"All you need to know?"

Scottish Survey of People's Experience of Psychiatric Drugs

The Scottish Association for Mental Health

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Initial analysis of the data was carried out at Strathclyde Centre for Disability Research with further analysis carried out at SAMH.

In some cases data shown in tables may not add up to 100%. This will be for one of the following reasons:

- Figures are rounded up.
- 'Not sure' responses are not displayed in all tables.
- In some cases it may be possible for respondents to record more than one answer.
- Drugs with fewer than ten responses are excluded from summary tables.

IMPORTANT MESSAGE

If you are currently taking a psychiatric drug, or think you might be getting a prescription in the future then we hope that this report provides valuable information. However, it should be remembered that we all react differently to medication; so don't be put off seeking help because of some of the comments in this report. Very many people who returned forms said they found medication helpful.

If you are concerned about any aspect of your drug treatment, you should speak to your doctor 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

The Scottish Association for Mental Health (SAMH) is a membership based mental health charity, which both campaigns and provides information on mental health issues, and is itself a major service provider, with 76 services throughout Scotland, provided by 660 staff.

SAMH has long campaigned for full recognition of the civil rights of people with mental health problems, an end to their social exclusion, easier access to welfare benefits, employment and training opportunities, and for better services and a wider choice of treatments.

It is rare for a psychiatric treatment not to have both enthusiasts and detractors. Just think about ECT, psychoanalysis or psychosurgery – all with their critics as well as advocates. For over 50 years, drugs have been the mainstay of psychiatric treatment. 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.

Before new drugs can be introduced, pharmaceutical companies are required to test them under controlled conditions, in trials, with the results published in medical journals. However, these trials will not necessarily highlight all the issues, or detect all of the problems that might later be encountered. Recently Richard Smith, editor of the British Medical Journal, drew to attention to the deficiencies of this system, in particular the fact that 70% of trials are actually funded by the pharmaceutical industry. He quoted one review that found that trials funded by individual companies, despite the fact that they were tightly regulated, were four times more likely to have results favourable to their own drugs, than those funded by others. He concludes that: "the public is being regularly deceived and exploited."[1]

SAMH is frequently asked for views on drugs, by mental health service users, by carers, by professionals, and by politicians and the media. Our policies are based on consultation with service users and members, but this is our first large scale systematic study of what mental health service users really think about psychiatric drugs. As the first ever Scotland wide survey of its kind, we hope that this report will be read attentively throughout the mental health community.

The Health Service, and the Scottish Executive, have also recognised the importance of incorporating the views of those who use mental health treatments and services in their assessment. Partnership for Care, the Scottish Executive Health White Paper, produced in 2003, states that the views of patients (as well as carers and local communities) should be "actively sought, listened to and acted on; and treated with the same priority as clinical standards and financial performance."[2] We hope this report will contribute towards a new evidence base of user views of treatments.

The survey intended to accomplish two things that aren't covered by more conventional randomised control trials (RCTs)[3]. Firstly, to be based on users' own views of the drugs and the whole process of being given treatment, and, secondly, to involve a large number of people with a wide variety of experiences and illnesses, thus giving us a broader 'sample' than those usually available for an RCT. This is important because people who are very ill are not usually included in RCTs because they would be too ill to give consent to taking part in research. Our survey, however, included people with a variety of conditions and experiences – nobody was 'discounted' because of the nature or extent of their illness.

1 Quoted in The Guardian, 14th January, 2004
2 Partnership for Care: Scotland's Health White Paper, The Scottish Executive, 2003
3 An RCT is a controlled observed experiment where subjects are separated into two groups, with one being given the medication, and the 'control' group being given a non-active substance (placebo). They are ideally 'double blind' i.e. neither subject nor observer knows which group is which.

Of course by the nature of the things, this type of survey research relies on people volunteering information – and thus our sample is self-selecting. However, no research methodology is perfect. This research needs to be read in conjunction with other methods – in the way that pieces make up a jigsaw. No single research method can give a definitive answer to the wide range of issues that we are considering.

This report, out of necessity, is fairly long and detailed. A shorter Summary Report is being prepared and will be available on our website: www.samh.org.uk

1 SURVEY PARTICIPANTS

We received 1,012 completed survey forms from across Scotland. This analysis is based on 756 forms where the respondent indicated that they had received a new or different prescription within the last three years. (see Appendix 1: Methodology for more details).

1.1 Age and Gender

51.1% of respondents were female and 42.2% were male (6.7% of respondents did not supply gender). The mean age of respondents was 41 years eight months, the youngest respondent being 16, and the oldest 78.

Table 1.1 Gender

Gender	Number	%
Female	386	51.1
Male	319	42.2
Not known	52	6.7

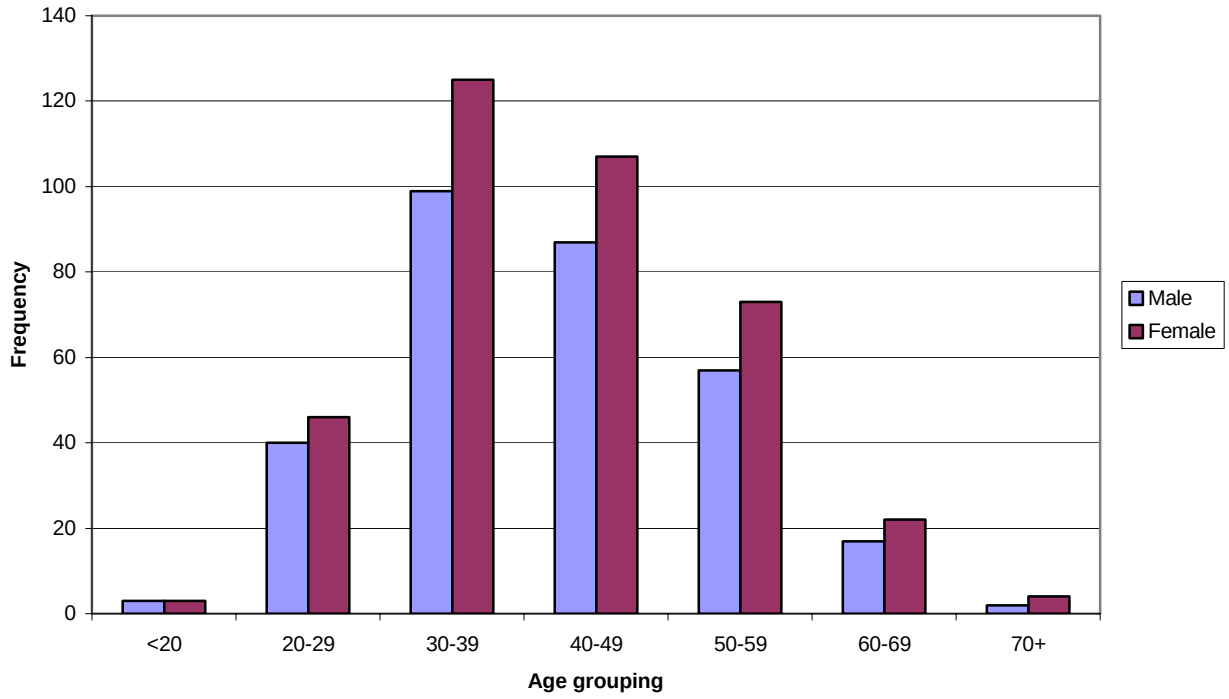
The majority of respondents were aged between 30 and 49 (61.1%). Less than 2% of respondents were aged below 20 or over 70.

Table 1.2 Age

Age	Number	%
Under 20	6	0.9
20-29	88	12.6
30-39	228	32.7
40-49	198	28.4
50-59	132	18.9
60-69	40	5.7
Over 70	6	0.9

The following chart shows the distribution of age by gender. There was no relationship between age and gender. Although there were a slightly higher proportion of females in every age group, this was not statistically significant.

Figure 1: Participants: Age group by gender



1.2 Ethnicity

The percentage of survey forms returned from people from ethnic minority communities was just under 3%, which is proportionate to the general population.

1.3 Current Diagnosis

The most common psychiatric diagnosis, reported by almost half of all respondents, was depression. This was followed by schizophrenia, anxiety disorder, manic depression (bipolar disorder), each being reported by approximately one in five respondents. A higher proportion of males than females reported having a diagnosis of schizophrenia, and slightly higher proportion of females than males reported having a diagnosis of manic depression. 34 respondents reported having a personality disorder and 62 had a diagnosis other than those listed in the survey form.

22 respondents reported that they did not have a current diagnosis and 17 were unsure what their diagnosis was. 195 respondents, just over a quarter, reported having been diagnosed with more than one condition.

Table 1.3 Diagnosis by gender: Total plus percentage of males and females

Diagnosis*	Total		%	
	Number	**%**	**Males**	**Females**
Depression	358	47.4	44.2	51.6
Schizophrenia	165	21.8	31.7	12.4
Anxiety disorder	156	20.6	21.6	19.2
Manic Depression	150	19.8	16.9	23.1
Personality Disorder	38	5.0	2.5	6.7
Other	67	8.9	7.8	9.6
No current diagnosis	23	3.0	3.8	2.6
Not sure	18	2.4	1.9	2.8

*Missing data: 13 respondents did not record a diagnosis, the gender of 52 respondents was not known.

How fairly represented are different diagnoses in our sample? The number of people with a diagnosis for anxiety and depression are roughly what would be expected from a broad sample of people with all mental health problems if we compare this with prevalence data from the Office for National Statistics (ONS).[4] However, the proportion of those with a diagnosis of personality disorder is considerably lower than that noted by ONS. Conversely the proportion of survey respondents with schizophrenia or manic depression is considerably higher than that found by ONS.

4 Psychiatric Morbidity Among Adults Living in Private Households, Office for National Statistics, 2000

2 EXPERIENCE AT LAST PRESCRIPTION

Survey respondents were asked a series of questions that related to the last time they had a prescription for a new or different psychiatric drug. This had to have been within the last three years for the data to have been considered.

Key findings

- Only a fifth of respondents were offered a choice of drugs at prescription.
- In a third of cases there was no discussion of the drug being prescribed between the service user and the person making the prescription.
- Over 30% of respondents said they did not feel able to ask questions of the person making the prescription.
- Half of respondents were happy that the prescription had been a joint decision.
- 60% of respondents reported having had some concerns about the newly prescribed drug once they started taking it.
- Over 70% of people who had a concern after starting taking a drug discussed it with the person who made the prescription. However, over a quarter of them did not feel their concerns had been listened to.
- In just under 30% of cases respondents reported was no written information about the drug provided at prescription.
- Of the people who went on to find more information about a drug the most popular source of information was the internet.

2.1 Who made last prescription

Psychiatric drugs are usually prescribed by either psychiatrists or GPs. In over 70% of cases in our survey, the most recent prescription was made by a psychiatrist. By contrast, in the general population, many more people with mental health problems seeking treatment are seen by their GP rather than by a psychiatrist.

Table 2.1 Who made the last prescription?

Prescribed by	Number	%
GP	200	26.6
Psychiatrist	545	72.5
Not sure	6	0.8

2.2 Last drug prescribed

Respondents were asked which drug was prescribed at the last new or different prescription. Just over one in five respondents (21.4%) reported having been prescribed more than one new or different drug on that occasion.

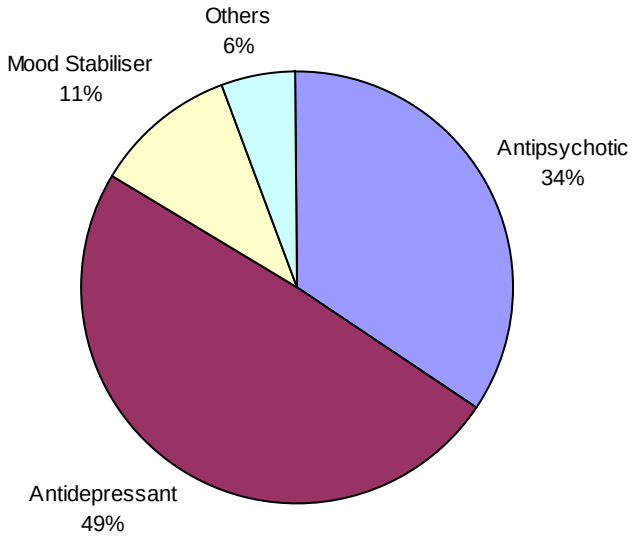
Just under half of prescriptions made were for an antidepressant. The most commonly prescribed drug types were SSRI type antidepressants and atypical antipsychotics (both 23.5%).

Table 2.2 What was the last drug prescribed? - Drug type

Psychiatric drug	Prescript-ions	%*
SSRI antidepressant	222	23.5
Tricyclic antidepressant	84	8.9
MAOI antidepressant	8	0.8
Other antidepressant	149	15.8
Atypical antipsychotic	222	23.5
Typical antipsychotic	89	9.4
Depot antipsychotic	14	1.5
Mood stabilisers	104	11.0
Anxiolytic	38	4.0
Hypnotic	14	1.5

*Percentages will exceed size of sample because some respondents received more than one new drug.

Figure 2: Drug group prescribed



2.3 Choice of drugs at prescription

Respondents were asked whether they had been offered a choice of drugs at the time of prescription.

Many mental health service users have a good working knowledge of psychiatric drugs, sometimes having taken different drugs for extended periods and some understand well what works best for them. Other people who completed the form will have had limited experience of taking psychiatric drugs and may feel happy to leave the choice of drugs to the health professional.

Over 70% of respondents were not offered a choice of drugs at the last new or different prescription.

Table 2.3 Were you offered a choice of drugs? - Total plus gender percentage

Offered a choice	Total		%	
	Number	%	Males	Females
Yes	170	22.8	20.3	24
No	535	71.9	75	70.4
Not sure	39	5.2	4.8	5.5

Women were slightly more likely than men to be offered a choice of drugs. People with a diagnosis of personality disorder were the least likely to be offered a choice of drugs, though the numbers are relatively small (Table 2.4). People diagnosed as having an anxiety disorder were also very unlikely to be offered a choice of drugs. People with schizophrenia and manic depression were the most likely to be offered a choice possibly reflecting the often long-term nature of these illnesses.

Table 2.4 Were you offered a choice of drugs? - Diagnosis

Diagnosis*	Yes	%	No	%
Depression	76	23.3	250	76.7
Schizophrenia	51	32.7	105	67.3
Anxiety Disorder	22	15.3	122	84.7
Bipolar Disorder	43	30.0	100	70.0
Personality Disorder	3	8.6	33	91.4

*It was possible to record more than one diagnosis.

Whether a psychiatrist or GP made the prescription had no bearing on the likelihood of being offered a choice.

2.3.1 What people said about choice of drugs

From comments it was clear that there were a number of distinct groupings within those who had not been offered a choice of drugs. For one group of respondents the lack of choice was not a problem. In some cases this was because the doctor or psychiatrist was considered to be the 'expert':

They're the experts.
You take your GP's advice, normally without question, as you trust them. They know better.
I was happy about this as my doctor knows the drugs better than I do.
Didn't question being offered a choice of drugs.
I found the choice the psychiatrist made was very good.
For all the drugs I take, I trust the doctor to give me the right script.

In other cases the service user felt that at the time of prescription they were too unwell to have any input:

I was too ill to discuss the drugs.
As I was very unwell I had no insight into my condition, so decisions were made for me…
You are normally told what you are being prescribed that the doctor's/psychiatrist's opinion is that it will be best suited and then asked if you are happy with that. Not well informed of the negatives, too low to complain.
As I was very unwell I had no insight into my condition, so decisions were made for me. I now respond well to the medication I still take.

However, other respondents were unhappy with this lack of choice:

I was told that I had a choice: 'Take the drug or go for a rest in hospital.' I was not given a choice of drugs and was lied to about how long I would be on it.
I was not asked. Told what to take. I felt that control was taken away from me.
I would prefer to discuss pros and cons of drugs with doctors, they seem to prescribe on trial and error…
I wasn't even asked if I would like to try it.

Others identified time constraints put on psychiatrists and GPs as a problem:

To be fair I don't think GP has sufficient time as I am probably in the surgery longer than most. Nothing against doctor, very patient.
GP knows I have working knowledge of drugs and mental health, but she's conventional and busy.

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

In-depth discussion at the hospital with psychiatrist and pharmacist.
Worked with psychiatrist and nurses to make decision.
Emergency GP, not usual GP, saw me. Asked me what drug I wanted. Amazed at attitude.
I was offered a choice of mood stabilisers. I chose on the basis of my psychiatrist's advice.
The above was openly discussed between myself and the psychiatrist. No pressure was put on me by the doctor...
Full explanation and options given but then I'm a consultant psychiatrist which, I suspect, sadly, makes things easier.

2.4 Choice of non-drug treatments

Respondents were asked if they had been offered a non-drug treatment in addition to the medication being prescribed, and just over a quarter (26.6%) reported that they had. Non-drug treatments mentioned included counselling and talking therapies, day centres and clinics and stress management classes.

2.5 Discussion of drug being prescribed

We asked a series of questions around the level of discussion that took place between the service user and health professional at the time of prescription.

It is concerning that in a third of cases there was no discussion of the drug being prescribed between the service user and the person making the prescription.

Table 2.5 Did doctor or pharmacist discuss the drug being prescribed with you? - Total plus gender percentage and GP and psychiatrist percentage

Discussed drug	Total		%			
	Number	%	Males	Females	GP	Psychiatr-ist
Yes	478	63.2	60.0	67.0	62.3	64.9
No	247	32.7	35.9	29.9	33.7	32.0
Not sure	26	3.4	4.1	3.1	4.0	3.1

Table 2.5 shows that women were more likely to have discussed their drug with the person making the prescription, just as we saw earlier with the question of drug choice. Whether it was a psychiatrist or GP who made the prescription made little difference to the likelihood of such a discussion taking place.

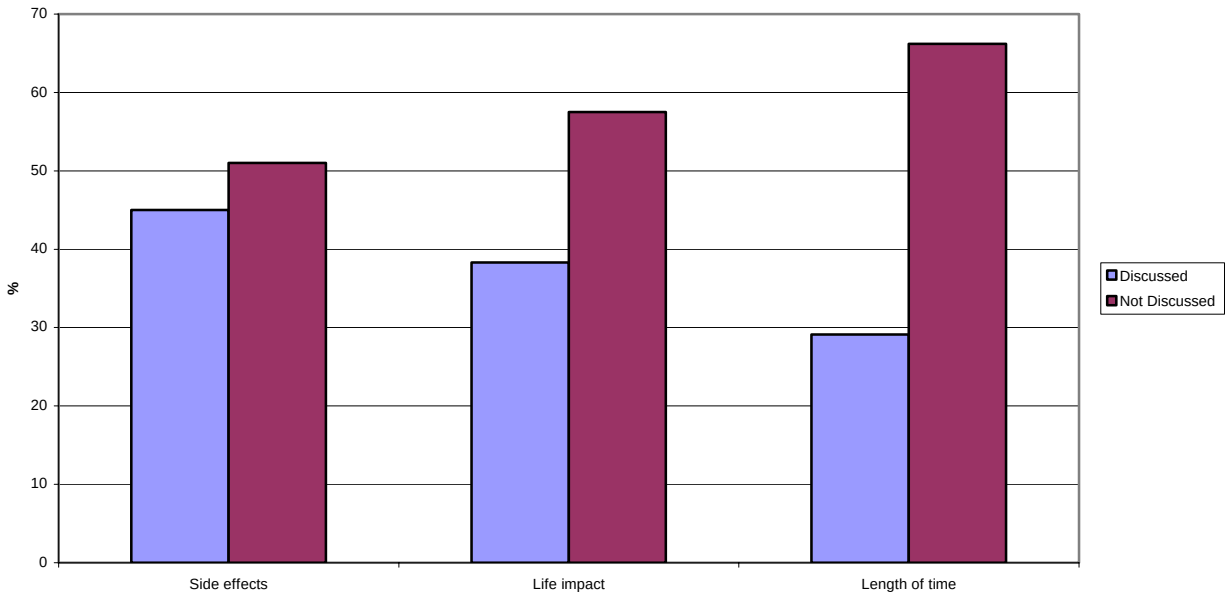
People who had discussed the drug at prescription were then asked three further questions about discussion topics.

Table 2.6 Specific topics discussed

Issue	Discussed	%	Not Discussed	%
Unwanted effects	337	45.0	382	51.0
Life impact	287	38.3	431	57.5
Length of time	218	29.1	496	66.2

Given that the above percentages are themselves a percentage (of the 63% who said they did have discussion about the drugs) this means that only around one third of patients had a discussion about unwanted effects, and less than this proportion discussed the possible impact on lifestyle, or the length of time they would have to take the drug.

Figure 3: Specific issues discussed



2.6 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 30% of people reported that they did not. In some cases this may have been because the respondent felt too ill to ask questions or enter dialogue.

Table 2.7 Felt able to ask questions?

Felt able to ask questions	Total		%	
	Number	%	Males	Females
Yes	472	62.7	64.8	59.7
No	229	30.4	29.4	32.1
Not sure	52	6.9	5.7	8.2

While gender made only a slight difference to the proportions of people who felt able to ask questions there were considerable differences between diagnoses (Table 2.8). For example, 70% of people with a diagnosis of bipolar disorder felt able to ask questions compared to just over 44% for people with a diagnosis of personality disorder (again based on a fairly small sample).

Table 2.8 Felt able to ask questions? - Diagnosis

Diagnosis*	Yes	%	No	%
Depression	212	59.7	114	32.1
Schizophrenia	106	64.6	49	29.9
Anxiety Disorder	86	55.5	52	33.5
Bipolar Disorder	105	70.0	39	26.0
Personality Disorder	17	44.7	18	47.4

*It was possible to record more than one diagnosis.

2.7 Joint decision making

Half of all respondents reported that they had been *very* or *fairly* happy that the prescription of their drug had been a joint decision between them and the person making the prescription. As we saw earlier in comments, many people seemed to take the view that either the doctor 'knew best', or reported being too unwell to genuinely participate.

