*

"Alternatives such as counselling, CBT should be made available at all health centres for people to access."

More information and honest discussion about potential side effects:

"Much more information on side affects and what you should do if you experience any."

"Lack of info re sexual dysfunction and their side effects."

"Full disclosure of all possible side effects at prescribing stage. Written information provided."

Better monitoring and reviewing after prescription:

"Drugs are prescribed too quickly and easily and not monitored effectively."

"More frequent reviews of medication."

More information, discussion and support in relation to stopping or changing a psychiatric drug:

"A discussion about how medication should be stopped; length of time, lowering dosage, potential side-effects from ceasing treatment."

"It would be good to know how difficult it can be to come off medication and to have time and good support if this is your choice to do so."

Discussion and recommendations

Based on the results of this survey, SAMH believes that there have been some positive developments in psychiatric drug prescribing since our original survey in 2003. For example, more people than before are being offered a choice of non-drug treatments and feel able to ask questions of the person making the prescription. However, it is also clear that more remains to be done to improve the prescribing process and empower people to become active partners in decisions about which treatment options are best suited to them.

In 2003, we recommended the introduction of good practice guidelines on the prescription of psychiatric drugs. This was to help ensure that, every time a new or different psychiatric drug was prescribed, there was a full and frank discussion on all relevant aspects of the drug and its part in a wider treatment plan. Since this time, a broad range of standards and guidelines have been introduced which are relevant to prescribing and treatment practice in Scotland. This includes:

Integrated Care Pathways (ICP): NHS boards in Scotland have to develop and implement ICPs. An ICP is an evidence-based framework which tells care

providers and people using services what should be expected at any point along the journey of care. The integrated care pathways (ICPs) for mental health describe the interactions and interventions that must be offered to all people who access mental health services, as well as those that must be offered to people with a specific condition.

Good Medical Practice (2006): Produced by the General Medical Council (GMC), this sets out the principles and values on which good practice is founded and includes the principles that doctors must follow when prescribing medicines

Good practice in prescribing medicines - guidance for doctors (2008): The General Medical Council expects doctors to comply with the standards of good practice set out in this more specific guidance, including that they must reach agreement with the patient on the use of any proposed medication and treatment by exchanging information and clarifying concerns. It also advises that doctors should ensure that people are given appropriate information about side effects and what to do should any problems occur.

Scottish Intercollegiate Guidelines Network (SIGN): SIGN has developed a number of evidence based clinical practice guidelines which are specific to mental health. These outline prescribing and treatment options for a range of conditions, such as specific guidance on the non-pharmaceutical management of depression.

The National Institute for Clinical Excellence (NICE): NICE develops clinical guidelines for the National Health Service (NHS) in England and Wales. In theory, these are not applicable in Scotland but Scottish practitioners often take account of them because of their value as the latest, evidence based, clinical guidelines developed by experts in the relevant field.

We believe that, if properly implemented, these standards and guidelines could go far to bring about the improvements that people want to see. Recent changes to the way that GPs and Psychiatrists are appraised and validated also bring new opportunities to afford increased priority to good prescribing practice, and ensure greater adherence to the range of standards and guidelines that apply. We are therefore making the following recommendations to the Scottish Government, Local Authorities, National Health Service for Scotland (NHS), General Medical Council (GMC), Royal College of General Practitioners (RCGP), Royal College of Psychiatrists (RCPsych), NHS Education for Scotland (NES) and Healthcare Improvement Scotland (HIS):

- **In accordance with the above guidelines, people must have easy access to a comprehensive range of community based mental health services e.g. counselling and physical activity programmes. This will require investment by the Scottish Government, NHS and Local Authorities.**

- **Information about community resources which can support mental health and wellbeing should be collated and made publically available. This relates directly to Commitment 15 of the Mental Health Strategy for Scotland (2012-2015) which seeks to connect existing sources of support and make local information easy to find. This will require collaborative working between NHS Boards, Local Authorities and the voluntary sector. The NHS should also ensure that GPs know what services are available in their communities and are able to refer people to them.**

- **Written information can be particularly important for people experiencing mental ill-health, who may be unable to absorb verbal information at times when they are unwell. The Scottish Government and NHS should undertake a review of the written information people receive with psychiatric drugs to ascertain whether existing regulations are being adhered to. It should also be considered how the quality and provision of written information could be improved.**

- **HIS should develop a resource for prescribers to make it explicitly clear when a particular guideline or standard applies e.g. NICE, SIGN and/or ICP. Access to this information should then be demonstrated as part of GP/Psychiatrist appraisal and revalidation.**

- **The GMC, RCGP, RCPsych and HIS should strengthen training in mental health prescribing. This should include reviewing the RCGP and RCPsych curriculum to give greater prominence to the knowledge and skills needed for safe prescribing.**

- **Greater attention should be given to prescribing for mental health in the continuing professional development of GPs and Psychiatrists. For example, new prescribing learning resources should be promoted to doctors as part of the Continuing Professional Development modular Credit-Based System. This training should also be part of the appraisal and revalidation process to ensure that all doctors keep up-to-date in this area of their work.**

- **The GMC, RCGP and RCPsych should enable prescribers to record educational activities, audits, and procedures specifically relating to prescribing. This should then be reviewed during Appraisal to identify areas for improvement.**

- **The GMC, RCGP, RCPsych and HIS should ensure that prescribers regularly review their repeat prescribing and medication monitoring procedures, and can demonstrate the outcomes of these reviews.**

- **The GMC and RCGP should recommend that each general practice appoint a prescribing lead to lead reviews and identify best prescribing-practice.**

- **Prescribers should be able to demonstrate that patients' views about medication and treatment are explored and their choices taken seriously at the point of prescribing. This could be investigated using patient experience surveys.**

ABOUT SAMH

SAMH is the Scottish Association for Mental Health, a charity working across Scotland. Every year, we provide over a million hours of support to people who need our help. Every week, we work with around 3,000 individuals in over 80 services. Every day, we campaign for better mental health for the people of Scotland.

SOURCES OF SUPPORT

If you have concerns about any of the issues raised in this report and would like to talk to someone about it, the following helplines/organisations can offer support and provide information:

SAMH
For information on topics related to mental health
- Information service: freephone 0800 917 34 66 (weekdays 2-4pm)
- General enquires: 0141 530 1000
- Email : info@samh.org.uk
- Website: www.samh.org.uk

Samaritans
Provides 24-hour, confidential emotional support to any person who needs to talk.
- UK helpline: 0845 790 9090
- Email: jo@samaritans.org
- Website: www.samaritans.org.uk

NHS Inform Helpline
Can give you details of all pharmacies and GP practices in Scotland. They can also give you information about illnesses and conditions, treatments, NHS services and other support services.
- Tel: 0800 22 44 88 (8am to 10pm, 7 days)
- Website: www.nhsinform.co.uk/mentalhealth

NHS 24

NHS 24 works in partnership with local NHS Boards out-of-hours services to provide patients with health advice and help when GP practices are closed.

- Call: 08454 24 24 24
- Visit: www.nhs24.com
- If you think you need an emergency ambulance, call 999 and speak to the operator