Table 2.9 How happy were you that the prescription was a joint decision?

How happy joint decision	Number	%
Very happy	157	21.1
Fairly happy	214	28.8
Neither happy nor unhappy	182	24.5
Fairly unhappy	76	10.2
Very unhappy	77	10.3

2.8 Raising concerns after prescription

Respondents were asked if they had had any concerns about the drug after they started taking it. Four hundred and forty eight respondents, almost six out of ten, reported having had some concerns about their new psychiatric drug once they started taking it.

Table 2.10 Did you have concerns about the drug after you started taking it?

Concerns after started	Concerns	%	%	
			Males	Females
Yes	448	60.6	59.8	62.1
No	261	35.3	35.0	34.2
Not sure	30	4.1	5.1	3.7

Concerns were reported most often by people who had been prescribed a mood stabiliser type drug, with three quarters reporting a problem, and lowest for those prescribed a tricyclic antidepressant, at just over 50%.

Table 2.11 Did you have concerns about the drug after you started taking it? - Drug type

Drug prescribed*	Yes	%	No	%
SSRI antidepressant	86	61.0	49	34.8
Tricyclic antidepressant	21	51.2	19	46.3
Other antidepressant	58	63.7	29	31.9
Atypical antipsychotic	86	55.5	64	41.3
Typical antipsychotic	27	62.8	14	32.6
Mood stabilisers	39	75.0	10	19.2

*Excludes cases where more than one drug was prescribed at the last new or different prescription and excludes some groups of drugs where the sample size was very small.

Of the most commonly prescribed drugs, the highest proportion of concerns related to Paroxetine (Seroxat) at 82.9% and the lowest Fluoxetine (Prozac) at 50.0%. However, these figures should be treated with some caution given the low sample sizes. For more exhaustive detail on individual drug issues please see Section Four of this report.

Table 2.12 Did you have concerns about the drug after you started taking it? - Generic drug

Generic drug name	Type	Yes	%	No	%
Citalopram	SSRI antidepressant	25	51.0	21	42.9
Fluoxetine	SSRI antidepressant	20	50.0	17	42.5
Paroxetine	SSRI antidepressant	29	82.9	6	17.1
Venlafaxine	Other antidepressant	42	66.7	19	30.6
Olanzapine	Atypical antipsychotic	28	50.9	25	45.5
Risperidone	Atypical antipsychotic	20	60.6	12	36.4

*Only includes data on selected drugs where more than 30 prescriptions were recorded.

2.9 Discussing concerns after prescription

It is encouraging that, of the people who had concerns about a drug after they started taking it, over 70% had discussed their concerns with the person who had prescribed the drug.

Table 2.13 Did you later discuss these concerns with the person that made the prescription?

Discussed concerns	Number	%	%	
			Males	Females
Yes	324	72.8	76.3	74.0
No	111	24.9	26.3	23.8
Not sure	10	2.2	2.7	2.1

However, more than a quarter of people who had raised concerns did not feel that they had been listened to.

Table 2.14 How happy were you that you were listened to when you discussed these concerns?

How happy	Number	%
Very happy	90	26.6
Fairly happy	117	34.6
Neither happy nor unhappy	34	10.1
Fairly unhappy	43	12.7
Very unhappy	50	14.8

2.9.1 What people said about raising concerns about a new drug

12 respondents specifically drew attention to health professionals who took time to ensure that they were happy with their medication:

My GP was excellent and makes time available to discuss everything to ensure I am OK with things.
My psychiatrist was direct and honest. I found this very reassuring.
I was given time and assurance about what I was asking.

Others reported a less positive experience:

It did not seem important to GP or psychiatrist.
I was seen as non-compliant.

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

I was told that loss of libido didn't matter…
Side effects not taken as valid as most important thing is seen as resolving symptoms.
I was told it was all in the mind and nothing to do with medication.

Others reported that they had been treated in a dismissive manner by their GP or psychiatrist:

Just said I was being attention seeking, I had breast milk, no periods and put on two and a half stone…
Didn't pay blind bit of notice to me.

2.10 Other information sources on newly prescribed drugs

In just under 30% of cases there was no written information about the drug provided at prescription. In over 90% of cases where information was provided it was in the form of a patient information leaflet, provided by the drug manufacturer. In a small proportion of cases (9%) people received written information from another source e.g. a pharmacist.

This is of some concern given 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, in part, to survey respondents not being aware of a PIL. Equally it may be due to patients not being given PILs when they are prescribed generic drugs. This issue requires further investigation.

Table 2.15 Written information provided at prescription?

Written information	Number	%
Yes	516	68.3
No	219	29.0
Not sure	20	2.6

Over half of respondents went on to find out more about the drug they had been prescribed after receiving the initial prescription. Women were more likely to seek out additional information than men.

Table 2.16 Did respondent personally find out more about the drug?

Find out more	Number	%	%	
			Males	Females
Yes	414	55.6	51.9	59.1
No	314	42.2	44.6	39.8
Not sure	16	2.1	3.5	1.0

The main source of information was the internet, used by almost a quarter of respondents; this was followed by GP or psychiatrist, other service users, pharmacist, and community or voluntary organisations. However, it should be borne in mind that respondents who reported having found information on the internet may have been using the web sites of voluntary organisations, or indeed health service information sources. One in five respondents had used a source of information other than those listed on the survey form.

2.11 Section 2 conclusion

Respondents seemed to fall roughly into three groups. The first group were on the whole happy to leave decisions to their doctor, the second group had a two-way relationship with their doctor over medication and negotiated changes and the third group would have liked to have had a two way relationship but did not feel that the doctor reciprocated.

The most troubling findings are that a quarter of respondents who had concerns about their medication did not feel able to discuss these with their doctor, and of those who did, over a quarter were not happy with the way those concerns were dealt with. This is not simply a case of people being unhappy because the doctor would not agree with them – some respondents did acknowledge that at times the doctor had been right even though they were not happy taking the drug.

If someone has a concern about taking medication clearly there is a need for more discussion, more information, more negotiation. It may not mean that someone should stop taking the drug, but whatever is decided the decision should be one that is made jointly. Our survey indicates that in too many cases this is not happening.

Both professionals and users agree that clinicians often don't have enough time to spend with patients and this is reinforced by our findings.

3 HISTORICAL EXPERIENCE OF PRESCRIPTION

Survey respondents were asked a series of questions that related to any previous experience of being prescribed a psychiatric drug (unlike Section Two where all responses were based on the last time a new or different prescription).

Key findings

- Just over half of the respondents had at some point disagreed with their psychiatrist or GP about a drug that had been prescribed for them.
- Almost a third of respondents reported being very unhappy about the extent to which their opinion was considered when they disagreed.
- Over 60% of respondents had at some point asked to stop taking a psychiatric drug.

3.1 Disagreeing with a GP or psychiatrist about drugs

Survey respondents were asked if they had ever disagreed with their GP or psychiatrist about a drug and just over half of respondents said they had. This is even more striking when you consider that a quarter of survey respondents had only been prescribed one drug in the last three years and would, therefore, have been less likely to come into disagreement.

Table 3.1 Ever disagreed with GP or psychiatrist about a drug?

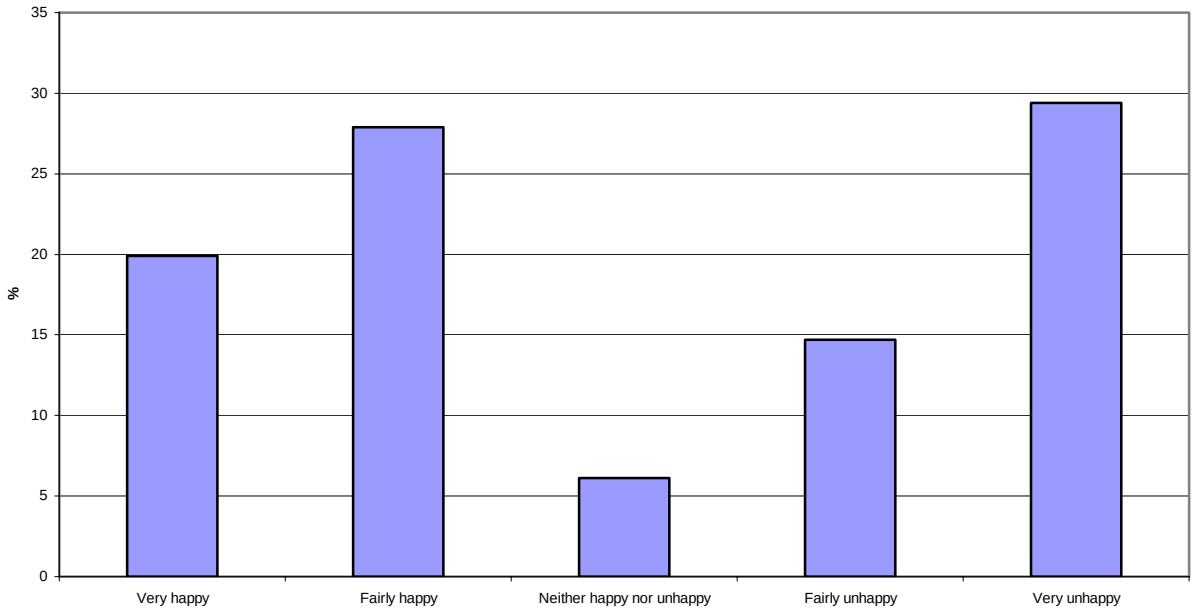
Ever disagreed	Number	%	%	
			Males	Females
Yes	376	50.6	48.9	53.2
No	341	45.9	47.0	43.7
Not sure	26	3.5	4.1	3.2

It is encouraging that almost everybody (96%) who had at some time disagreed let their psychiatrist or GP know. However, it is concerning that when asked how happy they were that their opinion had been considered, 44% of respondents in this group said they were *fairly* or *very* unhappy. Indeed the largest single response to the question was *very* unhappy at just under 30%.

Table 3.2 How happy were you that your opinion was considered when you disagreed?

How happy opinion considered	Number	%
Very happy	69	19.9
Fairly happy	97	27.9
Neither happy nor unhappy	21	6.1
Fairly unhappy	51	14.7
Very unhappy	102	29.4

Figure 4: How happy opinion was considered when disagreed



3.1.1 What people said about disagreeing with their GP or psychiatrist about a drug

One group of respondents identified variable practice between different health professionals:

> *He agreed with me. I was very lucky to have this psychiatrist… Other doctors in the past did not respect my opinion and were patronising.*
> *The GP accepted my right to choose. The psychiatrist was more adamant regarding administration of the drugs.*
> *Had to go to my GP to get antidepressants when psychiatrist would not prescribe one.*

Another group reported a positive outcome to disagreements:

> *We had a frank discussion resulting in a much better relationship.*
> *They listened and they argued amongst themselves, and with me, but agreed it had to be my decision in the end.*

Some of them reported having their medication changed or modified:

> *They went and researched my concerns and came back and agreed with me and changed treatment accordingly.*

In many cases comments indicated that treatment had not been changed or modified as a result of the disagreement:

> *My opinion was completely ignored and the debilitating side effects were dismissed.*
> *Threatened with sectioning. Discussed with my husband as if I wasn't there.*

For some the lack of choice or alternatives was a problem:

> *They think they know best. Your views and requests for 'talk therapy' are often denied - no matter how bad you feel.*
> *I was told that I didn't know what I was talking about. There was no discussion of alternatives.*

Some respondents drew attention to the issue of drugs which were no longer helping them or concerns about taking drugs over an extended period:

> *I had been on Melleril and Seroxat for six years and they were making me ill, and causing me to have palpitations, put on weight, and generally not leading to an improvement in my condition.*
> *Told GP I wasn't happy taking antidepressants over a long period of time. Was told to think of myself as diabetic.*

One group of respondents specifically drew attention to side effects, reporting that health professionals did not acknowledge that they were having side effects or did not appreciate the impact on their lives:

> *I was told by my GP that he knew best, and when I asked about the side effects he said, 'It's an antidepressant, that's all you need to know.'*
> *My GP told me I could not be having the side effects I was describing, i.e. being very confused.*

3.2 Stopping taking a drug

Further to being asked about disagreements, respondents were specifically asked if they had ever asked to stop taking a psychiatric drug. Over 60% reported that they had, with women slightly more likely than men to have discussed it.

Table 3.3 Ever asked to stop taking a drug?

Ever asked to stop a drug	Number	%	%	
			Males	Females
Yes	469	62.8	59.4	66.8
No	265	35.5	39.0	31.4
Not sure	13	1.7	1.6	1.8

3.2.1 What people said about asking to stop taking a drug

This question generated over four hundred comments giving some idea of the strength of feeling on the subject. Analysis shows that where people were supported to stop taking a drug a small proportion became unwell as a result. However, where people had stopped taking their drugs unilaterally, a far higher proportion became unwell.

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

> *My old consultant told me he would refuse to be my consultant if I stopped the medication.*
> *Told not to be silly, and did I think I was going 'high' again?*

In some cases there was the threat of hospitalisation if a drug was stopped:

> *I was told I would (not might) get ill and relapse. Possible sectioning was hinted at if I persisted in requesting to stop.*
> *I was told by my CPN that I would be taken into hospital.*
> *I was advised that my condition was long-term and that failure to take the drug would result in further hospitalisation.*

In others the possibility of having to take medication by a depot injection was mentioned:

> *Told that the medication would be better than injections.*
> *Would need to take medication or go on depot again.*

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

> *I was told that I would have to take it for the rest of my life…*
> *It was explained to me that I would always be on some kind of medication.*

Some felt that their doctors did not take the side effects seriously:

> *My opinion was completely ignored and the debilitating side effects - I could not speak for four months - were dismissed. The doctor did not accept that my physical and psychological difficulties in speaking were due to the drug - which they were.*
> *I was told it was a silly thing to do and was not believed about the side effects.*
> *Mostly was ignored. Was eventually taken off Risperidone after they did a hormone screen, after I asked about ten times. It showed that my prolactin level was 6000 and normal was 800.*

Others reported a more positive experience of negotiated reduction or withdrawal:

> *I was given sensible advice from the GP and psychiatrist about exercising caution and by reducing the dosage of powerful antidepressants over a given period of time I was able to avoid withdrawal symptoms.*
> *The GP gradually reduced the dose after listening to me and why I wanted to stop taking the drug.*
> *My opinion was respected and agreement reached.*

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:

> *My psychiatrist discussed it with me. I explained why I wanted to come off them and he listened to me and explained the possible consequences of coming off medication when I wasn't ready to.*

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

> *I was able to change from Paroxetine to Sertraline. My concerns were taken seriously.*

Others who had been advised not to stop taking a drug agreed that, in hindsight, this had been the right decision:

> *I asked my GP if I could stop taking Paroxetine shortly after I was prescribed it for my original diagnosis, which was depression and anxiety. I was told no - looking back this was probably the right advice.*

Another group who did stop taking a drug reported their symptoms had become worse as a result*:*

> *I discontinued Lithium and antidepressants slowly under medical supervision, and for about six months everything was fine, but then I became very ill and went back on the medication. After trying to withdraw from antidepressants, I became more unwell and suicidal.*

Psychiatrist said no but I stopped taking the drug anyway and became unwell.

However, in some cases there was some disagreement about whether it was drug withdrawal or the return of symptoms that was to blame:

They increased the dosage, saying it was the depression that was making me feel this way. With hindsight, this was completely wrong.
I have been trying to withdraw from Seroxat for five months…. My GP was trying to help me withdraw slowly but the tablets were not agreeing with me… I knew this but I don't think the GP fully believed me. I knew myself they were causing panic attacks etc. She seemed to think it was still in my depressive state.

One group of respondents felt that they had not felt adequately supported in attempts to stop taking a drug:

I did not get a constructive answer. I did not feel I would get the support I needed if I stopped and that this would cause problems for me.
I was initially told no. I was only permitted to stop taking the drug after I presented an A4 sheet of information about how I intended to cope.

Others reported that they had stopped taking a drug without their doctor's agreement:

A disagreement arose and I stopped taking it.
I stopped taking my medication without my psychiatrist knowing - he wanted me to reduce dose.
I am now off Seroxat, it was pure hell but I done it. I will never take it again. They were not pleased about me not wanting to take it.

3.3 Section 3 conclusion

Half of our respondents had at some time disagreed with their GP or psychiatrist about a drug - a high proportion. It is worrying that nearly half of those who did disagree were unhappy and felt that their opinion had not been considered, with nearly 30% *very* unhappy.

From our experience we are not surprised that over 60% of respondents had at some point asked to stop taking a drug, but the number and strength of comments illustrate the differing reasons behind this, and document the frustration many felt when trying to communicate the problems they were having.

4 TAKING PSYCHIATRIC DRUGS

Respondents were asked to name the three most recently prescribed psychiatric drugs they had taken. They were then asked how helpful each drug had been for relieving symptoms and if they had experienced any unwanted (or side) effects. Respondents who had stopped taking a drug were asked if they had experienced any unwanted effects at that time. A final question asked how helpful respondents had found each drug, taking into account both the positives (e.g. relief of symptoms) and the negatives (e.g. unwanted side effects).

In compiling this report we made great efforts to ensure that we selected respondent comments which gave a balanced and reasonable representation of expressed views. We were, however, struck by the fact that positive assessments of a drug on one of the quantitative measures were often followed by surprisingly negative qualitative comments and this should be borne in mind when considering this report. The following example perhaps indicates this point.

The mood stabiliser, Lithium Carbonate/Citrate, was one of the most positively rated drugs in the survey with 72% of respondents describing it as *fairly* or *very* helpful overall. However, when you look at the comments made by those people who gave the drug a positive rating on unwanted effects it is clear that a positive rating does not preclude respondents having serious concerns.

Table 4.1: Comments on unwanted effects from respondents who rated Lithium Carbonate/Citrate positively

How helpful overall	Comment on unwanted effects
Very	*Weight gain.*
Very	*Usual stuff, feel a bit low par most of the time, weight gain, memory has suffered slightly.*
Very	*At first I was very nauseous and felt it was poisoning me. The increase in weight depressed me. I was also thirsty a lot.*
Very	*Bloated feelings, dry mouth, Increased weight gain. Slowed down physical movements, trouble getting up in the morning.*
Very	*Weight gain. Thyroid dysfunction.*
Very	*The pills at first make you sick but after a few days I was fine.*
Very	*After 25 years it weakened my kidneys and I now have water diabetes.*
Very	*Nausea, hand tremor*
Very	*Weight gain, (4 stones) Poyluria, Polydipsia, lack of co-ordination, dulled concentration.*
Very	*Going to the toilet often, drinking all the time, dry mouth.*
Very	*I have bowel upsets due to Lithium.*
Very	*Weight gain, feeling flat, thyroid problems.*
Very	*I can live with having to urinate 2/3 times a night. I can also cope with the weight gain by watching my diet, running, and by going to the gym.*
Very	*Loss of thyroid function; polyuria; polydipsia.*
Very	*Unsure what long-term effects may be, e.g. thyroid / kidney function, etc.*
Very	*It gives you a thirst, weight gain, and mood swings.*
Very	*I pile on weight. I have a permanent tremor and often have double vision.*
Very	*I have to have regular blood tests to check the levels.*
Very	*Thirst*
Fairly	*Extreme lethargy and loss of confidence creating similar symptoms to those experienced before taking them, memory problems, making work difficult. Problems with driving. General physical anxiety and tension.*
Fairly	*Weight gain - two and a half stones, lack of energy, skin problems - acne.*

Fairly	*Thirsty.*
Fairly	*I have the shakes.*
Fairly	*I feel nauseous and shaky in the morning but usually this soon passes.*
Fairly	*Tremors, shaking, sickness, fatigue.*
Fairly	*On brand again - different side effects.*
Fairly	*Shake, thirst, put on weight, don't experience much emotion.*
Fairly	*Weight gain.*
Fairly	*Made me nauseous, had no emotions - felt nothing, put on weight.*
Fairly	*Weight gain, can't drink much alcohol, (disabled lifestyle) time limited driving licence.*
Fairly	*It affected my thyroid, severe weight gain thought processes slowed down.*
Fairly	*Keeps me on a level kind of depressing mood.*
Fairly	*Weight gain.*
Fairly	*I become more thirsty, and I also have weight gain.*
Fairly	*Weight gain.*
Fairly	*Affected my thyroid gland and now have to take Thyroxine. Excessive urination. Tremor. Visual disturbance. Irritable Bowel Syndrome. Sense of unreality. Lethargy. Memory problems.*

It should also be noted that some of the unwanted effects described in the report may have been short-lived. It is quite common for some, though not all, initial unwanted effects to reduce after two to three weeks of taking a new drug.

In order to aid interpretation of the data gathered in this section analysis focused on prescriptions rather than individual respondents. There were 1,538 prescriptions recorded in total. Almost half of the respondents recorded three drugs with around a quarter recording two and a similar proportion recording just one.

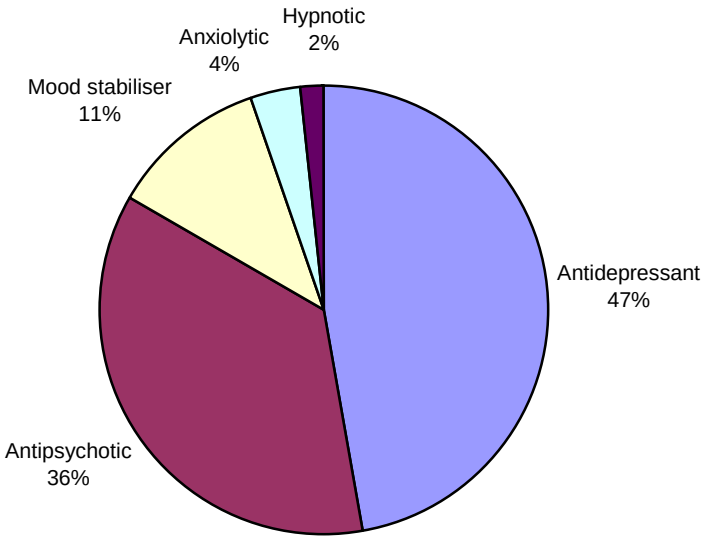
From Table 4.2 we can see that the three most commonly prescribed drugs in this survey were antidepressants with Venlafaxine (part of the Other antidepressant grouping) the most common. The most commonly prescribed drug, which was not an antidepressant, was the antipsychotic, Olanzapine.

Table 4.2 Last three drugs prescribed: Drug type

Drug type	Number	%
SSRI antidepressant	373	24.3
Atypical antipsychotic	291	18.9
Typical antipsychotic	214	13.9
Other antidepressant	206	13.4
Mood Stabiliser	172	11.2
Tricyclic antidepressant	143	9.3
Anxiolytic	59	3.8
Depot antipsychotic	43	2.8
Hypnotic	24	1.6
MAOI antidepressant	13	0.8

Almost half of the prescriptions recorded were for an antidepressant. Over a third were for an antipsychotic (see Figure 5).

Figure 5: Prescriptions made by drug group



Inspection of table 4.3 shows that different categories of psychiatric drugs were prescribed widely across different diagnoses. For example, 50% of comments relating to atypical antipsychotics were from respondents who did not have a diagnosis of schizophrenia.

Table 4.3 Drug type prescribed: Diagnosis of recipient

Diagnosis*	**Drug type (number)**									
	Antidepressants				Antipsychotics			Others		
	SSRI (n=373)	Tricyclic (n=143)	MAOI (n=13)	Other (n=206)	Atypical (n=292)	Typical (n=213)	Depot (n=43)	Mood stabilisers (n=172)	Anxio-lytic (n=59)	Hypnotic (n=24)
Depression (n=340)	240	101	8	144	67	56	8	27	35	13
Schizophrenia (n=149)	27	15	0	11	144	83	30	15	6	3
Manic Dep. (n=149)	46	18	3	29	60	59	5	114	10	6
Anxiety disorder (n=143)	111	38	3	51	25	27	4	11	28	7
Other (n=62)	42	12	0	26	29	18	0	13	8	3
Personality Disorder (n=34)	19	8	0	11	6	14	2	6	6	6
No current diagnosis (n=22)	17	6	0	7	4	5	1	1	4	1

*Totals will exceed size of sample because some respondents had dual diagnosis and others received more than one drug in each category

Table 4.4 Last three drugs prescribed: Generic name and type

Generic drug name	Drug type	Number
Venlafaxine	Other antidepressant	119
Fluoxetine	SSRI antidepressant	113
Paroxetine	SSRI antidepressant	109
Olanzapine	Atypical antipsychotic	104
Citalopram	SSRI antidepressant	88
Chlorpromazine Hydrochloride	Typical antipsychotic	87
Lithium Carbonate/Citrate	Mood stabiliser	78
Risperidone	Atypical antipsychotic	70
Sertraline	SSRI antidepressant	50
Mirtazapine	Other antidepressant	46
Sodium Valproate	Mood stabiliser	45
Clozapine	Atypical antipsychotic	43
Trazodone Hydrochloride	Tricyclic antidepressant	40
Diazepam	Anxiolytic	39
Quetiapine	Atypical antipsychotic	38
Amisulpride	Atypical antipsychotic	34
Flupentixol Deconate	Depot antipsychotic	34
Lofepramine	Tricyclic antidepressant	30
Carbamazepine	Mood stabiliser	30
Haloperidol	Typical antipsychotic	27
Sulpiride	Typical antipsychotic	26
Reboxetine	Other antidepressant	25
Clomipramine	Tricyclic antidepressant	22
Zuclopenthixol Dihydrochloride	Typical antipsychotic	21
Amitriptyline	Tricyclic antidepressant	18
Dosulepin Hydrochloride/Dothiepin Hydrochloride	Tricyclic antidepressant	18
Trifluoperazine	Typical antipsychotic	17
Thioridazine	Typical antipsychotic	17
Nefazodone Hydrochloride	Other antidepressant	14
Zopiclone	Hypnotic	12
Valproic Acid	Mood stabiliser	10
Flupentixol/Flupenthixol	Typical antipsychotic	9
Lamotrigine	Mood stabiliser	9
Busiprone Hydrochloride	Anxiolytic	8
Phenelzine	MAOI antidepressant	7
Lorazepam	Anxiolytic	7
Fluphenazine Hydrochloride	Typical antipsychotic	7
Imipramine Hydrochloride	Tricyclic antidepressant	7
Moclobemide	MAOI antidepressant	6
Zuclopenthixol Deconate	Depot antipsychotic	5
Doxepin	Tricyclic antidepressant	5
Zolpidem Tartrate	Hypnotic	4
Temazepam	Hypnotic	4
Chlordiazepoxide	Anxiolytic	4
Pipotiazine Palmitate	Depot antipsychotic	4
Pericyazine	Typical antipsychotic	4
Nitrazepam	Hypnotic	3

Droperidol	Typical antipsychotic	3
Levomepromazine/Methotrimeprazine	Typical antipsychotic	3
Trimipramine	Tricyclic antidepressant	3
Fluvoxamine Maleate	SSRI antidepressant	3
Zotepine	Atypical antipsychotic	2
Tryptophan	Other antidepressant	2
Clorazepate Dipotassium	Anxiolytic	1
Promazine Hydrochloride	Typical antipsychotic	1
Loprazolam	Hypnotic	1
Loxapine	Typical antipsychotic	1
Escitalopram	SSRI antidepressant	1

4.1 ANTIDEPRESSANTS

Antidepressants are the most commonly prescribed psychiatric drugs in Scotland. In recent years their prescription has increased dramatically. In 2002/03 there were three and a quarter million antidepressant prescriptions in Scotland, with a gross ingredient costs of over £55 million – in other words we spend £11 per head of population on antidepressants. In the last ten years the number of antidepressant prescriptions in Scotland has trebled. Over the same period the cost has more than quadrupled.[5]

Spending on antidepressants in Scotland is 40% higher per head than in England. It is difficult to tell whether this is because of increased levels of depression in Scotland, a greater propensity for doctors in Scotland to prescribe antidepressants, or Scots staying on antidepressants for longer than people in England and Wales. While surveys do not suggest that prevalence rates for depression are higher in Scotland than in England and Wales[6], the suicide rate is higher than south of the border.

Key findings

- Taking positives and negatives into account antidepressants were rated helpful by 56% of respondents.
- Just under 60% of people reported unwanted effects when taking the drugs, and 45% reported problems when stopping.
- Newer SSRI type antidepressants did not rate better than older tricyclic (or related) drugs on any measure.
- We did not find that new drugs had less adverse effects than older drugs.
- The two drugs rated most positively overall were both tricyclics (or related) drugs (Trazodone Hydrochloride and Clomipramine).
- Paroxetine (Seroxat) performed badly compared to other SSRIs.
- Unwanted effects varied considerably between different drug groups, but included anxiety, agitation, suicidal feelings, self harming, psychotic experiences, a range of sexual difficulties, drowsiness, and weight gain.
- We found that many reported serious difficulties trying to stop taking antidepressants, particularly SSRIs and SNRIs (most notably Paroxetine and Venlafaxine).
- Comments ranged from very positive to very negative. Some people felt antidepressants had saved their lives.

In this survey we used four main groupings for antidepressant type. Just over half of all antidepressants included in the survey were SSRI type antidepressants (see Table 4.5, over).

5 Prescribing data from ISD Scotland (the Information and Statistics Division of NHS Scotland).
6 Mental Health in Scotland: Information Sources and Selected Insights, ISD Scotland, 2001

Table 4.5 Antidepressants type prescribed

Drug type	Number	%
SSRI antidepressant	373	50.7
Other antidepressant	206	28.0
Tricyclic antidepressant	143	19.4
MAOI antidepressant	13	1.8
Total	735	

4.1.1 SSRI antidepressants

These drugs work by selectively inhibiting the reuptake of the neurotransmitter serotonin, which is believed to play a part in mood (SSRI stands for Selective Serotonin Reuptake Inhibitor). SSRIs are the most commonly prescribed group of antidepressants.

Fluoxetine (Prozac) was the first SSRI, launched in 1987. More recently there has been considerable controversy around SSRIs in general, and Paroxetine (Seroxat) in particular, following a number of high profile court cases and claims made in a BBC Panorama programme about their safety.[7]

In 2003 the Medicines Control Agency (now the Medicines and Healthcare products Regulatory Agency) set up a committee to investigate the safety of SSRI antidepressants. However, despite these claims, many still regard the SSRIs as breakthrough drugs - enabling people with depression to make dramatic recoveries.

Venlafaxine shares many of the characteristics of an SSRI but is in fact an SNRI (it acts on the noradrenaline neurotransmitter as well as serotonin). Following BNF categorisation (see Appendix 1: Methodology) data on Venlafaxine is included under the 'Other antidepressants' category.

SSRIs accounted for around a quarter of all antidepressant prescriptions in our survey. The main recipients had a diagnosis of depression and/or anxiety disorder. Drugs in this category included seven generic brands. Inspection of Table 4.6 (over) reveals that prescriptions for Fluoxetine, Paroxetine, and Citalopram accounted for more than four out of five prescriptions.

One crucial advantage of SSRIs over older antidepressants is that they are safer in overdose.

4.1.1.1 Symptom relief and SSRIs

Just over half the respondents who had been prescribed one of the two most frequently prescribed drugs in this groups, Fluoxetine or Paroxetine, reported that they were *very* or *fairly* helpful for relieving symptoms (56% and 54% respectively). The drug identified as being best for symptom relief was Citalopram with over 60% of respondents identifying it as *very* or *fairly* helpful for symptom relief.

Overall a quarter of respondents found SSRIs to be *fairly* or *very* unhelpful for relieving symptoms. The drugs reported by most respondents as being unhelpful were Fluoxetine and Sertraline.

7 Panorama: The Secrets of Seroxat, 10th Oct 2002 and E-mails From The Edge, 11th May 2003. Both broadcast on BBC1.

Table 4.6 How helpful for symptom relief is SSRI?

SSRI	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Fluoxetine	113	21.2	34.5	10.6	15.9	15.9
Paroxetine	105	22.9	31.4	16.2	7.6	18.1
Citalopram	88	27.3	36.4	11.4	6.8	10.2
Sertraline	50	32.0	26.0	10.0	18.0	12.0
Fluvoxamine Maleate	3	-	33.3	-	-	66.6
Escitalopram	1	-	100.0	-	-	-
Total	360	24.4	33.1	12.2	11.3	15.0

4.1.1.2 What people said about SSRIs and symptom relief

Some of the respondents who found the drug helpful spoke very positively of their experience:

It saved my life. I was suicidal and homeless and it got me through it. (Fluoxetine)
I am really amazed at the total change in myself; I am now in full-time work. (Citalopram)
It makes me feel brand new - normal - got a level again. (Paroxetine)
It has given me relief from chronic depression. (Paroxetine)

Other positive comments on symptom relief included:

I don't get so angry, boiling or falling out with people… (Paroxetine)
Helped both anxiety and depression. (Citalopram)
I have had numerous psychiatric drugs over the past twenty years. Overall Seroxat has given the most result/outcome. (Paroxetine)

Time was frequently identified as an important factor. One group reported that it had taken a while before their drug had started to have an effect:

I am trying to keep an open mind because the leaflet implies I would feel worse before feeling better. Things are gradually getting better but slower than I imagined… (Citalopram)
OK after a few months of use but bad symptoms before it settled down. (Fluoxetine)

Others felt the effectiveness of the drug had diminished over time:

It worked for a while, but seemed to be less effective after one and a half years of taking it. (Citalopram)
Was helpful in the beginning. (Paroxetine)
Only for a number of months. (Paroxetine)

In some cases people felt unable to say whether or not the drug had made a difference or felt neutral about the drugs effect:

It's difficult to know if six years of good health were due to Seroxat. (Paroxetine)
Although I don't notice any difference taking these drugs, my family say I have changed for the better. (Citalopram)
It is a drug that I have intermittently utilised in the past six years and I'll always find it helpful, however I then wonder how helpful it really is since I'm still using it… (Paroxetine)

It neither added nor helped the way I felt inside, I still felt likewise - I was left with the problems that I have had for over twenty years. (Paroxetine)

20 respondents indicated that they had been disappointed in the lack of improvement while taking their drug:

Have still felt suicidal at times. Feel I've exhausted all assistance; it's just not the same as drugs used for physical illness. (Fluoxetine)
No effect at all. (Citalopram)

Worryingly a considerable number reported that the drug actually had a detrimental effect on their health:

This drug caused me to feel more unwell I became withdrawn and fearful of contact with others. (Fluoxetine)
This drug played havoc with me, causing sudden immense agitation feelings of terror and painful palpitations. From being ill just managing at home, I was whisked into hospital and put on sedatives… The drug also caused suicidal feelings. (Paroxetine)
Hyper anxiety, suicidal thoughts after the introduction to Prozac! I began to suffer from akathisia, extreme restlessness, jittery legs, this drug worsened my psychological problems. (Fluoxetine)

4.1.1.3 Unwanted effects when taking SSRIs

Just under 60% of people taking an SSRI reported an unwanted effect when taking a drug (also known as side effects). The highest percentage was noted for Paroxetine (Seroxat) with three quarters of respondents identifying a problem (excluding one drug prescribed on just two occasions). Citalopram had the lowest proportion of recorded problems with less than half of respondents reporting an unwanted effect.

Table 4.7 Unwanted effects when taking an SSRI?

SSRI	Number	%		
		Yes	No	Not sure
Fluoxetine	113	54.0	31.0	15.0
Paroxetine	108	75.0	16.7	8.3
Citalopram	87	46.0	37.9	16.1
Sertraline	50	56.0	34.0	10.0
Fluvoxamine Maleate	2	100.0	-	-
Escitalopram	1	-	100.0	-
Total	361	58.7	28.8	12.4

4.1.1.4 What people said about unwanted effects when taking an SSRI

When asked about unwanted effects when taking an SSRI a considerable number reported that they had experienced increased anxiety, agitation, and/or mood swings:

Increased anger, some mood swings, violent episodes... (Paroxetine)
I had bouts of rage, panic and fear. (Citalopram)
No control over my temper so I got into a lot of trouble. (Fluoxetine)
Itches, rashes, confusion, mania, fits of violence. (Citalopram)
When the dosage was increased the anxiety levels rose. (Fluoxetine)

Other respondents commented that they felt suicidal, or started to self-harm and attributed these feelings to the effects of the SSRI:

Side effects were awful. I spent most of the time feeling suicidal and had to take Diazepam to counteract the increased anxiety. (Paroxetine)
I had Panic Attacks after I started taking this drug. I also became suicidal and wanted to cut myself… (Paroxetine)
I experienced severe side effects with this drug immediately – nausea, dizziness, mental confusion, flu-like symptoms, aching limbs, exhaustion, sweating, suicidal urges. (Paroxetine)
I tried to go off it but got very depressed and had to go into hospital after attempting to commit suicide. (Fluoxetine)

Four respondents specifically mentioned 'psychotic' feelings:

I became severely anxious at a dosage of 60mg and had to stop taking it as I was becoming psychotic. (Citalopram)
When taking the liquid I had what I can only explain as psychotic thoughts (fear that I might hurt my family!). (Paroxetine)
The drug made me extremely agitated physically and mentally. It played havoc with my thoughts and decision-making ability. It caused me delusional thinking, and persistent voice in my head. (Fluoxetine)
Made me psychotic. (Sertraline)

There is an increasing awareness of the link between sexual dysfunction and SSRI use. Recent studies suggest that between 30 and 70% of people will experience problems, depending on the drug.[8] In our survey numerous male and female respondents reported problems.

Some commented that the drug had affected their libido:

Did not realize at the time the complete lack of sexual sensation was caused by drugs as had no previous experience to compare it with, so blamed and hated self. Has left me with long-term fear, inhibition, affected ability to form relationships. (Paroxetine)
Loss of sexual ability but dramatic swings in sexual urge. (Paroxetine)
Loss of emotions, and sexual feelings… dizziness… increased depression. (Paroxetine)
Sleep disruption, loss of libido, weight gain/increased appetite. (Fluoxetine)
Dry mouth, dizziness, sexual difficulties and headache. (Paroxetine)

In some cases the drug caused other specific problems like erectile dysfunction or, more commonly, problems with ejaculation:

Whilst taking Prozac destroyed erectile function. (Fluoxetine)
Loss of sexual ability but dramatic swings in sexual urge. (Paroxetine)
Sexually it made ejaculation impossible, which was extremely frustrating… (Paroxetine)
Loss of sexual performance inability to reach orgasm. (Paroxetine)
At any dose above 50mg It affects my ability to reach orgasm during sex. (Sertraline)

Some people reported problems with incontinence:

8 See, for example, Incidence of Sexual Dysfunction Associated with Antidepressant Agents: A Prospective Multicenter Study of 1022 Outpatients. Spanish Working Group for the study of psychotropic-related sexual dysfunction. Montejo AL, Llorca G, Izquierdo JA, Rico-Villademoros F, J Clin Psychiatry. 2001;62 Suppl 3:10-21. and Antidepressant-Induced Sexual Dysfunction During Treatment with Moclobemide, Paroxetine, Sertraline, and Venlafaxine, Sidney H. Kennedy, M.D., F.R.C.P.C.; Beata S. Eisfeld, Hons.B.Sc.; Susan E. Dickens, M.A.; Jason R. Bacchiochi, B.A.; and R. Michael Bagby, Ph.D., C.Psych., J Clin Psychiatry 2000;61:276-281

Had to run to the toilet in the morning, could get caught out very often scared to go out for a walk had to jump hedges, walls etc (to go) very embarrassing. (Paroxetine)

In some cases people reported that initial unwanted effects had been short lived:

Worst side effects seemed to wear off after a week and a half. (Citalopram)
Felt sick for the first two weeks, was assured that this would clear, which it did. (Fluoxetine)

For some people the drug produced a high or 'mania', which lead to behaviour that was out of character or embarrassing:

It can make me come out with uninhibited remarks that can be embarrassing. It can make me a bit high at times. (Fluoxetine)
Mania – was a loud irritating idiot. Felt humiliated by own behaviour. Felt personality and integrity had been violated. (Paroxetine)
I felt as if I was high and full of energy. People could see the difference in me and that I was different to them. (Sertraline)
It made me very aggressive and outgoing, almost to the point of mania. I made some very bad decisions while I was on it, which I believe were to do with me taking it. (Paroxetine)

Conversely for others, taking an SSRI led to a numbness – a loss of emotional feeling:

I felt it made me worse, I felt dead inside. No interest in life, stayed indoors, summer and autumn until I finally came off it. (Citalopram)
Sweating, emotional blunting. (Fluoxetine)
The only thing I've noticed are that emotions are dulled slightly and it is more difficult to cry. (Citalopram)

Many people reported sweating, particularly at night:

Very heavy overnight sweating with this drug. I'd like to ask a doctor how they'd like to wake up in the morning absolutely stinking of sweat that you never had before. (Paroxetine)
Sweating so bad that GP prescribed special deodorant. (Paroxetine)
Sweating, the whole time I took it. It never wore off. It made my lack of a social life worse, which was not helpful. (Sertraline)

Other unwanted effects commented on included nausea and dizziness, headaches, dry mouth, weight gain or loss, sleep disturbance including insomnia and nightmare, lethargy and/or drowsiness, muscle spasms/tingling, lack of concentration or confusion, constipation, rashes and hair loss.

4.1.1.5 Unwanted effects when stopping SSRIs

Almost three-quarters of respondents who had been prescribed an SSRI recorded information about stopping taking it. There has been considerable publicity around 'discontinuation' and SSRIs with an active debate between pharmaceutical companies, health professionals and pressure groups around what constitutes a withdrawal effect, whether a withdrawal effect is indeed addiction, and whether someone stopping a drug may just be experiencing the return of symptoms.

Half of the respondents in our survey reported unwanted effects when they stopped taking an SSRI. Paroxetine stands out as the drug where many problems were reported, for example only

a quarter of people reported no problems on discontinuation compared to just under a half for Citalopram.

Table 4.8 Unwanted effects when stopping an SSRI?

SSRI	Number stopped	%		
		Yes	No	Not sure
Fluoxetine	78	37.2	43.6	19.2
Paroxetine	96	57.3	25.0	17.7
Citalopram	54	42.6	48.1	9.3
Sertraline	37	48.6	40.5	10.8
Fluvoxamine Maleate	3	100.0	-	-
Total	268	47.3	37.5	15.3

4.1.1.6 What people said about unwanted effects when stopping an SSRI

In about a fifth of cases people reported that their symptoms came back when they stopped taking an SSRI:

Made me feel anxious and depressed again. Also very weepy again. (Citalopram)
I felt immediately depressed, this lasted for weeks and I had to go back on to Citalopram. (Citalopram)
My depression returned. (Fluoxetine)
The depression came back very quickly after stopping this drug. (Fluoxetine)
Similar to before (i.e. headaches, shakiness, nausea etc) but mood swings were predominant. Withdrawal was very sudden at GPs direction. (Fluoxetine)

Ten people specifically mentioned feeling suicidal, and others mentioned self-harming:

Felt suicidal which I had never done previously either on or off this drug. (Sertraline)
Increase in depressive symptoms, suicidal ideation, suicide attempts. (Citalopram)
...Suicidal thoughts and increased self-harming, nightmares and sweating. (Paroxetine)
The withdrawal symptoms when I came off Seroxat were very scary, and my psychiatrist didn't warn me that there would be any… I had self-harming impulses and was suicidal at least one point. (Paroxetine)

Feelings of dizziness and vertigo were commonly reported on stopping an SSRI:

Severe dizziness, loss of balance, I fell down stairs, cut my eye. (Paroxetine)
Increasingly vertigo related effects and dizziness. (Fluvoxamine Maleate)
…Dizziness and ringing in my ears. (Sertraline)

Other effects experienced when stopping an SSRI included shaking and flu-like symptoms, mood swings, headaches, nausea and stomach problems, disturbed sleep (including nightmares) and memory loss:

Disturbed sleeping patterns, restlessness, flu-like symptoms rashes, lowered mood. (Sertraline)
Withdrawal symptoms including shaking and feeling flu-like. (Paroxetine)
It was a shakiness, it was a horrible experience. (Paroxetine)
Flu-like symptoms, very bad mood swings. (Fluoxetine)
Worse sweats and shakes, diarrhoea and vomiting. (Fluoxetine)
Disturbed sleep, more nightmares and increased anxiety for a period of time. (Fluoxetine)

Respondents drew attention to how quickly withdrawal symptoms appeared; even a lowered dose could trigger symptoms:

> *If I stop taking it I get very hot and sweating. If I miss two days I hear a bird chirping in my head and panic attacks.* (Paroxetine)
> *If I stopped taking it for more than two days, I had symptoms similar to labyrinthitis - dizzy, any noise unbearable, nauseous. Awful, wouldn't wish it on my worst enemy.* (Sertraline)

One example of a benign withdrawal effect was the restoration of libido:

> *The impotence has gone but I'm not convinced* [that] *I'm now as I was in that respect.* (Paroxetine)
> *…my erectile function returned, this having one less thing to be depressed about – seriously.* (Fluoxetine)

There have been many documented cases of people reporting 'electric shock' type sensations when withdrawing from SSRIs. A number respondents to this survey reported similar experiences:

> *Within days I became very physically ill. I felt as though electric shocks were going through my brain. Also dizziness.* (Citalopram)
> *As I came off Prozac I had a bizarre 'exploding head' feeling that lasted all morning and was both painful and alarming.* (Fluoxetine)
> *… tingling – pins and needles – electric type shocks.* (Fluoxetine)
> *Increased electric shock sensations* (Paroxetine)
> *I experienced dizziness, confusion, jolts in my body and head-like electric shocks, difficulty walking, lack of focus and concentration.* (Paroxetine)
> *If I turned my head quickly everything went in motion blur. Every step induced a severe shock to the nervous system, buzzing feeling in the nervous system.* (Paroxetine)

It is worth noting that some people reported electric shock type symptoms also while they were taking an SSRI.

4.1.1.7 Overall evaluation of SSRIs

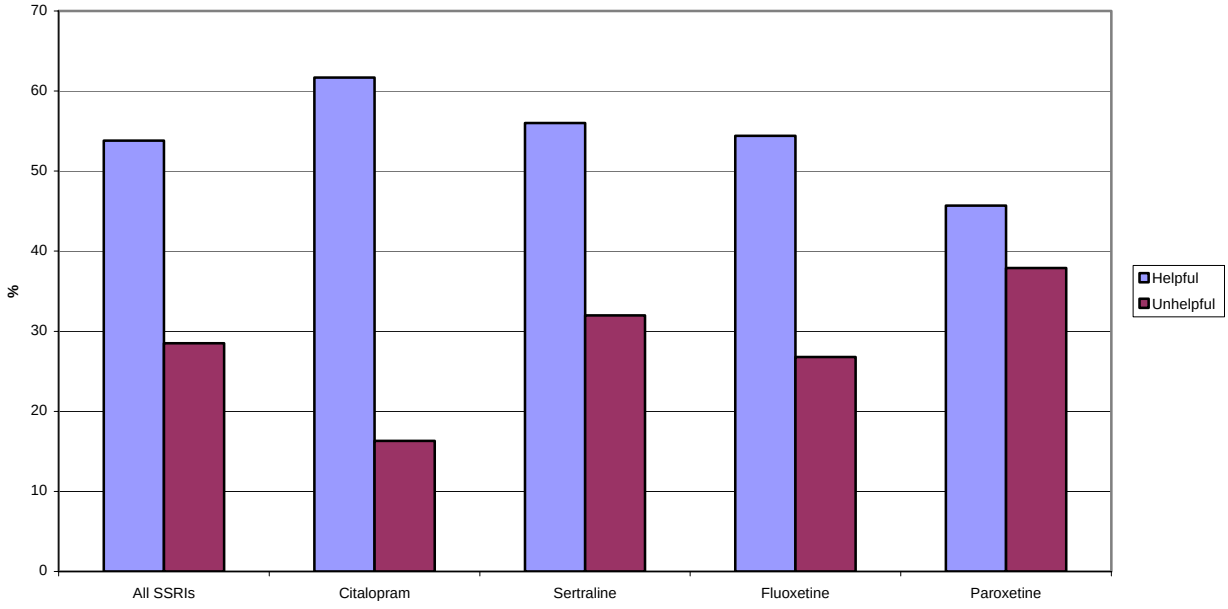
We asked respondents to rate the overall helpfulness of SSRIs taking into account the positives and negatives (see Table 4.9, over). The majority found SSRIs to be helpful overall, however, over a quarter of respondents had not found them helpful. The drugs rated most favourably (where there was a reasonable sample were Citalopram (62% found it to be helpful) and Sertraline (56% helpful).

The drug with the lowest 'helpfulness rating' was Paroxetine with 46% finding to be helpful and 38% finding it to be unhelpful (including 28% of respondents who found the drug to be *very* unhelpful).

Table 4.9 Overall how helpful was SSRI?

SSRI	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Fluoxetine	112	21.4	33.0	16.1	10.7	16.1
Paroxetine	103	14.6	31.1	11.6	9.7	28.2
Citalopram	86	23.3	38.4	15.1	10.5	5.8
Sertraline	50	34.0	22.0	12.0	18.0	14.0
Fluvoxamine Maleate	3	-	33.0	-	-	66.0
Escitalopram	1	-	100.0	-	-	-
Total	355	21.4	32.4	13.8	11.3	17.2

Figure 6: Overall how helpful was SSRI rated



4.1.1.8 What people said about their overall evaluation of SSRIs

Again, as seen with comments on symptom relief, one group talked very favourably about the SSRI they were taking:

> *There is no doubt in my mind about this medication, taking it has given me back my life.* (Citalopram)
> *Excellent mood uplifter, particularly initially upon taking this drug.* (Paroxetine)
> *Could have saved my life.* (Paroxetine)
> *This drug has helped me to regain my energy and enthusiasm for life, although not 100% cured, I can rebuild aspects of my life again and acknowledge my limitations.* (Citalopram)

Interestingly, many people who said that overall they found SSRIs *very* or *fairly* helpful were still unhappy about particular aspects:

> *Yes, it got me through a very bad depression, but I had a lot of psychological side effects such as: dissociation, mania, anger etc.* (Fluoxetine – fairly helpful)

Difficult to balance and also dread having to stop it and cope with withdrawal effects. (Paroxetine – fairly helpful)
Combination of drugs make me tired. I accept that I have to live like this to stay well. (Citalopram – fairly helpful)
Very helpful when prescribed, but feel unable to stop taking it (Citalopram - Very helpful)

Some of the less positive comments centred on the initial effectiveness of the drug wearing off:

Difficult for me to say overall. As I have said at first it worked fantastically. But this last time has been a living nightmare. (Paroxetine)
The positives did outweigh the negatives initially, but, again, its effectiveness seemed to diminish. (Citalopram)

For others the balance between side effects and effectiveness was key:

In the great scheme of things nausea was a small price to pay. (Fluoxetine)
Better to have than return to former condition. (Fluoxetine)
Anything is better than this illness. It is so powerful and out with people's control no matter how much some people try to fight it. Nine times out of ten it always wins. (Fluoxetine)

Others clearly felt that the drug had been of little help and in some cases had made them feel worse:

[I] *want it banned, nobody is interested, Panic attacks make my life hell.* (Paroxetine)
Took months to come off this drug, would never take this drug willingly again. (Sertraline)
It added problems instead of alleviating. (Paroxetine)
Initially good, but long-term effects reversed any benefits and almost proved fatal. (Paroxetine)

Others felt that they had not been given sufficient information or support from their doctors:

The drug was prescribed because the doctor didn't have time to talk to me. It felt like a cattle market. (Paroxetine)
I seriously don't think the doctors have any idea as to how these drugs work and seem to pay more attention to what the drug companies say about their own product than take seriously what the patient has to say. More importantly, the withdrawal symptoms from SSRIs is actually worse and is invariably diagnosed wrongly as a relapse of depression. (Citalopram)

One group of respondents pointed out that the drugs only treat the symptoms without altering the underlying causes:

Depression is like seasickness. Removing the malady does not remove the causes - but I've kept dealing with them. (Sertraline)

Some also questioned whether other treatments might have worked better:

There was a noticeable effect when taking them. Though I accept I could function a bit again rather than sleep all the time, but don't think the withdrawal helped at all. I since stopped taking the drugs and now feel much better for it. I think a course of exercise or some form of therapy would have been more beneficial. (Paroxetine)

As already mentioned, there has been recent media coverage about Paroxetine (Seroxat). Interestingly there were only two references to this and both had given the drug a positive rating:

> *I became concerned when press reports highlighted dangers of Seroxat… doctor suggested a change of medication.* (Very helpful)
> *This drug was okay but the side effects were too much. I had also heard bad reports i.e. TV programme.* (Fairly helpful)

Finally one respondent did respond positively to the fact that SSRIs taken in overdose are safer than other antidepressants:

> *At this time I wanted to die. The best way to achieve this or so I thought was through drug/alcohol ingestion. One afternoon I ingested 40 Prozac…and one bottle of Glenmore 67% whisky. Apart from extreme intoxication, no other memorable effect other than it's no good for suicide!* (Fluoxetine)

4.1.2 Tricyclic and tricyclic related antidepressants

Tricyclic antidepressants have been on the market for longer than SSRIs, and consequently are looked on by some as 'older generation' antidepressants. They are considered to be effective in the treatment of moderate to severe depression. The seven generic brands of tricyclic (and related) accounted for about 9% of all prescriptions, and two drugs, Trazodone Hydrochloride and Lofepramine, accounted for half of the tricyclic (and related) drugs prescribed.

There are two generations of tricyclic related antidepressants, which vary slightly in chemical structure. The newer generation of tricyclic related drugs, which includes Trazodone Hydrochloride, are considered to have fewer antimuscarininc side effects, like dry mouth or constipation. All tricyclic type drugs recorded in this survey, other than Trazodone Hydrochloride, were older generation tricyclics.

4.1.2.1 Symptom relief and tricyclic and related drugs

Three quarters of respondents who had been prescribed Trazodone Hydrochloride, and six out of ten prescribed Lofepramine, Clomipramine, or Dosulepin/Dothiepin Hydrochloride reported that they were helpful for relieving symptoms. However, only half of those prescribed Amitriptyline reported that they were helpful for relieving symptoms (see Table 4.10, over).

Table 4.10 How helpful for symptom relief is tricyclic or tricyclic related drug?

Tricyclic or related	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Trazodone Hydrochloride	40	35.0	40.0	10.0	7.5	7.5
Lofepramine	29	20.7	41.4	20.7	6.9	10.3
Clomipramine	22	36.4	27.3	18.2	9.1	9.1
Amitriptyline	18	16.7	33.3	5.6	16.7	22.2
Dosulepin/ Dothiepin Hydrochloride	18	16.7	44.4	22.2	-	11.1
Imipramine Hydrochloride	7	-	42.9	-	14.3	42.9
Doxepin	5	20.0	20.0	-	20.0	20.0
Trimipramine	3	33.3	33.3	33.3	-	-
Total	142	25.4	37.3	14.1	8.5	12.7

4.1.2.2 What people said about tricyclic or tricyclic related drugs and symptom relief

16 reported that their drug had made no difference to their symptoms and some indicated that although their drug had helped initially its effects had been short-lived:

> *Made me feel 100 times worse.* (Clomipramine)
> *Didn't relieve depression and gave me a lot of unwanted side effects.* (Dosulepin/ Dothiepin Hydrochloride)
> *Made little difference to mood. Made me dull, making life difficult…* (Trazodone Hydrochloride)
> *At first it helped with depression/anxiety, then it failed to help with serious depression.* (Doxepin)

For others, the drug had clearly helped to relieve their symptoms, at least to some extent:

> *It puts a floor under my mood. The negative thoughts and 'roller coaster' remain but not as debilitating.* (Lofepramine)
> *My depressions have been shorter and less severe.* (Clomipramine)

Nine respondents reported that their drug enabled them to sleep better, which contributed to overall well being:

> *Helps keep me sleeping which aids depression.* (Trazodone Hydrochloride)
> *Now I get a good night's sleep. May be sleepy in the morning but it wears off.* (Amitriptyline)

However, others reported problems with sleep:

> *I could not sleep when taking these. I was getting by on one to two hours a day, which was too little.* (Amitriptyline)
> *Takes a long time to fall asleep and the next day you are drowsy for around four hours or longer.* (Trazodone Hydrochloride)

Two indicated that they found this medication better than others they had tried in the past:

I had been on this drug for several years prior to trying Seroxat and Prozac, and was glad to go back on it. (Lofepramine)

While others respondents reported that their drug worked well in combination with others:

The combination of Quetiapine and Clomipramine has been a great help to me and has introduced wellbeing in the last two years - A great relief! (Clomipramine)

4.1.2.3 Unwanted effects when taking tricyclic and related drugs

Just over half of the respondents taking a tricyclic or related drug reported unwanted effects when taking their drug and a third reported no problems. Of the five most commonly prescribed tricyclics the highest number of unwanted effects were reported for Clomipramine (64%) and Amitriptyline (61%).

Table 4.11 Unwanted effects when taking a tricyclic or tricyclic related drug?

Tricyclic or related	Number	%		
		Yes	No	Not sure
Trazodone Hydrochloride	40	57.5	35.0	7.5
Lofepramine	30	43.3	33.3	23.3
Clomipramine	22	63.6	31.8	4.5
Amitriptyline	18	61.1	33.3	5.5
Dosulepin/ Dothiepin Hydrochloride	17	47.1	35.3	17.6
Imipramine Hydrochloride	6	83.3	16.7	-
Doxepin	5	40.0	40.0	20.0
Trimipramine	3	33.0	-	66.0
Total	141	53.9	33.3	12.8

4.1.2.4 What people said about unwanted effects when taking a tricyclic or tricyclic related drug

When asked to comment on unwanted effects when taking a tricyclic the most frequently reported problem was tiredness and drowsiness:

Tiredness, felt like I had a hangover. (Trazodone Hydrochloride)
Extreme lethargy, tiredness, poor concentration and memory. (Dosulepin/Dothiepin Hydrochloride)
Confusion, tiredness, difficulty thinking, dull personality, fatigue in limbs. (Trazodone Hydrochloride)

Several respondents described feeling like they had a hangover. Some reported dizziness, sweating, nausea, headache, and feeling generally unwell:

Sweating, flushes, dry mouth, hungover feeling. (Imipramine Hydrochloride)
Sweating, but I had that with SSRI I took before. Really bad nausea and dizziness. (Lofepramine)
Headaches, severe sweating, dizziness, generally felt unwell. (Lofepramine)

One group of respondents reported considerable weight gain and drew attention to how distressing this could be for someone whose self-esteem is already low:

The side effects of four stones in weight gain in just over one year (especially on a very self-conscious person) were unbearable. (Dosulepin/Dothiepin Hydrochloride)
Have gained a colossal amount of weight. (Clomipramine)

Other unwanted effects, which were less commonly reported, included impaired memory and concentration, insomnia, confusion, palpitations, blurred vision, tremor, raised blood pressure, and chest pains. However, it was noticeable that a number of respondents reported that their unwanted side effects were not long term:

Headaches, nausea, dizziness, dry mouth. This lasted for about six weeks - it's a lot less now. (Trazodone Hydrochloride)
When I first started had nausea and headaches but settled down after a couple of weeks. (Trazodone Hydrochloride)
…Couldn't eat, travel, listen to radio, completely stopped my life for four weeks. Then it disappeared and I was so happy maybe I didn't need the pills. (Lofepramine)

4.1.2.5 Unwanted effects when stopping tricyclic and related drugs

Two-thirds of respondents in this category reported having stopped taking their drug at some point. A third of this group reported an unwanted effect on stopping. Of the most commonly prescribed drugs, Clomipramine had the highest reported rate of unwanted effects (44%). The lowest number of reported problems was for Lofepramine (23%).

Table 4.12 Unwanted effect when stopping a tricyclic or tricyclic related drug?

Tricyclic or related	Number stopped	%		
		Yes	No	Not sure
Trazodone Hydrochloride	22	36.4	50.0	13.6
Lofepramine	22	22.7	50.0	27.3
Clomipramine	18	44.4	44.4	11.1
Amitriptyline	14	42.9	21.4	35.7
Dosulepin/ Dothiepin Hydrochloride	12	25.0	50.0	25.0
Imipramine Hydrochloride	6	33.3	16.7	50.0
Doxepin	3	-	100.0	-
Trimipramine	2	50.0	-	50.0
Total	99	33.3	43.4	23.2

4.1.2.6 What people said about unwanted effects when stopping a tricyclic or tricyclic related drug

The most commonly reported unwanted effects recorded were insomnia and feeling depressed and anxious:

Poor sleep, very irritable, takes a long time to feel calm. (Trazodone Hydrochloride)
Felt very anxious. (Dosulepin/Dothiepin Hydrochloride)

Some respondents reported that their symptoms returned and four respondents indicated that they had moved straight on to another drug and thus were unsure which effects were due to which drug. Others drew attention to the importance of coming off a drug slowly, however one respondent felt that she had not been adequately supported at this stage:

My intake was not stepped down slowly enough. This caused a bad relapse with bad anxiety, lethargy and restlessness. I had three months off work. (Lofepramine)

Two respondents reported having severe withdrawal symptoms, one of whom was admitted to hospital:

Suicidal, unable to speak to people, anxious and uptight. (Clomipramine)

Other difficulties described included dry mouth, headache, nausea, irritability, shakes and sweats.

4.1.2.7 Overall evaluation of tricyclic and related drugs

When respondents were asked to take the positives and negatives into account a high proportion reported tricyclics to be helpful (over 60%). The best performing drug was Trazodone Hydrochloride with over 70% saying they found it to be helpful overall (of these 40% rated it as *very* helpful). The poorest performing drug was Amitriptyline with just under 40% of people finding it to be unhelpful overall.

Table 4.13 Overall how helpful was tricyclic or tricyclic related drug?

Tricyclic or related	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Trazodone Hydrochloride	40	40.0	32.5	5.0	7.5	10.0
Lofepramine	30	33.3	26.7	20.0	3.3	13.3
Clomipramine	21	23.8	47.6	14.3	-	14.3
Amitriptyline	18	27.8	22.2	5.6	11.1	27.8
Dosulepin/ Dothiepin Hydrochloride	17	17.6	52.9	11.8	5.9	5.9
Imipramine Hydrochloride	7	14.3	14.3	-	42.8	28.6
Doxepin	5	20.0	20.0	40.0	-	20.0
Trimipramine	3	33.3	33.3	-	-	-
Total	141	29.8	33.3	11.3	7.1	14.2

4.1.2.8 What people said about their overall evaluation of tricyclics or tricyclic related drugs

Comments relating to the overall efficacy of tricyclic (and related) antidepressant drugs indicated that respondents had very different experiences. Of the respondents who indicated that their drugs had helped overall, few commented with any real enthusiasm:

This drug calmed me down as I was having anxiety attacks quite often. It has been the most helpful of all the psychiatric drugs I have ever taken. (Trazodone Hydrochloride)
I would say for me personally this drug helped me greatly. (Clomipramine)

A number of respondents indicated that although their drug had helped initially the benefits did not last. Others felt that as time went on the negative aspects overtook any benefits. Thus it was suggested that perhaps it was not a drug for long-term use:

It did help at first but the side effects outweighed the positive effects after some time… (Lofepramine)
Very helpful at the time, but has not removed symptoms in the longer term. (Trazodone Hydrochloride)

Respondents highlighted the problems associated with finding a balance between unwanted effects and improvement in mood and coping:

The lift in mood was so easily counteracted by the side effects. I have gone from a size 14 to a size 22 in clothes. (Imipramine Hydrochloride)

Some respondents reported that their symptoms had not improved and in some cases they felt that their situation was worse than before they took their drug:

Didn't work on anxiety at all. Developed full-blown Agoraphobia. (Imipramine Hydrochloride)

Two respondents specifically drew attention to the benefits of non-drug therapy:

Talking therapies, my own research and self-help have proved the key to acceptance, overcoming depression, anxiety, and finding new purpose… (Lofepramine)

4.1.3 MAOI Antidepressants

MAOI antidepressants are not commonly prescribed and our survey only included 13 prescriptions, less than one percent of all prescriptions. SSRI and Tricyclic antidepressants tend to be preferred because MAOIs, which are the oldest grouping of antidepressants, may have potentially dangerous interactions with certain foods.

Moclobemide works differently to Phenelzine and is known as a 'reversible' MAOI.

4.1.3.1 Symptom relief, unwanted effects when taking and stopping, and overall evaluation of MAOI antidepressants

It can be seen from the following table that just over half the respondents prescribed an MAOI antidepressant reported that their drug had been helpful for relieving their symptoms, a slightly higher proportion of those prescribed Phenelzine, compared to those prescribed Moclobemide. However, a higher proportion of respondents prescribed Phenelzine reported unwanted side effects when taking the drug, and when coming off it, although both the number of respondents and the proportion experiencing withdrawal symptoms was low. Again a slightly higher proportion of respondents prescribed Phenelzine, compared to those prescribed Moclobemide reported that, taking both the positive and negative aspects of their drug into account, they had found it helpful.

Table 4.14 MAOI antidepressants: Symptom relief, unwanted effects when taking and stopping, and overall evaluation

MAOI	No.	%									
		Helpful for relieving symptoms			**Unwanted effects when taking**		**Unwanted effects when stop***		How helpful overall		
		Helpful	neither	Not helpful	Yes	No	Yes	No	Helpful	neither	Not helpful
Phenelzine	7	57.2	14.3	28.6	85.7	14.3	33.3	33.3	57.2	14.3	28.6
Moclobemide	6	50.0	33.3	16.7	33.3	50.0	-	66.7	50.0	33.3	16.7
Total	13	53.9	23.1	23.1	61.5	30.8	16.7	50.0	53.9	23.1	23.1

*6 respondents, 46.2% had stopped taking a drug in this category.

4.1.3.2 What people said about MAOIs

Comments relating to drugs in this category covered the same areas as above. Four respondents reported that their drug had helped to relieve their symptoms, one reported that the improvement was short-lived, and one reported that it made no difference:

> *Having been on medication from different groups of antidepressants, this seemed to 'lift' me*. (Phenelzine)
> *Made a rapid climb out of depression.* (Phenelzine)
> *Slight improvement over first six weeks then no effect.* (Moclobemide)
> *Don't make me feel any better.* (Moclobemide)

Unwanted effects when taking a drug in this category included nausea, visual irregularities, dizziness, confusion, sensitivity to light, lack of concentration, insomnia, weight gain, gastric problems and anxiety and agitation:

> *Dizziness, hand and eye coordination was different, sensitivity to light, feeling sick, confused, poor concentration.* (Phenelzine)
> *Gastric problems - bowel movement, flatulence etc, hardly sleep - not tired ever, low blood pressure often breathless, slight weight gain, dietary problems, odd taste in mouth.* (Phenelzine)

However, respondents reported being unsure about which symptoms were associated with stopping their drug:

> *Agitation and compulsive thoughts were worse, but I'm not sure if they got worse on stopping...* (Moclobemide)

In the overall evaluation two respondents specifically stated that their drug had helped them, one reported no difference, and one indicated that she had felt vulnerable and questioned her own ability while taking this drug:

> *Third time over the last ten years I've been on this antidepressant - it's the most effective for me.* (Moclobemide)
> *I felt very unsafe going out while on this drug, especially while crossing roads, as my alertness was slow.* (Phenelzine)

4.1.4 Other antidepressants

This grouping contains antidepressants which are neither SSRI, tricyclic or MAOI. The grouping contains five generic brands. Venlafaxine, Nefazodone and Reboxetine are similar to SSRIs in that they affect the reuptake of neurotransmitters (Nefazodone was discontinued in the UK in April 2003). Venlafaxine affects both serotonin and noradrenaline while Reboxetine acts on noradrenaline alone.

Mirtazapine increases noradrenaline and serotonin transmission while Tryptophan is used in some instances to treat depression that other drugs have not helped.

The most frequently prescribed drug in this group, and indeed in the entire survey, was Venlafaxine, which accounted for almost six out of ten prescriptions in this category. It is most commonly used as a 'second line' antidepressant, in other words it won't be used until other drugs have been tried.

4.1.4.1 Symptom relief and other antidepressants

It can be seen from the table below that over 70% of respondents who had been prescribed Venlafaxine found it helpful for relieving their symptoms, as did six out of ten of those prescribed Nefazodone Hydrochloride, and almost half of those prescribed Mirtazapine. Just 36% of people found Reboxetine to be helpful for symptom relief, with 20% finding it to be *very* unhelpful.

Table 4.15 How helpful for symptom relief is other antidepressant?

Other antidepressant	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Venlafaxine	117	32.5	37.6	11.1	4.3	11.1
Mirtazapine	46	23.9	28.3	13.0	10.9	15.2
Reboxetine	25	16.0	20.0	24.0	12.0	20.0
Nefazodone Hydrochloride	13	30.8	30.8	23.1	-	7.7
Tryptophan	2	50	-	50	-	-
Total	203	28.6	32.5	14.3	6.4	12.8

4.1.4.2 What people said about other antidepressants and symptom relief

A number of respondents spoke very positively about their drug's usefulness for symptom relief:

> *This is the best drug I have been on. I have been taking it for two years and nine months. I have been able to hold down a job and have a better life.* (Mirtazapine)
> *Has been the most useful antidepressant I have had in over 37 years of illness* (Venlafaxine)
> *Not long after I started taking Venlafaxine the depression started to lift.* (Venlafaxine)

A further group of respondents indicated that their drug had reduced symptoms rather than eliminated them:

> *It has improved my moods compared to how I was previously, but I am nowhere as good as I should be....* (Venlafaxine)

In some cases while the drug had not banished symptoms it had maintained them on a level and reduced mood fluctuation:

> *It has maintained mood at a low level without the tendency to peak and trough.* (Venlafaxine)
> *Feel I don't have a sudden drop in mood anymore, but don't feel depression really lifts either, but glad it's the same.* (Reboxetine)

Some respondents felt that their drug was better than others they had taken in the past. Four reported that their sleep had improved with knock-on effects for their general well being. However, 11 respondents reported that initial benefits were short-lived:

> *Helpful only for a short period.* (Nefazodone Hydrochloride)
> *At first very good and then I no longer felt all the effects…* (Venlafaxine)

Unfortunately not all respondents reported having experienced benefits:

> *No relief of symptoms.* (Mirtazapine)
> *Don't feel any significant benefit.* (Reboxetine)
> *Was the worst experience of my life - had the most horrific side effects.* (Venlafaxine)
> *I have been on this drug since August 2002 with no appreciable benefit and no other drug has been suggested.* (Reboxetine)

Some reported actually feeling worse as a result of taking the drug:

> *It did not relieve the symptoms at all, but worsened the depression and feelings of suicide.* (Mirtazapine)
> *This drug did nothing to relieve symptoms and in some ways worsened daily functioning.* (Venlafaxine)

4.1.4.3 Unwanted effects when taking other antidepressants

Overall, just under 60% of respondents reported unwanted effects when taking other antidepressants. There was a high reported incidence of unwanted effects for Nefazodone Hydrochloride but the sample size was small. Mirtazapine came out most favourably with 42% saying they did not experience any unwanted effects when taking the drug.

Table 4.16 Unwanted effect when taking other antidepressant?

Other antidepressant	Number	%		
		Yes	No	Not sure
Venlafaxine	118	62.7	22.9	14.4
Mirtazapine	45	46.7	42.2	11.1
Reboxetine	25	56.0	40.0	4.0
Nefazodone Hydrochloride	14	78.6	14.3	7.1
Tryptophan	2	-	100	-
Total	204	58.8	29.4	11.8

4.1.4.4 What people said about unwanted effects when taking other antidepressants

A wide variety of unwanted effects were recorded for Venlafaxine and Reboxetine including loss of libido, nausea, increased appetite, involuntary movements, tinnitus, sweating and headaches:

> *Tired, no sex drive, high temperature, sweating, confused on occasions...* (Venlafaxine)

Complete sexual dysfunction; the consultant reduced the dose to half of the recommended minimum - much better. (Reboxetine)
Cravings for sweets, crisps, chips etc., had never been like that before. (Venlafaxine)

Other reported problems included high blood pressure, tiredness and sleep problems, aggression and mania, vertigo-like symptoms and nausea:

It induced Tinnitus, vertigo related problems, difficulties with circulation, abnormally high blood pressure. (Venlafaxine)
Difficulty sleeping (two to three hours per night), excessive sweating, dry mouth. (Reboxetine)
… Occasionally I get very agitated. I have had one manic episode whilst taking it. (Venlafaxine)

A number of respondents taking Reboxetine commented on constipation:

Constipation was a big problem. (Reboxetine)

Two respondents were keen to point out that while they still had unwanted effects from Venlafaxine these were not as bad as drugs they had tried before:

Restless legs - but I can cope. It's better than the psychological side effects from previous medication. (Venlafaxine)
Milder though still unpleasant side effects compared to previous drug. (Venlafaxine)

Similar unwanted effects were noted for Mirtazapine with the most commonly noted being weight gain:

Eating like a horse. (Mirtazapine)
I had a voracious appetite and was gaining 4lbs weekly. (Mirtazapine)

4.1.4.5 Unwanted effects when stopping other antidepressants

Overall just under half of all respondents taking other antidepressants reported unwanted effects when stopping. The highest percentage of problems was recorded for Nefazodone Hydrochloride (based on a small sample) and the lowest for Mirtazapine. Over half of respondents who had stopped Venlafaxine reported unwanted effects.

Table 4.17 Unwanted effects when stopping other antidepressant?

Other antidepressant	Number stopped	%		
		Yes	No	Not sure
Venlafaxine	83	56.6	32.5	10.8
Mirtazapine	25	28.0	56.0	16.0
Reboxetine	17	35.3	47.1	17.6
Nefazodone Hydrochloride	11	63.6	27.3	9.1
Total	136	49.3	38.2	12.5

4.1.4.6 What people said about unwanted effects when stopping other antidepressants

Two-thirds of respondents who had been prescribed a drug in this category had stopped taking it at some point. Half of them experienced unwanted effects when they stopped.

Some respondents reported that their symptoms returned:

> *Depression returned rapidly.* (Reboxetine)
> *I stopped taking it myself because I was feeling so much better, but my depression came back.* (Mirtazapine)

Many respondents reported severe symptoms when they stopped taking their medication:

> *Felt suicidal after two to three days, anxious, very tearful.* (Nefazodone Hydrochloride)
> *My mood became much worse. I became suicidal and severely depressed.* (Reboxetine)
> *I was ill for a week after stopping taking this drug. I could not lift my head from the pillow for a week.* (Mirtazapine)

Some of the comments recorded by people who had stopped taking Venlafaxine were particularly powerful, with numerous reports of severe adverse reactions on discontinuation, including self-harming, suicidal feelings and one suicide attempt:

> *As I mentioned in previous section, also became aggressive. I contemplated killing someone. I experienced related mental and suicidal and self-harming thoughts. In essence it was a nightmare.* (Venlafaxine)
> *Attempted suicide, extreme pain in my head, vomiting.* (Venlafaxine)
> *Waves of crying for about two weeks, then hyperactive - agitated, extremely depressed/ suicidal.* (Venlafaxine)
> *Extreme side effects - so bad I decided to remain on same dose! Venlafaxine seems to be a difficult one to wean yourself off…* (Venlafaxine)

Other people commenting on Venlafaxine remarked on how quickly they experienced unwanted effects on stopping:

> *Severe dizziness, even if I miss a single dose.* (Venlafaxine)
> *Severe mood crash within a day or so of not taking it due to food poisoning. Became suicidal, cut my arms with a blade, cried constantly, no energy of motivation, paranoia heightened, visual and audio hallucinations….* (Venlafaxine)
> *Ran out of tablets accidentally and 48 hours later became aggressive, very agitated and manic.* (Venlafaxine)
> *If I miss a day I feel quite unwell. It's like small electric shocks through my body and head.* (Venlafaxine)

Four respondents stated that they were unable to stop taking their drug because of the withdrawal effects:

> *I found I had to re-commence taking it, not because of mood fluctuations, but to reduce the increasing and persistent side effects.* (Venlafaxine)

Amongst respondents whose withdrawal symptoms could be considered to be less severe, the most commonly reported symptom were dizziness/light headedness, irritability, nausea, aches and pains, problems with balance, and tiredness:

> *Achey, painful legs, panic feelings in stomach and feeling very tired.* (Reboxetine)
> *I get grumpy and irritable.* (Nefazodone Hydrochloride)
> *Got terrible withdrawals - shakes, vomiting, dizziness, light headedness. Had to phone NHS 24…* (Venlafaxine)

4.1.4.7 Overall evaluation of other antidepressants

Just over half of people reporting on other antidepressants found them to be helpful taking the positives and negatives into account. The drug with the best rating was Venlafaxine with almost 64% finding it to be helpful and over a quarter rating it as *very* helpful. Less than half the respondents prescribed Mirtazapine, Reboxetine, or Nefazodone Hydrochloride reported that their drug had been helpful overall.

Table 4.18 Overall how helpful was other antidepressant?

Other antidepressant	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Venlafaxine	118	26.3	38.1	12.7	5.1	13.6
Mirtazapine	46	23.9	23.9	13.0	10.9	17.4
Reboxetine	24	16.7	25.0	16.7	12.5	25.0
Nefazodone Hydrochloride	14	14.3	21.4	35.7	-	14.3
Tryptophan	2	50.0	-	50.0	-	-
Total	204	24.0	31.9	15.2	6.9	15.7

4.1.4.8 What people said about their overall evaluation of other antidepressants

One group of respondents commented on how their drug had helped. A considerable number mentioned that they had tried other antidepressants and found these ones to be most effective:

> *It has changed my life for the better.* (Mirtazapine)
> *I have been on over 30 antidepressants in over 37 years. I have had to take many courses of ECT because no helpful drug could be found. Now I think we have found it.* (Venlafaxine)
> *It's the best of a bad lot. I have always had bad side effects with antidepressants.* (Nefazodone Hydrochloride)
> *...Venlafaxine though is the only antidepressant in four years that has actually done something, so I am reluctant to change.* (Venlafaxine)
> *After years of trying different antidepressants, I find this the most effective.* (Venlafaxine)

However, some respondents who were no longer taking their drug reported that they would not take it again:

> *I will never take this drug again I have been prescribed it twice and had the same effects both times.* (Venlafaxine)
> *The positives are not worth having the negatives.* (Mirtazapine)

Some reported mixed feelings about the benefits of their medication. Some were fairly neutral, reporting that the drugs kept them on an 'even keel' without improving their overall condition:

> *May have taken the edge off but no great help in lifting mood or reducing anxiety.* (Reboxetine)
> *Symptoms did not worsen on this, but withdrawal was unpleasant and overall the drug did not improve my condition.* (Venlafaxine)

Others were more negative:

> *No antidepressant that I've been on over 50 years has ever helped me.* (Venlafaxine)

Heightened all the symptoms that they were supposed to help alleviate. Felt physically unwell throughout. (Mirtazapine)

One group of comments drew attention to the need to achieve a balance between positive and negative aspects:

I guess gaining two and a half stones is a small price to pay for my improvement in my depression… (Venlafaxine)
I've a fear of getting fat. It doesn't seem worth taking, but there again it's so good to get rid of insomnia and to know I'll sleep every night. (Mirtazapine)

A number of respondents reported that they did not know how they would feel without their drug, and in other cases, respondents were unsure which drug was responsible for which effect:

I've taken antidepressants continuously for two to three years. I sometimes wonder how I might feel if they were withdrawn. (Venlafaxine)
I find it difficult to tell what is due to the effect of the drugs compared to other parts of the treatment plan... (Mirtazapine)
Unsure if the drug relieves depression after two or three weeks or if the improvement is just caused by the natural mood swing. (Mirtazapine)

However, the following two comments highlight the difference between individual experiences, which can make prescription a question of trial and error:

I would not be alive today without this drug. (Venlafaxine)
I wasted a year of my life on this drug. I was a zombie… (Venlafaxine)

4.1.5 Antidepressant conclusions

When looking at symptom relief for the most commonly prescribed antidepressants (20 prescriptions or over) Trazodone Hydrochloride, a tricyclic related drug, comes out best, with 75% finding it helpful, followed by other antidepressant, Venlafaxine at 70%.

Assessing symptom relief can be complicated. For example, one of the drugs most commonly rated as helpful, Lofepramine also has the highest 'unhelpfulness rating'. The drug least likely to be rated as helpful was Reboxetine – described as helpful by just 36%. It is perhaps relevant that Reboxetine tend to be used primarily as a 'second line' antidepressant in cases where other drugs have already been found to be of limited value.

On average just under 60% of all antidepressant respondents said they were helpful.

On average tricyclic or related antidepressants were rated slightly better for symptom relief than the more commonly prescribed and more expensive SSRIs.

Table 4.19 Antidepressant symptom relief summary

Antidepressant	Type	Number	Symptom relief %	
			Rated helpful	Rated unhelpful
Trazodone Hydrochloride	Tricyclic	40	75.0	15.0
Venlafaxine	Other	117	70.1	15.4
Nefazodone Hydrochloride	Other	13	61.6	7.7
Citalopram	SSRI	88	63.7	17.0
Clomipramine	Tricyclic	22	63.7	18.2
All tricyclic and related	**-**	**142**	**62.7**	**21.2**
Lofepramine	Tricyclic	29	62.1	37.9
All others	**-**	**203**	**61.1**	**19.2**
Dosulepin/Dothiepin Hydrochloride	Tricyclic	18	61.1	11.1
Sertraline	SSRI	50	58.0	30.0
All SSRIs	**-**	**360**	**57.5**	**26.3**
Fluoxetine	SSRI	113	55.7	31.8
Paroxetine	SSRI	105	54.3	25.7
Amitriptyline	Tricyclic	18	50.0	38.9
Mirtazapine	Other	46	52.2	26.1
Reboxetine	Other	25	36.0	32.0
All antidepressants	**-**	**718**	**59.4**	**23.3**

When considering unwanted effects tricyclics again outperformed SSRIs (and the other antidepressant grouping) on both unwanted effects when taking and when stopping, most notably the latter. Most problems on taking and stopping were noted for the discontinued drug, Nefazodone Hydrochloride (78% on taking and 64% on stopping - though the sample was very small) and the SSRI, Paroxetine (75% on taking and 57% on stopping). Problems on stopping were also commonly reported for Venlafaxine, part of the other antidepressant grouping. Most favourably judged was the tricyclic, Lofepramine, with under a quarter reporting unwanted effects on stopping and just over 40% while taking.

Table 4.20 Antidepressant unwanted effects summary

Antidepressant	Type	Unwanted effect			
		When taking		When stopped	
		Number	%	Number	%
Nefazodone Hydrochloride	Other	14	78.6	11	63.6
Paroxetine	SSRI	108	75.0	96	57.3
Clomipramine	Tricyclic	22	63.6	18	44.4
Venlafaxine	Other	118	62.7	83	56.6
Amitriptyline	Tricyclic	18	61.1	14	42.9
All others	**-**	**204**	**58.8**	**136**	**49.3**
All SSRIs	**-**	**361**	**58.7**	**268**	**47.3**
Trazodone Hydrochloride	Tricyclic	40	57.5	22	36.4
Sertraline	SSRI	50	56.0	37	48.6
Reboxetine	Other	25	56.0	17	35.3
Fluoxetine	SSRI	113	54.0	78	37.2
All tricyclics and related	**-**	**141**	**53.9**	**99**	**33.3**
Dosulepin/Dothiepin Hydrochloride	Tricyclic	17	47.1	12	25.0
Mirtazapine	Other	45	46.7	25	28.0
Citalopram	SSRI	87	46.0	54	42.6
Lofepramine	Tricyclic	30	43.3	22	22.7
All antidepressants	**-**	**719**	**57.9**	**515**	**45.0**

The two drugs rated overall most helpful overall were both tricyclics or related**,** Trazodone Hydrochloride and Clomipramine, both rated helpful by over 70%. Tricyclics or related drugs had an above average helpfulness rating and again outperformed SSRIs, though the difference was not statistically significant.

The drugs most commonly described as unhelpful were Paroxetine and Reboxetine (see over).

Table 4.21 Antidepressants overall helpfulness summary

Antidepressant	Type	Number	Overall rating %	
			Rated helpful	Rated unhelpful
Trazodone Hydrochloride	Tricyclic	40	72.5	17.5
Dosulepin/Dothiepin Hydrochloride	Tricyclic	18	70.5	11.8
Clomipramine	Tricyclic	21	71.4	14.3
Venlafaxine	Other	118	64.4	18.7
All tricyclics and related	**-**	**141**	**63.1**	**21.3**
Citalopram	SSRI	86	61.7	16.3
Lofepramine	Tricyclic	30	60.0	16.6
All others	**-**	**204**	**55.9**	**22.6**
Sertraline	SSRI	50	56.0	32.0
Fluoxetine	SSRI	112	54.4	26.8
All SSRIs	**-**	**355**	**53.8**	**28.5**
Amitriptyline	Tricyclic	18	50.0	38.9
Mirtazapine	Other	46	47.8	28.3
Paroxetine	SSRI	103	45.7	37.9
Reboxetine	Other	24	41.7	37.5
Nefazodone Hydrochloride	Other	14	35.7	14.3
All antidepressants	**-**	**658**	**56.2**	**25.2**

When looking at the differences between the antidepressant types overall ratings it is interesting to note that given the claims made on behalf of SSRIs, and their higher cost, one might have expected them to outperform the older tricyclic and tricyclic related drugs. There was, of course, variation between the overall performance of individual SSRIs, however, as a group, they were outperformed on every indicator by tricyclic and related drugs – although as noted above, not all the differences were statistically significant.

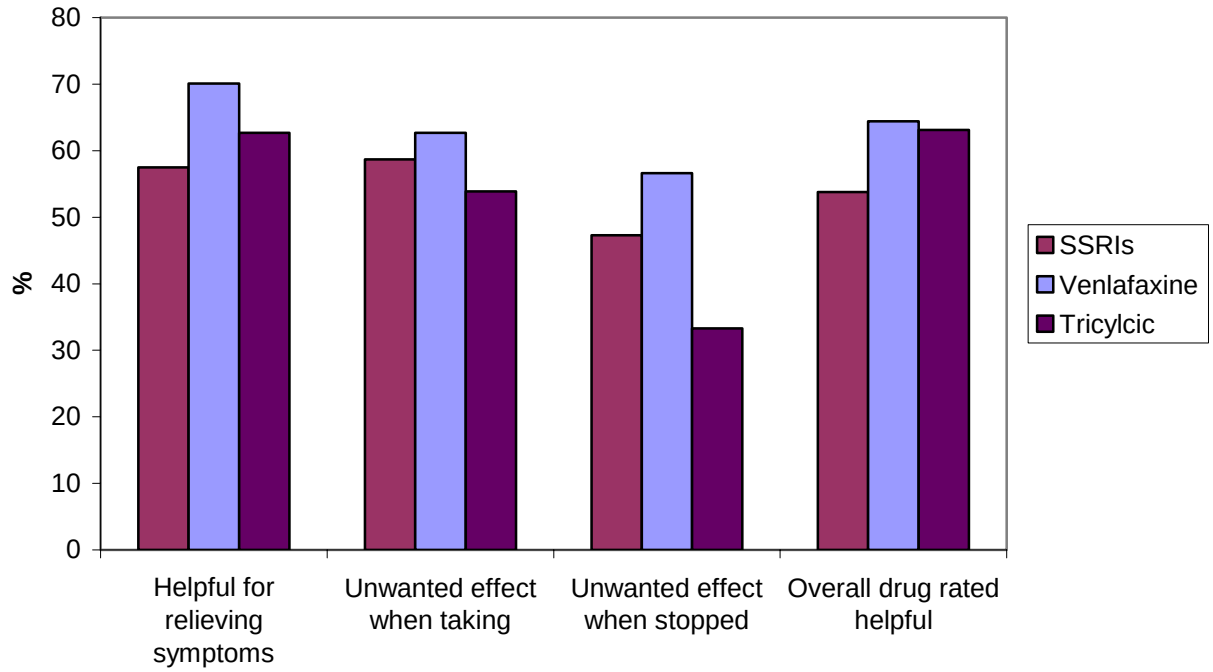
Three years ago a 'meta-analysis' of randomised control trials comparing SSRIs and tricyclics came to a similar conclusion:

"Overall efficacy between the two classes is comparable but SSRIs are not proven to be as effective as TCAs in in-patients and against Amitriptyline. SSRIs have a modest advantage in terms of tolerability against most TCAs."[9]

It is, however, important to reiterate that tricyclic and related antidepressants can cause serious adverse reactions in overdose not associated with SSRIs, for example, cardiac failure.

9 Selective serotonin reuptake inhibitors versus tricyclic antidepressants: a meta-analysis of efficacy and tolerability. Anderson IM, J Affect Disord, 2000 Apr; 58(1): 19-36.

Figure 7: Summary comparison of antidepressants



4.2 ANTIPSYCHOTICS

Antipsychotics, or neuroleptics, are drugs that have been developed primarily to treat schizophrenia although, as our survey shows, psychiatric drugs tend to be used across a range of different diagnoses. It is not uncommon for antipsychotics to be used in the treatment of mania, confusion, and depression, if psychosis is present. For example, antipsychotics were prescribed in 44 cases where a survey respondent had a diagnosis of depression alone – this represents just under 5% of all drugs prescribed to people with this diagnosis.

Many of these drugs have a tranquillising effect and indeed they are sometimes known as major tranquillisers. However, in the treatment of schizophrenia the tranquillising effect is of secondary importance as they primarily relieve psychotic symptoms including delusions and hallucinations. They appear to work by affecting the transmission of brain chemicals, or neurotransmitters, primarily dopamine.

Antipsychotics were first developed in the 40s and 50s. A new generation of antipsychotics, known as atypicals were developed in the 70s and 80s. These were hailed as being more effective with fewer and less severe unwanted effects, than their older equivalents. These drugs are considerably more expensive, costing on average 17 times as much as the older drugs.[10]

Key findings

- 62% of respondents rated antipsychotics helpful overall.
- Nearly 70% reported unwanted effects when taking antipsychotics, with 40% reporting unwanted effects on stopping.
- New atypical and older typical drugs scored fairly evenly across the categories – the newer drugs performed marginally better overall (taking the positives and negatives into account) than the older drugs.
- More unwanted effects were reported on stopping with newer atypical drugs than older typical drugs.
- There was a wide variation within different drug types. The best performing antipsychotic overall was the older typical drug, Sulpiride, rated helpful by four out of five respondents.
- Depot antipsychotics rated consistently badly, with under 40% of respondents considering them to be overall helpful. This was the only drug with an overall negative rating (more people rated them unhelpful than helpful).
- Unwanted effects varied considerably between different drug types. Serious weight gain was commonly reported for atypicals, and movement problems were reported for typical medications. Drowsiness and sexual difficulties were experienced across drug types.

In 2002 the National Institute for Clinical Excellence (NICE) recommended that newer atypicals should be made available as the first choice drug in various scenarios, including where schizophrenia has been newly diagnosed and where side effects from taking older typical drugs are considered to be unacceptable.[11] However, there is some scepticism about claims made for modern atypicals and not everyone believes they are better than the older drugs.

10 Costing per person per year. Figures from Health Technology Board for Scotland (now Quality Improvement Scotland) media release on the use of newer (atypical) antipsychotics for schizophrenia, July 2002

11 National Institute for Clinical Excellence (NICE), Guidance on the Use of Newer (Atypical) Antipsychotic Drugs for the Treatment of Schizophrenia, 2002

Side effects are a major issue with antipsychotic medication. Because of adverse effects people are sometimes reluctant to take medication, even when they help with symptoms.

Of all the drugs considered in this survey just over a third were antipsychotics.

We used three subcategories of antipsychotic medication - typical, atypical and depot. A depot is a long-acting injection used most often where compliance with oral medication is unreliable. Most depots are typicals – but Risperidone is now also available as a depot.

Table 4.22 Antipsychotic type prescribed

Drug type	Number	%
Atypical	291	53.1
Typical	214	39.1
Depot	43	7.8
Total	548	

4.2.1 Atypical antipsychotics

Atypicals are the newer generation of antipsychotic drugs. They accounted for almost one in five prescriptions in the survey and just over half of antipsychotic prescriptions. Most recipients had a diagnosis of schizophrenia (144), followed by depression (67), and manic depression (60). Drugs in this category included seven generic brands.

Prescriptions for Olanzapine accounted for more than a third of prescriptions, and Risperidone just under a quarter.

4.2.1.1 Symptom relief and atypical antipsychotics

Atypical antipsychotics rated well for symptom relief with just under 70% of respondents saying they were helpful as a group. The individual drug rated most helpful overall was Olanzapine at 73%. However, Clozapine had the highest *very* helpful rating with just under half of respondents giving it this top rating.

Risperidone and Amisulpride were rated less favourably for overall helpfulness with symptom relief (62 and 60.0% respectively). Despite these fairly positive ratings there was a considerable group who did not find atypicals particularly helpful for symptom relief.

One in five respondents overall suggested that an atypical was not helpful. Of particular note here are the 28.5% of respondents who rated Risperidone as unhelpful, the vast majority of whom said it was *very* unhelpful.

Table 4.23 How helpful for symptom relief is atypical antipsychotic?

Atypical antipsychotic	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Olanzapine	104	39.4	33.7	8.7	5.8	5.8
Risperidone	70	30.0	30.0	8.6	7.1	21.4
Clozapine	42	47.6	23.8	4.8	9.5	9.5
Quetiapine	38	39.5	31.6	5.3	5.3	15.8
Amisulpride	34	26.5	35.3	8.8	5.9	17.6
Zotepine	2	-	100	-	-	-
Total	290	36.6	31.7	7.6	6.6	12.6

4.2.1.2 What people said about atypical antipsychotics and symptom relief

29 respondents reported that their drug had helped reduce symptoms:

It has completely relieved my symptoms. (Risperidone)
It was like a new beginning. (Quetiapine)
Calmed down overnight… (Risperidone)
Keeps paranoia at bay, also delusions and mania. (Olanzapine)

Some respondents referred specifically to the effect of the drug in eliminating hallucinations:

It took the voices away. (Olanzapine)
Stopped voices for a while. (Quetiapine)
Very helpful for relief from hallucinations. (Risperidone)

However others reported the opposite effect i.e. the drug increased hallucinations:

> *The drug had the effect of increasing my hallucinations, instead of stopping them.* (Quetiapine)
> *Made me hallucinate.* (Risperidone)

Some respondents indicated that although they still experienced symptoms, including hallucinations and delusions, they felt better able to cope:

> *Thoughts/voices still bother me at times although I can cope fairly well at times.* (Clozapine)

Seven respondents reported feeling calmer and another seven reported improved sleep:

> *My stress levels were markedly lower, I was much calmer, and I found that I could sleep at night.* (Olanzapine)
> *My sleeping was transformed to the good and other symptoms disappeared.* (Amisulpride)

For some the usefulness of the drug had been mixed:

> *It probably prevented the psychosis from getting worse, but didn't help the mood disorder much.* (Quetiapine)
> *I still had many of the symptoms that it had been prescribed to relieve.* (Amisulpride)

Other respondents noticed no effects:

> *Unfortunately it neither added nor took away from the problems I experience. The problems that I have are still the same problems that I have been experiencing for 20 plus years, but it did give me a lot of weight gain!* (Olanzapine)
> *As far as I'm concerned, the tablets don't help me in the slightest.* (Clozapine)
> *I couldn't say I notice the affect of this drug.* (Olanzapine)

4.2.1.3 Unwanted effects when taking atypical antipsychotics

Overall 66% of respondents reported unwanted effects when taking an atypical antipsychotic. The drug rated most problematic was Risperidone with unwanted effects reported in almost three quarters of cases. The best rated drug was Amisulpride with 59% reporting unwanted effects.

It is interesting to note that the proportion of respondents who rated atypicals as helpful for relieving symptoms was similar to the proportion who reported unwanted effects (68.3% and 66.3% respectively).

Table 4.24 Unwanted effects when taking an atypical antipsychotic?

Atypical antipsychotic	Number	%		
		Yes	No	Not sure
Olanzapine	104	62.5	27.9	9.6
Risperidone	69	73.9	17.4	8.7
Clozapine	42	71.4	21.4	7.1
Quetiapine	37	64.9	27.0	8.1
Amisulpride	34	58.8	32.4	8.8
Zotepine	2	50.0	0	50.0
Total	288	66.3	24.7	9.0

4.2.1.4 What people said about unwanted effects when taking an atypical antipsychotic

A very wide range of unwanted effects were commented on. The most commonly reported side effects were tiredness and/or drowsiness:

> *Extreme drowsiness, lethargy, motivational suppression, and an inability to dream. Also caused weight gain.* (Clozapine)
> *Permanently sedated, unable to perform at work*. (Quetiapine)
> *Extreme sedation, e.g. not waking up till 3pm in the afternoon. If forced to get up earlier I felt very bad.* (Quetiapine)

Altered appetite and weight gain were a significant problem for a considerable number of respondents. In some cases the gain was severe and disabling:

> *Made me increase in weight - I went from ten to fifteen stones and seven pounds in one month. This depressed me more...* (Quetiapine)
> *Weight gain, went from seven and a half stone to seventeen and a half stone in seven months!* (Olanzapine)
> *The sheer greed/appetite that Olanzapine gave me was almost as alarming as the illness!* (Olanzapine)

The negative impact of weight gain on self-esteem was, in some cases, compounded by concurrent loss of libido and sexual problems:

> *Loss of libido and weight gain (a fat eunuch).* (Amisulpride)
> *Weight gain, severe loss of sex drive...* (Risperidone)

Other difficulties included; increased saliva causing dribbling, dry mouth, poor memory and lack of concentration, dampened emotions, visual problems, involuntary movements, stiffness, dizziness, nausea, high blood pressure, shortness of breath, movement problems, headaches and incontinence:

> *I couldn't sleep, my sex drive and my emotions were suppressed. My memory and the ability to think were impaired.* (Amisulpride)
> *Loss of balance, loss of memory, headaches every day, dribbling during sleep, incontinence. While on it I took pericarditis.* (Clozapine)
> *I became crippled to the point I couldn't walk and my eyesight was affected so badly I could hardly see...* (Risperidone)

Some brought attention to the interaction between unwanted effects and dosage:

> *Too high a dose brought depressive symptoms…* (Risperidone)
> *Very very heavy sedation and knocked me for six on 4mg dose.* (Risperidone)

Respondents also drew attention to hormonal changes associated with their drugs (including interruption or cessation of menstrual cycle), increased anxiety, nightmares, feeling detached, difficulty with speech, mood swings, and increased temper:

> *Periods stopped completely for the two year period that I was taking them.* (Amisulpride)
> *Flying into rages, violent temper, and then I experienced bad depression.* (Olanzapine)

Respondents also commented on strange sensations resulting from taking this drug:

> *When I take this drug I feel spidery and floaty and I can't get up in the morning my legs feel like jelly. (Olanzapine)*

Some people reported serious physical complications as a result of taking atypicals:

Put on two and a half stones, got breast milk, no periods, fuzzy vision, constipation, over-sedation. Was a zombie, spent most of the time sleeping. Distressed my family and myself. Eventually they discovered I had hyperprolactinaemia. [My] *prolactin was 6000 and I had to have a CT scan as the doctor told me I may have a brain tumour. They did not realize this was due to the tablet…Was referred to endocrinologist who demanded that I be taken off the medication. It is a terrible drug and all the problems from it led to my being in hospital for four months*. (Risperidone)
I continued taking it despite my physical health deteriorating as well as my mental health. (Risperidone)
Extremely drowsy – high dose and unpleasant heart palpitations. Had to come off it. (Quetiapine)

4.2.1.5 Unwanted effects when stopping atypical antipsychotics

Unwanted effects on stopping an atypical antipsychotic were recorded in over 40% of cases overall. The drug where problems were most commonly noted on discontinuation was Risperidone with over half of respondents noting unwanted effects. The best performing drug was Amisulpride with 35% reporting unwanted effects and 65% reporting none.

Table 4.25 Unwanted effect when stopping an atypical antipsychotic?

Atypical antipsychotic	Number stopped	%		
		Yes	No	Not sure
Olanzapine	74	39.2	47.3	13.5
Risperidone	42	54.8	38.1	7.1
Quetiapine	27	40.7	48.1	11.1
Clozapine	26	46.2	46.2	7.7
Amisulpride	20	35.0	65.0	-
Zotepine	1	100	-	-
Total	190	43.7	46.8	9.5

4.2.1.6 What people said about stopping taking an atypical antipsychotic

Two-thirds of respondents who had been prescribed an atypical antipsychotic had stopped taking it at some time. The main problem reported by respondents stopping a drug in this category was a return of symptoms:

I became ill again, even though I felt better for a while. (Clozapine)
Return of psychotic and paranoid symptoms. (Amisulpride)

Some reported particularly bad paranoia and delusions on stopping an atypical:

Severe paranoia leading to an overdose. (Olanzapine)
Became incredibly paranoid and delusional. (Olanzapine)

Other unwanted side effects included sleep problems and tiredness, sweats, dizziness, headaches, lack of concentration, visual problems, nausea, anxiety and mood swings:

Not sleeping, headaches, I was just not well at the time, hot/cold sweats and frightened in [the] *house.* (Risperidone)

Resumption of agitation and frequent mood changes. (Risperidone)

A small number of respondents reported moving straight on to another drug and thus avoiding withdrawal symptoms:

I was put on to another drug straightaway with no interval between stopping Olanzapine and starting the new drug. (Olanzapine)
Switched to Amisulpride instantly without side effects. (Olanzapine)

4.2.1.7 Overall evaluation of atypical antipsychotics

We asked respondents to rate the overall helpfulness of atypical antipsychotics taking into account the positives and negatives. In the majority of cases respondents felt fairly positive about taking an atypical antipsychotic with 65% describing them as helpful. However, there was again a considerable group of people who rated their overall experience of an atypical as negative with just under a quarter of respondents saying they found their drug to be *fairly* or *very* unhelpful.

The individual drugs likely to be rated most positively were Clozapine and Olanzapine (both rated as helpful by over 70% of respondents) with Clozapine the most likely to rated as *very* helpful (44%) – an interesting finding when you consider that the availability of Clozapine is limited.[12]

The drugs with the poorest rating were Risperidone and Amisulpride. They were both rated as unhelpful in around a third of cases. The poor comparative rating of Amisulpride is interesting given the drugs comparatively good rating on unwanted effects.

Table 4.26 Overall how helpful was atypical antipsychotic?

Atypical antipsychotic	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Olanzapine	103	37.9	35.0	9.7	6.8	7.8
Risperidone	69	30.4	26.1	5.8	5.8	27.5
Clozapine	41	43.9	29.3	7.3	7.3	12.2
Quetiapine	38	36.8	28.9	13.2	2.6	18.4
Amisulpride	34	26.5	29.4	5.9	8.8	23.5
Zotepine	2	-	-	50.0	-	-
Total	287	35.2	30.3	8.7	6.3	16.4

4.2.1.8 What people said about their overall evaluation of atypical antipsychotics

Individual experiences differed markedly with some respondents believing that their drugs were vital to their survival:

I don't know what I would do without my Paroxetine and Risperidone. (Risperidone)
I am alive. I am participating in society. I have never been an inpatient. I only need six to eight week check-ups and some psychotherapy... (Quetiapine)

Others reported little or no benefit from taking the drug:

It really did very little of anything to help. (Amisulpride)

12 Clozapine is only used where people have been found to be unresponsive to, or intolerant of, other antipsychotic drugs.

> *…being forced to take Risperidone had an entirely negative effect on me and made me more ill than I have ever been in my life.* (Risperidone)

Several respondents drew attention to the balance between unwanted side effects and the benefits that they derived from staying on their medication:

> *My concentration is still very poor, however I think I would be more ill if I was not taking this drug.* (Amisulpride)
> *I have to live with the side effects if I want to maintain good health.* (Amisulpride)
> *The relief of psychosis outweighs the side effects.* (Clozapine)

For some the balance between positive and negative aspects was acceptable:

> *I feel that the positive effects completely outweigh the negative ones.* (Risperidone)

However, others indicated that their side effects outweighed the benefits:

> *I found the weight gain and loss of libido made me feel asexual. As having a sex life is an expression of one's humanity, this made me feel very depressed.* (Risperidone)
> *Voices stopped - weight gain and constant hunger never left during one and a half years, this meant spending on clothes and junk food, money I didn't have, result – depressed.* (Olanzapine)

A number of respondents commented on their drugs effect on overall quality of life:

> *Despite my reluctance to take it, it does improve my quality of life.* (Olanzapine)
> *Side effects affect quality of life, although it helps things a lot.* (Olanzapine)

Seven respondents felt that it reduced their symptoms rather than eliminating them:

> *I have had only minor symptoms since taking Olanzapine. The periods of relapse have been shorter.* (Olanzapine)

Six respondents reported that their drug was better than others that they had tried in the past, particularly those who had previously had injections:

> *It is much handier not having to attend the doctor for depot injections once a fortnight as I had done for 15 years previously.* (Risperidone)

4.2.2 Typical antipsychotics

Typical antipsychotics are the older generation of antipsychotic drugs. They have a different unwanted effects profile to the newer atypical drugs with particular, and sometimes severe, problems relating to movement disorder.

This category included 12 generic drugs, and accounted for 14% of all prescriptions. The most frequently prescribed drug was Chlorpromazine Hydrochloride, which accounted for four out of ten prescriptions in this category. Five drugs Haloperidol, Sulpiride, Zuclopenthixol Dihydrochloride, Thioridazine, and Trifluoperazine accounted for just over half the prescriptions for typical antipsychotic drugs, each being prescribed between 17 and 27 times. The remaining six drugs were each prescribed in a small number of cases.

The main recipients of drugs in this category had a diagnosis of schizophrenia, manic depression, and/or depression.

4.2.2.1 Symptom relief and typical antipsychotics

The majority of people found typical antipsychotics to be helpful for symptom relief (64% rating them as *fairly* or *very* helpful). However, there was also a considerable number who did not find them to be helpful, with one person in six rating them as *very* unhelpful. The best performing of the most commonly prescribed drugs was Sulpiride with over 80% of respondents rating it as *very* or *fairly* helpful for symptom relief and under 10% rating it as unhelpful. At the other end of the scale was Haloperidol, rated helpful by just over half of respondents and unhelpful by a third.

Table 4.27 How helpful for symptom relief is typical antipsychotic?

Typical antipsychotic	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Chlorpromazine Hydrochloride	87	34.5	34.5	9.2	9.2	10.3
Haloperidol	27	33.3	18.5	7.4	7.4	25.9
Sulpiride	25	52.0	32.0	8.0	-	8.0
Zuclopenthixol Dihydrochloride	20	15.0	45.0	10.0	5.0	20.0
Thioridazine	17	17.6	35.3	29.4	-	17.6
Trifluoperazine	17	29.4	23.5	11.8	11.8	23.5
Fluphenazine Hydrochloride	6	33.3	16.7	-	16.7	33.3
Pericyazine	4	-	50.0	-	-	50.0
Droperidol	3	66.6	-	-	33.3	-
Loxapine	1	100.0	-	-	-	-
Promazine Hydrochloride	1	-	100.0	-	-	-
Total	211	32.2	32.2	10.4	7.1	15.6

4.2.2.2 What people said about typical antipsychotics and symptom relief

Comments in this section indicated that although the drugs did relieve symptoms, respondents often didn't like taking them:

> *It did work a treat - like blotting paper absorbing all the emotions - but overall I was not happy.* (Chlorpromazine Hydrochloride)
> *It did some positive things while on a psychiatric ward but I hated it.* (Chlorpromazine Hydrochloride)

Some respondents reported that they had been very happy with the way their drugs worked:

> *Feel more active and interested in everyone around me - felt very hyper.* (Sulpiride)
> *I no longer hear voices on this medication. I can wake up early and I am no longer over weight.* (Trifluoperazine)
> *Got rid of symptoms within three weeks.* (Haloperidol)
> *Calming effect, quick acting, no side effects, pleased to take it.* (Sulpiride)

One group of respondents reported that their sleep patterns had improved. Others reported that the main benefit from their drug was that it calmed them down:

Made me sleep and be more calm. (Chlorpromazine Hydrochloride)
Relieved manic episode quickly. (Haloperidol)

The speed with which drugs worked was perceived to be useful in acute situations, either in the community or in hospital:

When I have a cutting attack I take one and while I'm waiting for it to work I phone the Samaritans. (Chlorpromazine Hydrochloride)

However, two respondents reported that their drugs had taken a long time to have any effect, two felt that the benefits had been short-lived and three indicated that there had been no improvement at all:

I felt I had no positive effects from this drug only side effects. (Chlorpromazine Hydrochloride)
Effect seems almost negligible. (Trifluoperazine)

A number of people commented on the powerful sedative effect of typical antipsychotics bringing relief from symptoms but interfering with day-to-day living:

It sedates me to such an extent that I can barely participate in life. (Chlorpromazine Hydrochloride)
Made me like a zombie, I was unable to function. Lost out on my daughter's formative years. (Chlorpromazine Hydrochloride)

4.2.2.3 Unwanted effects when taking typical antipsychotics

Just over 70% reported unwanted effects when taking a typical antipsychotic. Of the most commonly prescribed drugs most problems were reported for Haloperidol with 85% reporting unwanted effects. The drug rated most favourably was Sulpiride with over a third of respondents reporting no unwanted effects.

Table 4.28 Unwanted effects when taking typical antipsychotic?

Typical antipsychotic	Number	%		
		Yes	No	Not sure
Chlorpromazine Hydrochloride	85	68.2	25.9	5.9
Haloperidol	27	85.2	11.1	3.7
Sulpiride	26	61.5	34.6	3.8
Zuclopenthixol Dihydrochloride	21	81.0	9.5	9.5
Thioridazine	17	64.7	23.5	11.8
Trifluoperazine	17	52.9	35.3	11.8
Fluphenazine Hydrochloride	6	66.7	16.7	16.7
Pericyazine	4	100.0	-	-
Droperidol	3	66.6	33.3	-
Loxapine	1	100.0	-	-
Promazine Hydrochloride	1	100.0	-	-
Total	211	70.1	23.2	6.6

4.2.2.4 What people said about unwanted effects when taking typical antipsychotics

As previously stated typical antipsychotics can have a powerful sedative effect and despite a wide ranging list of recorded unwanted effects (see below) the overwhelming concern appeared to be the general tiredness and slowness caused by the drugs interfering with normal functioning, both mentally and physically:

> *The drug relieves my symptoms, but in doing so, leaves me feeling lifeless and very depressed.* (Zuclopenthixol Dihydrochloride)
> *It slowed my brain down and I couldn't think like normal people.* (Chlorpromazine Hydrochloride)
> *Felt like I had the brakes on, made me feel frustrated.* (Thioridazine)
> *Excessive tiredness when taken once - complete physical and mental inaction when taken regularly.* (Levomepromazine/Methotrimeprazine)

Problems with movement including involuntary muscle spasms and tardive dyskinesia were also commonly reported:

> *My bottom jaw and my tongue have a life of their own.* (Chlorpromazine Hydrochloride)
> *Mouth was dropping to one side and started to drag leg...* (Haloperidol)

Other side effects included stiffness, shakiness and jerking, weight gain (but with less frequency than noted with atypical antipsychotics), dry mouth, visual problems (e.g. blurred vision), poor memory and lack of concentration, loss of libido, depression, sensitivity to the sun, slurred speech, anxiety, dizziness, insomnia, dribbling, nausea, constipation and hormonal imbalance:

> *Anxiety, Parkinsonian effects, drowsiness, loss of libido to name some of the side effects.* (Droperidol)
> *I felt as if I was walking with lead boots on, and I had jerky movements in all my limbs.* (Chlorpromazine Hydrochloride)
> *Excessive weight gain, dry mouth, excessive restlessness, tremor.* (Thioridazine)
> *Extreme tiredness, stiffness in joints/muscles, weight gain, vision problems - after taking this drug I had to undergo two cornea grafts.* (Chlorpromazine Hydrochloride)
> *Made me very sleepy. I couldn't function properly, reacts badly to the sun, makes you get burnt…Severe weight gain.* (Chlorpromazine Hydrochloride)
> *I had to have a number of appointments at an endocrinology clinic, as my* [prolactin] *hormone levels were eight times higher than a pregnant woman...* (Sulpiride)
> *Can't focus on anything, feel depressed all the time, feel unwell all the time.* (Zuclopenthixol Dihydrochloride)

Some made specific reference to the drug simply controlling symptoms and as such preventing recovery:

> *… Almost certainly prevents the cure for schizophrenia. In my opinion* Thioridazine *controls symptoms at the wit of reorganisation of thought processes, which should lead to recovery.* (Thioridazine)
> *In controlling my symptoms, the drug leaves me feeling depressed and alienated.* (Zuclopenthixol Dihydrochloride)

4.2.2.5 Unwanted effects when stopping typical antipsychotics

Three quarters of respondents who had taken typical antipsychotic drugs reported that they had at some time stopped taking it. Unwanted effects were recorded in 37% of cases, lower than the figure recorded for the newer typical antipsychotics (44%). It is difficult to extrapolate too much

from these figures because the sample size is fairly small, however, of the two most commonly prescribed typical antipsychotics most problems were recorded for Haloperidol.

Table 4.29 Unwanted effect when stopping typical antipsychotic?

Typical antipsychotic	Number stopped	%		
		Yes	No	Not sure
Chlorpromazine Hydrochloride	67	29.9	56.7	13.4
Haloperidol	21	42.9	47.6	9.5
Thioridazine	16	50.0	43.8	6.7
Sulpiride	15	40.0	46.7	13.3
Trifluoperazine	14	35.7	57.1	7.1
Zuclopenthixol Dihydrochloride	13	53.8	46.2	-
Fluphenazine Hydrochloride	5	60.0	40.0	-
Pericyazine	3	-	100.0	-
Droperidol	2	-	100.0	-
Loxapine	1	100.0	-	-
Promazine Hydrochloride	1	-	-	100.0
Total	160	36.8	51.9	11.3

4.2.2.6 What people said about stopping taking typical antipsychotics

A large group described a return of symptoms on stopping:

> *The voices became louder and I ended up back in hospital.* (Zuclopenthixol Dihydrochloride)
> *I became psychotic.* (Sulpiride)

One respondent bemoaned the lack of options available to them on stopping:

> *My voices came back, but also my life came back to me, but I had no-one to turn to to show me other ways of dealing with my voices, so I went back on my medication.* (Zuclopenthixol Dihydrochloride)

Nine respondents reported experiencing insomnia:

> *I could not sleep at all - my mind was racing and I could not concentrate on anything.* (Chlorpromazine Hydrochloride)

Other difficulties mentioned included increased anxiety, muscle spasms, shaking, nausea and diarrhoea:

> *Some difficult withdrawals - muscular spasms, some anxiety attacks.* (Chlorpromazine Hydrochloride)
> *Four days* [of] *diarrhoea.* (Haloperidol)
> *Anxiety was acute if I stopped the drug.* (Thioridazine)

A number of respondents indicated that withdrawal symptoms had taken lasted for a considerable period:

> *Withdrawal effects lasted for six months.* (Chlorpromazine Hydrochloride)

> *I stopped it suddenly: Horrendous!! Insomnia, hot and cold sweats, panicky feelings, disturbed thoughts, which all lasted about two to three months.* (Chlorpromazine Hydrochloride)

Some respondents reported having experienced particularly severe withdrawal symptoms:

> *Went through three to four weeks of sweat, diarrhoea, vomiting, hot/cold flushes, excessive thirst, shaking, lost two and a half stones in weight.* (Thioridazine)

Others had moved on to another drug immediately and avoided problems:

> *After a few nights with Sodium Valproate, I was able to dispense with this drug, very gladly.* (Chlorpromazine Hydrochloride)

4.2.2.7 Overall evaluation of typical antipsychotics

When rating the overall helpfulness of typical antipsychotics, taking both positive and negative aspects into account, we again found, as with atypical antipsychotics, that there was a considerable group of respondents (26%) who did not consider their drug to be helpful with the vast majority of this group (22%) reporting that the drugs were in fact *very* unhelpful. However, the majority of respondents considered typical antipsychotics to be helpful.

The drug with the best overall rating was, by some distance, Sulpiride, with four out of five respondents rating it as overall helpful. Indeed 46% of respondents rated Sulpiride as *very* helpful overall. However, it is important not to ignore the 12% of respondents who said that Sulpiride was very unhelpful.

Drugs rated as least helpful, where there were a reasonable number of responses, were Zuclopenthixol Dihydrochloride and Haloperidol. Just over half of respondents considered them to be helpful overall. Just under 40% of respondents considered Zuclopenthixol Dihydrochloride to be unhelpful overall, a third considering it to be *very* unhelpful. A third of respondents considered Haloperidol to be unhelpful (see Table 4.30, over).

Table 4.30 Overall how helpful was typical antipsychotic?

Typical antipsychotic	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Chlorpromazine Hydrochloride	86	34.9	25.6	10.5	4.7	19.8
Haloperidol	27	18.5	33.3	11.1	3.7	29.6
Sulpiride	24	45.8	33.3	4.2	-	12.5
Zuclopenthixol Dihydrochloride	21	14.3	38.1	9.5	4.8	33.3
Trifluoperazine	17	23.5	41.2	5.9	11.8	17.6
Thioridazine	16	18.8	31.3	18.8	6.3	18.8
Fluphenazine Hydrochloride	6	33.3	33.3	-	-	33.3
Pericyazine	4	-	50.0	-	-	50.0
Droperidol	3	-	66.7	-	-	33.3
Loxapine	1	100.0	-	-	-	-
Promazine Hydrochloride	1	-	100.0	-	-	-
Total	209	28.3	33.0	9.1	4.3	22.0

4.2.2.8 What people said about their overall evaluation of typical antipsychotics

One group specifically reported that their quality of life had improved due to their drug:

Brilliant feeling; normal again; a new lease of life. (Chlorpromazine Hydrochloride)
For me the relief of psychotic symptoms outweighs the unwanted side effects. (Sulpiride)

Others reported that their drug played an important role in symptom relief:

I really needed it at the time as I was totally mad. (Chlorpromazine Hydrochloride)
Did not like taking this drug but realised the necessity of something to make me sleep, when I was probably manic. (Chlorpromazine Hydrochloride)

Some considered typical antipsychotics to be helpful when taken as required:

…I only take a fraction of the usual dose - 10-20 mgs at night and I only take it when I need it - average of once or twice a week. (Thioridazine)
But only as a sedative, taken when required, by me. (Levomepromazine/Methotrimeprazine)

Some of the comments from respondents who reported feeling worse as a result of taking typical antipsychotics were dramatic:

I would rather have the illness than the cure. (Chlorpromazine Hydrochloride)
A thoroughly nasty and poisonous psychiatric drug. (Droperidol)
It is a horrible drug, which left me with no feelings or emotions. (Chlorpromazine Hydrochloride)
A drug that caused four hour long panic attacks was unhelpful. (Zuclopenthixol Dihydrochloride)

Some questioned the dose they had been given:

I feel that at a lower level dosage there are some benefits, but not in the liquid cosh administration. (Chlorpromazine Hydrochloride)
… I have found that on higher dosages I have constant nightmares and was drowsy (quite a bit)…I'm now on a low dose of five mg and I'm OK with this. (Trifluoperazine)

Three respondents talked about the importance of alternative forms of support:

Why can't I have other options to turn to? Why am I forced on to medication instead of an alternative…? (Zuclopenthixol Dihydrochloride)
I don't rely on them completely and find the other things, like talking to people… I phone the Samaritans occasionally, write a diary, draw pictures, go for walks…. (Pericyazine)

A small number of respondents felt that it became difficult to distinguish between the effects of their illness and the effects of the drug. While some respondents thought that the side effects outweighed the benefits, others felt that the had no option but to take their prescribed drugs and that they were in a 'no win' situation:

Damned if you do, and damned if you don't. (Chlorpromazine Hydrochloride)

4.2.3 Depot antipsychotic

These drugs are antipsychotics that are administered by long-acting injection rather than orally. They tend to be used where people are unwilling to take drugs or are being given compulsory treatment. Depot recipients will often have more severe symptoms. These drugs can lead to more severe movement-related problems than their oral equivalents.

Four out of five prescriptions in this category were for Flupentixol Deconate. The majority of people prescribed depot antipsychotics had a diagnosis of schizophrenia.

4.2.3.1 Symptom relief, unwanted effects when taking and stopping, and overall evaluation of depot antipsychotics

Just over half of respondents prescribed a depot antipsychotic reported that it was helpful for relieving symptoms with just under 40% reporting them to be unhelpful in this sense (see Table 4.31, over). Just under 70% experienced side effects when taking their drug, however side effects when stopping were less common (31%).

It is worrying that less than four out of ten respondents prescribed a depot antipsychotic rated this form of treatment as helpful after taking both the positive and negative aspects into account. The majority considered them to be unhelpful (43%).

Table 4.31 Depot antipsychotics: Symptom relief, unwanted effects when taking and stopping, and overall evaluation

Depot anti-psychotic	No.	%									
		Helpful for relieving symptoms			Unwanted effects when taking		Unwanted effects when stop*		How helpful overall		
		Helpful	Neither	Not helpful	Yes	No	Yes	No	Helpful	Neither	Not helpful
Flupentixol Deconate	34	54.5	9.1	36.3	73.5	20.6	30.4	60.9	40.0	13.3	36.6
Zuclopenthi-xol Deconate	5	-	25.0	75.0	75.0	25.0	33.0	66.7	20.0	40.0	40.0
Pipotiazine Palmitate	4	75.0	-	25.0	-	75.0	-	-	50.0	25.0	25.0
Total	43	51.3	9.8	39.0	66.7	26.2	30.8	61.5	38.4	17.9	43.3

*6 respondents, 46.2% had stopped taking a drug in this category.

4.2.3.2 What people said about depot antipsychotics

When commenting on symptom relief eight respondents reported that their drug did not help to relieve their symptoms, some of whom felt that they were worse:

> *Did not do a thing for me.* (Pipotiazine Palmitate)
> *I felt that this medication caused a lack in maintaining mood and personal hygiene, and I felt withdrawn when taking it.* (Flupentixol Deconate)

Two respondents reported that they felt that they were 'doped up':

> *Slept 20 hours a day and suicidal for a year.* (Flupentixol Deconate)

Another two felt that their prescription was inappropriate for their circumstances. Five respondents reported that their drug had helped them:

> *It reduced the voices in my head and intrusive thoughts.* (Flupentixol Deconate)

Commenting on unwanted effects when taking a depot antipsychotic six respondents reported extreme tiredness and lethargy, five reported that they had gained a considerable amount of weight, two reported that they felt like zombies:

> *Extreme obesity - I put on nine stone in weight. Over tranquillised, i.e. sleeping all the time, lethargy, etc - could not think, speak, or interact with others. I became almost a zombie…* (Flupentixol Deconate)

Others reported shakes/tremor, visual problems, mood swings, dry mouth, increased saliva, constipation, poor concentration, insomnia and hormonal problems:

> *Huge weight gain, water retention, increased appetite, decrease in motivation and energy and I was lactating the whole time I was on it.* (Flupentixol Deconate)
> *It severely affected my sight; I had very blurred vision. I generally felt unwell too.* (Flupentixol Deconate)

Some reported movement problems:

I walked like a zombie… I could hardly bend my knees, elbows or shoulders. I was then given Procyclidine to combat the effects. (Flupentixol Deconate)
Made me stiff, Parkinson's Disease like symptoms. (Flupentixol Deconate)

When asked about their experiences when they stopped taking their drug, two reported that they had moved onto other drugs which now controlled their symptoms, and three reported a return of symptoms:

I was ill after four months of stopping... (Flupentixol Deconate)

Comments relating to the overall helpfulness of drugs in this category were almost equally divided between positive and negative. Around half of respondents indicated that they had found their drug helpful:

It seems to arrange chemistry in my head i.e. to sort out the imbalance. It would be scarier to come off it. (Flupentixol Deconate)
I found it very helpful as it kept me well. I didn't know about the high prolactin level until it had had a bad effect on me. (Flupentixol Deconate)

While others were less positive:

It created more problems than it solved such that I wished I hadn't asked to see a psychiatrist. (Flupentixol Deconate)
The negatives outweighed the benefits. (Flupentixol Deconate)

Two respondents indicated that they were unable to balance the positive and negative aspects and one reported that another drug had produced better results.

4.2.4 Antipsychotic conclusions

Looking at the symptom relief associated with the most commonly prescribed antipsychotics it is interesting to note that the older typical antipsychotic, Sulpiride, performed best with 84% describing it as helpful for symptom relief. This was followed by the atypical, Olanzapine, at 73%.

Overall there was very little difference between typicals and atypicals for reported symptom relief - atypicals were rated helpful by 68% and typicals by 64%. Depot medication was described as helpful for symptom relief by just over half of respondents (see Table 4.32, over).

Table 4.32 Antipsychotic symptom relief summary

Antipsychotic	Type	Number	Symptom relief	
			Rated helpful	Rated unhelpful
Sulpiride	Typical	25	84.0	8.0
Olanzapine	Atypical	104	73.1	11.6
Clozapine	Atypical	42	71.4	19.0
Quetiapine	Atypical	38	71.1	21.1
Chlorpromazine Hydrochloride	Typical	87	69.0	19.5
All atypicals	**-**	**290**	**68.3**	**19.2**
All typicals	**-**	**211**	**64.4**	**22.7**
Amisulpride	Atypical	34	61.8	23.5
Risperidone	Atypical	70	60.0	28.5
Zuclopenthixol Dihydrochloride	Typical	20	60.0	25.0
Flupentixol Deconate	Depot	33	54.5	36.3
Thioridazine	Typical	17	52.9	17.6
Trifluoperazine	Typical	17	52.9	35.3
Haloperidol	Typical	27	51.8	33.3
All depots	**-**	**41**	**51.3**	**39.0**
All antipsychotics	**-**	**542**	**65.5**	**22.1**

From Table 4.33 (over) you can see that slightly more unwanted effects are reported, on average, for typical drugs compared to atypicals. The two drugs where problems were most commonly reported when taking them were typicals, Haloperidol and Zuclopenthixol Dihydrochloride (both rated as having unwanted effects by over 80%). However, when you look at unwanted effects when stopping an antipsychotic the fewest problems are in fact reported for depot medication. This may in part be due to the higher likelihood that people stopping a depot medication are more likely to be going onto another medication rather than stopping completely, ameliorating discontinuation problems. This may also be due to the fact that depot drugs leave the body very slowly – unlike oral medications.

It is also very interesting to note that more unwanted effects were reported by people stopping an atypical antipsychotic than the older typical drugs. The drugs where most problems were reported on stopping were the atypical, Risperidone and the typical Zuclopenthixol Dihydrochloride. This may be due to the fact that atypicals have a shorter 'half life' (i.e. they leave the body more quickly) and, as a result, have sharper withdrawal effects.

Table 4.33 Antipsychotic unwanted effects summary

Antipsychotic	Type	Unwanted effect			
		When taking		When stopped	
		Number	%	Number	%
Haloperidol	Typical	27	85.2	21	42.9
Zuclopenthixol Dihydrochloride	Typical	21	81.0	13	53.8
Risperidone	Atypical	69	73.9	42	54.8
Flupentixol Deconate	Depot	34	73.5	23	30.4
Clozapine	Atypical	42	71.4	26	46.2
All typicals	**-**	**211**	**70.1**	**160**	**36.8**
Chlorpromazine Hydrochloride	Typical	85	68.2	67	29.9
All depots	**-**	**42**	**66.7**	**26**	**30.8**
All atypicals	**-**	**288**	**66.3**	**190**	**43.7**
Quetiapine	Atypical	37	64.9	27	40.7
Thioridazine	Typical	17	64.7	16	50.0
Olanzapine	Atypical	104	62.5	74	39.2
Sulpiride	Typical	26	61.5	15	40.0
Amisulpride	Atypical	34	58.8	20	35.0
Trifluoperazine	Typical	17	52.9	14	35.7
All antipsychotics	**-**	**541**	**67.8**	**376**	**39.9**

The antipsychotic rated most helpful overall by respondents was the older typical drug, Sulpiride, with four out of five respondents describing it as overall helpful, taking the positives and negatives into account (see Table 4.34, over). It's performance overall compared to the newer atypical, Amisulpride, is interesting given they share a similar chemical structure.

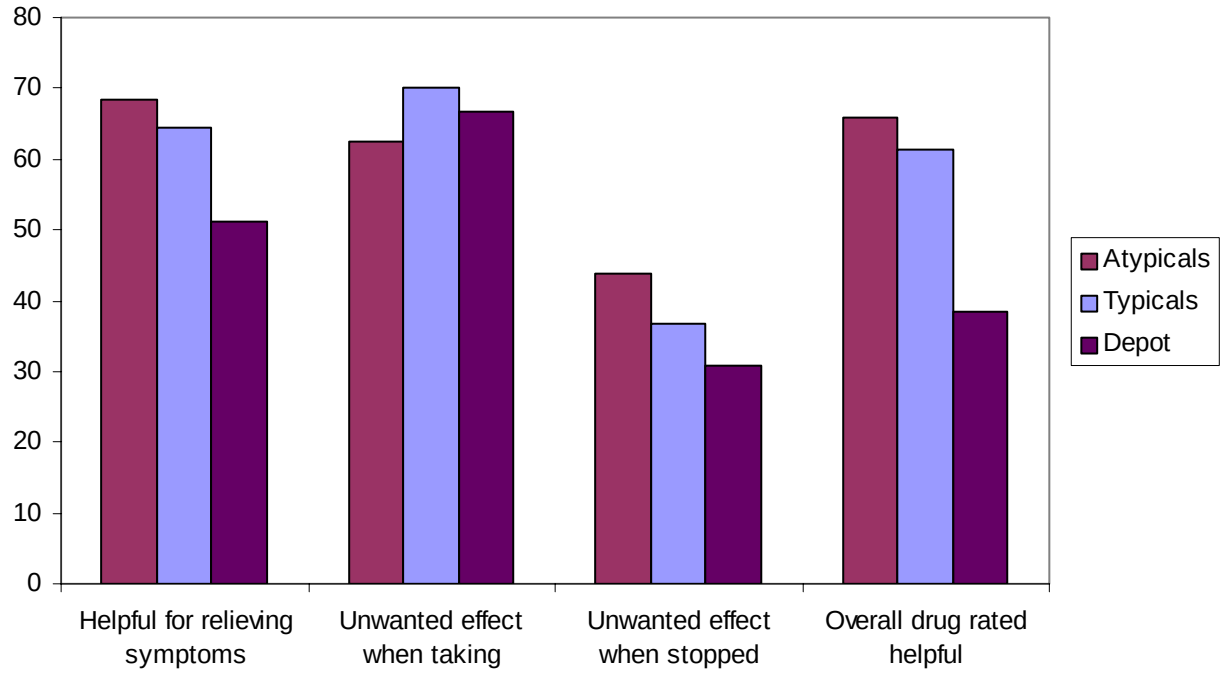
The next three drugs, all atypical antipsychotics (Clozapine, Olanzapine and Quetiapine), were rated overall helpful by between 65 and 73% of respondents.

On average typical and atypical antipsychotics were rated overall helpful by similar proportions of respondents with slightly more favouring atypicals. Depot antipsychotics were rated much less favourably with under 40% rating them as helpful overall.

Table 4.34 Antipsychotic overall helpfulness summary

Antipsychotic	Type	Number	Symptom relief %	
			Rated helpful	Rated unhelpful
Sulpiride	Typical	25	79.1	12.5
Clozapine	Atypical	42	73.2	19.5
Olanzapine	Atypical	104	72.9	14.6
Quetiapine	Atypical	38	65.7	21.0
All atypicals	**-**	**290**	**65.5**	**22.7**
Trifluoperazine	Typical	17	64.7	29.4
All typicals	**-**	**211**	**61.3**	**26.3**
Chlorpromazine Hydrochloride	Typical	87	60.5	24.5
Risperidone	Atypical	70	56.5	33.3
Amisulpride	Atypical	34	55.9	32.3
Zuclopenthixol Dihydrochloride	Typical	20	52.4	38.1
Haloperidol	Typical	27	51.8	33.3
Thioridazine	Typical	17	50.1	25.1
Flupentixol Deconate	Depot	34	40.0	36.6
All depots	**-**	**43**	**38.4**	**43.3**
All antipsychotics	**-**	**544**	**61.9**	**25.6**

Figure 8: Summary comparison of antipsychotics



If we look at the overall picture it is clear that atypicals, as a group, only performed marginally better than the older typicals – and the top performing drug was actually an older typical drug (Sulpiride). Many will not be surprised, however, that we did not find a greater efficacy for the more modern atypicals. Claims for their superiority are usually based on a more benign side effect profile. So how did our survey bear these claims out?

66% of people taking atypicals said that they experienced side effects whilst taking the drug – this compares to 70% of people taking the typical antipsychotics. So here atypicals have a small but insignificant advantage. However when we look at side effects when the drug is stopped 44% of people on atypicals experience these compared to 37% of people on typicals. The overall picture then as reported by respondents to our survey is of little difference between the two classes of drugs.

Of course the severity of side effects may be greater for one of the classes but if this was marked one would have expected this to be reflected in the assessment on overall helpfulness but, as noted earlier, there was only a marginal difference on these scores. What is clear is that unwanted effects differ between the drug types, for example, severe weight gain is more commonly reported with the new atypical drugs, whilst movement problems are more commonly reported for the older drugs. Our finding is that people do not experience unwanted effects from modern drugs as necessarily more benign.

Are these results inconsistent with other research? A systematic overview of research published three years ago in the British Medical Journal concluded that:

"There is no clear evidence that atypical antipsychotics are more effective or are better tolerated than conventional antipsychotics." [13]

The same study noted that: "Most trials compared the effectiveness of atypical antipsychotics with Haloperidol."[14] In other words, atypicals are being compared to the worst performing antipsychotic in our survey.

On the basis of our survey we only found a very slight advantage overall for the new antipsychotic medication. There is sometimes an automatic assumption that the newer drugs are better – but response to drugs is an individual and subjective issue. We need to be cautious about claims about particular drugs or groups of drugs having special benefits.

13 Atypical antipsychotics in the treatment of schizophrenia: systematic overview and meta-regression analysis, Geddes et al, BMJ vol 321 Dec 2000
14 Ibid p1372

4.3 MOOD STABILISERS

Mood stabilisers are used to treat mania and to help prevent the recurrence of mood changes in people who have manic depression (also know as bipolar disorder), and also for some types of recurrent depression. It is unclear exactly how all the mood stabilisers work, but it is understood that they act (perhaps in different ways) to correct an imbalance of brain chemicals.

Key findings

- Almost 80% of respondents considered that mood stabilisers were helpful – taking into account both positive and negative factors – the highest rating for any drug group.
- Over 70% found mood stabilisers helpful for symptom relief, with 30% finding them *very* helpful.
- 64% experienced unwanted effects while taking these drug and just under 40% experienced unwanted effects when trying to stop taking them.
- The most commonly prescribed drug in this group, Lithium Carbonate/Citrate, performed very well on symptom relief – with 36% describing it as *very* helpful and 41% as *fairly* helpful. However, it rated poorly for unwanted effects while being taken, with 73% reporting problems.
- There was a wide variety of unwanted effects while taking mood stabilisers, including weight gain, tremors or shaking, nausea, thyroid problems, impaired memory, lethargy, excessive thirst, and increased anxiety.

This category included five generic drugs, and accounted for 11.2% of all prescriptions. The most frequently prescribed drug was Lithium Carbonate/Citrate, which accounted for 45.3% of prescriptions in this category, followed by Sodium Valproate and Carbamazepine, which accounted for 43.6% of prescriptions between them.

4.3.1 Symptom relief and mood stabilisers

Overall mood stabilisers were rated very positively in terms of symptom relief with over 70% of respondents considering them to be helpful as a group. Lithium Carbonate/Citrate was rated most positively with three quarters of respondents rating it as helpful for symptom relief. Of the most commonly prescribed mood stabilisers, Carbamazepine, had the poorest rating with just over half of respondents finding it helpful and a quarter finding it unhelpful.

Table 4.35 How helpful for symptom relief is mood stabiliser?

Mood stabiliser	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Lithium Carbonate/ Citrate	78	35.9	41.0	9.0	5.1	7.7
Sodium Valproate	44	29.5	36.4	9.1	2.3	11.4
Carbamazepine	29	24.1	31.0	3.4	6.9	17.2
Valproic Acid	10	20.0	70.0	10.0	-	-
Lamotrigine	9	11.1	66.7	11.1	-	-
Total	170	30.0	41.2	14.2	4.1	9.4

4.3.2 What people said about mood stabilisers and symptom relief

18 respondents reported that it had relieved their symptoms to some extent, for some the reported effect had been dramatic:

> *It has dramatically transformed my life. I've had acute depression and hypomania for 37 years. Since taking this drug I've had no recurrence of the illness for 14 months.* (Lithium Carbonate/Citrate)
> *Very helpful in calming mania and in preventing the depression, which follows on from mania. To date, I have not experienced further manic attacks since starting on Lithium.* (Lithium Carbonate/Citrate)

For some the drug had clearly been effective in helping control mood swings:

> *Has helped stop rapid cycling.* (Valproic Acid)
> *Rapid cycling swings are much more controlled and much less devastating. However, I am on a combination of drugs, so it's difficult to separate the effects.* (Lamotrigine)

Others experience was less favourable in this respect:

> *Didn't manage to control my mood swings.* (Lithium Carbonate/Citrate)
> *Takes the edge off things and partially relieves a couple of the symptoms.* (Carbamazepine)

Some found a mood stabiliser to be useful in combination with other drugs or were unable to distinguish the effects of different drugs:

> *This drug in combination with an antidepressant and tranquilliser provides stability for me.* (Carbamazepine)
> *It took at least three months, plus the addition of another drug (Olanzapine) to work.* (Sodium Valproate)

Another group were unsure of the extent to which their drug helped relieve symptoms or felt neutral about its effectiveness:

> *Takes the edge off things and partially relieves a couple of the symptoms.* (Carbamazepine)
> *I really don't know if the drug has any effect. It makes me slightly drowsy.* (Carbamazepine)
> *Still have mood swings although manageable on Lithium.* (Lithium Carbonate/Citrate)

Another group reported that their symptoms had failed to improve, and a further four indicated that early improvements had not been maintained:

> *Didn't stop recurrence of manic and depressive episodes.* (Lithium Carbonate/Citrate)
> *It had no effect whatsoever - the CPN and psychiatrist could not even agree on the dose, so I stopped taking it.* (Sodium Valproate)

Others indicated that they actually felt worse as a result of taking the drug:

> *It gave no symptom relief. I was very low when I started and became so low on it I was suicidal, comatose and out of contact with reality.* (Sodium Valproate)

4.3.3 Unwanted effects when taking mood stabilisers

64% of people reported unwanted effects when taking a mood stabiliser. Most problems were reported for the most commonly prescribed drug, Lithium Carbonate/Citrate, with almost three quarters of respondents reporting problems.

Table 4.36 Unwanted effects when taking a mood stabiliser?

Mood stabiliser	Number	%		
		Yes	No	Not sure
Lithium Carbonate/Citrate	78	73.1	17.9	9.0
Sodium Valproate	43	53.5	32.6	14.0
Carbamazepine	30	63.3	26.7	10.0
Valproic Acid	10	40.0	30.0	30.0
Lamotrigine	9	66.7	33.3	-
Total	170	64.1	24.7	11.2

4.3.4 What people said about unwanted effects when taking a mood stabiliser

The unwanted effects most frequently mentioned were weight gain and tremors or shaking:

> *I pile on weight. I have a permanent tremor and often have double vision.* (Lithium Carbonate/Citrate)
> *Weight gain, (four stones)…* (Lithium Carbonate/Citrate)
> *…it caused spontaneous muscle twitches, which resulted in falls. Also caused tremors.* (Lithium Carbonate/Citrate)

The variety and, in some cases, severity of unwanted effects was noteworthy:

> *Severe rare reaction, hospitalised for ten days, bone marrow affected liver damage for two months, skin damage for three to four weeks all made more severe due to staff not spotting the growing number of obvious side effects and reaction built up to severe levels.* (Carbamazepine)

Horrendous side effects were not recognised as such - I was violently sick for a week as a result of the levels in my blood being too high, this was ignored by the nursing staff and the doctors until one junior doctor made the connection. Unforgivable, at one point I truly thought I might die, I was so ill no one cared. (Lithium Carbonate/Citrate)

A number of respondents commented on thyroid problems caused by Lithium Carbonate/Citrate:

It affected my thyroid, severe weight gain, thought processes slowed down. (Lithium Carbonate/Citrate)
Affected my thyroid gland and now have to take Thyroxine. Excessive urination. Tremor. Visual disturbance. Irritable Bowel Syndrome. Sense of unreality. Lethargy. Memory problems. (Lithium Carbonate/Citrate)

Some respondents reported poor concentration and impaired memory:

Difficulties with memory, cognitive processing, and concentration... (Sodium Valproate)
… memory problems making work difficult, problems with driving, general physical anxiety and tension. (Lithium Carbonate/Citrate)

Other difficulties included feelings of exhaustion and lethargy and lack of motivation, nausea, extreme thirst and urination, flattened emotions and lack of motivation, skin problems, dizziness, visual problems, damage to thyroid, irritable bowel, headaches, lack of co-ordination, increased anxiety, and hair loss:

It affected my thyroid… severe weight gain… thought processes slowed down. (Lithium Carbonate/Citrate)
Flattened, dull life experience, no motivation, unable to act as I might, sex problems, thirst, tremors. (Carbamazepine)
It's damaging my liver, making me nauseous and giving me blurred vision, but at least I'm not mad! (Carbamazepine)
Going to the toilet often, drinking all the time, dry mouth. (Lithium Carbonate/Citrate)
Horrific acne, impaired mental functioning and concentration, bad co-ordination…Wrong choice for someone with low self-esteem who bases her entire self-worth on her intelligence. (Lithium Carbonate/Citrate)

4.3.5 Unwanted effects when stopping mood stabilisers

Six out of ten respondents in this group had at some point stopped taking a mood stabilising drug. Just under 40% of them reported unwanted effects on stopping. Most problems were reported for Lithium Carbonate/Citrate (46%) and fewest for Sodium Valproate (17%).

Table 4.37 Unwanted effects when stopping a mood stabiliser?

Mood stabiliser	Number stopped	%		
		Yes	No	Not sure
Lithium Carbonate/Citrate	50	46.0	36.0	18.0
Sodium Valproate	24	16.7	66.7	16.7
Carbamazepine	20	35.0	45.0	20.0
Valproic Acid	4	50.0	50.0	-
Lamotrigine	4	75.0	25.0	-
Total	102	38.2	45.1	16.7

4.3.6 What people said about unwanted effects when stopping a mood stabiliser

The majority of unwanted effects on stopping a mood stabiliser related to return of symptoms:

> *Yes I became manic and had to be hospitalised.* (Lithium Carbonate/Citrate)
> *… became manic very quickly so had to go on original dose.* (Lithium Carbonate/Citrate)

Six respondents became very depressed, five reported that all their original symptoms returned, two experienced increased mood swings, and four reported feeling agitated and restless:

> *Made me extremely irritable and caused 'crazy' mood swings - high and low.* (Lithium Carbonate/Citrate)

Other unwanted effects on stopping, which did not relate to return of symptoms, included feeling generally unwell, headaches, nausea and problems with coordination:

> *Suffered from nausea, tension headaches, unable to sleep, agitation/restlessness.* (Carbamazepine)
> *Nightmare, no co-ordination, falling down etc.* (Carbamazepine)

Two respondents reported that they felt much better when they stopped taking their drug:

> *It was a relief to be off it. I withdrew from it slowly as I know that, however bad a drug is, you cannot come off it quickly.* (Sodium Valproate)

4.3.7 Overall evaluation of mood stabilisers

Almost 80% of respondents said they considered mood stabilisers to be helpful taking both the positives and negatives into account. Of the most commonly prescribed mood stabilisers Lithium Carbonate/Citrate was rated as most helpful overall (just under three quarters of respondents found it to be helpful). Carbamazepine was rated least favourably overall with a quarter of respondents considering it to be *very* unhelpful overall.

Table 4.38 Overall how helpful was mood stabiliser?

Mood stabiliser	Number	How helpful %				
		Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Lithium Carbonate/ Citrate	77	36.4	36.4	5.2	5.2	11.7
Sodium Valproate	44	36.4	29.5	9.1	9.1	20.5
Carbamazepine	28	35.7	17.9	10.7	-	25.0
Valproic Acid	9	33.3	55.6	-	-	-
Lamotrigine	9	22.2	55.6	11.1	-	11.1
Total	167	35.3	33.5	7.2	2.4	14.4

4.3.8 What people said about their overall evaluation of mood stabilisers

For some respondents the reported benefits of a drug had been dramatic:

I have been on a lot of different drugs at different times and I feel this one is heaven-sent. (Lithium Carbonate/Citrate)

Others highlighted the importance of gaining control and stability in their lives and felt that the drug had helped them achieve this:

It stabilised my mood… I could think more clearly and be in more control, and made things less frightening. (Carbamazepine)
My mood and anxiety is much more stable, and I find this easier to cope with. (Sodium Valproate)
It has helped me maintain some stability, enough to do some day-to-day tasks. (Carbamazepine)

One group of respondents felt that they *had* to keep taking their medication and it was therefore a question of balancing the positive and negative:

I hate taking it. It puts me out of control, but does seem to work. (Lithium Carbonate/Citrate)
I don't like taking this drug but I don't have any choice as I know that I need it to protect myself from a manic episode and being hospitalised, which is very frightening. (Lithium Carbonate/Citrate)
I think this drug had the most effect on my illness, even though it possibly has the most side effects. (Lithium Carbonate/Citrate)

However, another group reported that their drug had not helped at all and in some cases had in fact made things worse:

It suppressed my life for four years and incapacitated me. (Carbamazepine)
This drug made me a lot worse. I don't expect psychiatric drugs to make me more psychotic than I already am. (Sodium Valproate)
There was no relief of symptoms. It did not work at all and I became suicidal. I should never have been given it all. (Sodium Valproate)

Some people were simply unclear as to the beneficial effect of a drug:

Very helpful after and during a manic attack. Unsure of exact effect now (two years after I started taking it), since I had previously been symptom-free between manic attacks for eight years, and two and a half years respectively. (Lithium Carbonate/Citrate)

One group mentioned the importance of non-drug treatments:

…No other drug was offered. I asked for CBT, but I was told this wasn't suitable for sufferers of manic depression. (Lithium Carbonate/Citrate)
Immediately I commenced self-management in 1998 I began to improve. (Lithium Carbonate/Citrate)

4.4 ANXIOLYTICS

Anxiolytics are primarily prescribed for anxiety problems but in some instances they are also used to help alleviate the side effects of other drugs, in treating addictions and in the treatment of some physical health complaints. These drugs are sometimes referred to as minor tranquillisers.

Four of the five anxiolytics included in our survey were of the benzodiazepine class. These drugs have been controversial since the 1980s when widespread problems came to light with dependency at a time when they were widely prescribed for both anxiety and depression.

In 1988 the Committee on the Safety of Medicines recommended that benzodiazepines should not be prescribed for more than four weeks and should not be used to treat depression.

Key findings

- Anxiolytics were rated as helpful overall by three quarters of respondents.
- Anxiolytics were seen as being helpful for symptom relief by just over 70% of people.
- Unwanted effects were reported by just over a third of respondents while taking and, perhaps surprisingly, just a quarter on stopping.
- The most commonly reported unwanted effect was feeling drowsy or out of control. Withdrawal problems were reported on stopping.

Benzodiazepines work by boosting the neurotransmitter GABA. Busiprone, the one non-benzodiazepine in this group, is thought to act at serotonin receptors.

It is perhaps worth noting that these drugs are also abused and bought as recreational drugs for their effects – unlike other classes of psychiatric drugs.

4.4.1 Symptom relief, unwanted effects when taking and stopping, and overall evaluation of anxiolytics

One drug, Diazepam, accounted for two-thirds of the prescriptions in this category. Overall seven out of ten respondents prescribed an anxiolytic reported that it helped to relieve their symptoms and just over a third experienced unwanted effects when taking their drug.

It is perhaps surprising, given the controversy surrounding benzodiazepines, that just a quarter of respondents recorded unwanted effects on stopping an anxiolytic. Taking account of both positive and negative aspects, just over three-quarters of respondents prescribed a drug in this category reported that it had been helpful.

82% of respondents prescribed Diazepam reported that overall it had helped them. This was a higher proportion than amongst those prescribed Busiprone Hydrochloride (50%) or Lorazepam (29%), both of which were associated with a higher proportion of side effects when taking them. However, these figures should be treated with caution given the sample size is so small.

Table 4.39 Anxiolytics: Symptom relief, unwanted effects when taking and stopping, and overall evaluation

Anxiolytic	No.	%									
		Helpful for relieving symptoms			Unwanted effects when taking		Unwanted effects when stop*		How helpful overall		
		Helpful	Neither	Not helpful	Yes	No	Yes	No	Helpful	Neither	Not helpful
Diazepam	39	82.0	12.8	5.1	31.6	60.5	24.2	66.7	81.6	10.5	7.9
Busiprone Hydrochlo-ride	8	50.0	12.5	37.5	50.0	37.5	-	40.0	62.5	25.0	12.5
Lorazepam	7	28.6	14.3	42.9	42.9	-	40.0	60.0	42.9	-	57.2
Chlordiaze-poxide	4	75.0	25.0	-	25.0	75.0	-	100.0	100.0	-	-
Clorazepate Dipotassium	1	100.0	-	-	-	100.0	100.0	-	100.0	-	-
Total	59	71.2	13.6	13.6	34.5	51.7	24.4	62.2	75.9	10.3	13.8

*45 respondents, 76.3% had stopped taking a drug in this category.

4.4.2 What people said about anxiolytics

In terms of symptom relief the biggest group of respondents reported that their drug helped to keep them calm and relieved feelings of anxiety:

> *It was very useful during my worst periods of depression to control high levels of anxiety.* (Diazepam)
> *It calms my nerves and helps me to face things.* (Diazepam)

In some instances they were helpful to prevent or alleviate panic attacks with respondents commenting on how quickly they were effective:

> *When taking panic attacks, this can calm me down within half an hour.* (Chlordiazepoxide)
> *Valium is the most 'instant relief of tension' tablet I have ever known.* (Diazepam)

Some respondents indicated that they could take their medication as required allowing a sense of control:

> *This can be taken on occasion - rather than as a course - which usually relaxes a person, and there is a certain choice as to when you take them.* (Diazepam)

However, two respondents reported that they no longer experienced symptom relief, two reported no difference at all, and two reported feeling worse as a result of taking the drug:

> *It was initially very good but now the effect is wearing off.* (Diazepam)
> *Found this drug to be ineffective.* (Busiprone)

The most commonly reported problem when taking a drug in this category was tiredness. Despite sleeping a great deal some respondents reported that they were still tired. Four respondents felt that they were not in control of their actions:

> *It quietened me down, but it made me sleep a lot and I was not in control of my actions - very scary.* (Diazepam)
> *Sleep a lot but do not feel I have had a good sleep.* (Lorazepam)

Other unwanted effects included dizziness, nausea, bruising easily, problems with appetite and speech problems:

> *Difficulty in speaking, especially in higher dosages, but now addressed fully by Orphenadrine. Also some tiredness…* (Diazepam)
> *I spent most of the eight weeks I took this drug either vomiting or sleeping! I was covered in bruises and couldn't continue to function. I didn't eat a lot during this time.* (Diazepam)

Some commented specifically on issues around addiction:

> *I was very unhappy about taking this drug due to its reputation for being addictive.* (Lorazepam)

For some stopping and starting an anxiolytic presented no problem:

> *I am on and off the tablets without side effects (apart from a good night's sleep). (*Busiprone)

Reported difficulties included shaking and disorientation:

> *Shaking occurred due to withdrawal, even for a short period (one day). Scary as if the whole house was shaking.* (Diazepam)
> *…I was drowsy, dizzy, and disorientated with them. I had an attack every half an hour. It was very frightening. I couldn't even make a cup of tea.* (Diazepam)

In some cases usage was clearly long term:

> *…I have been taking them now for 31 years…and I would never want to come off them.* (Diazepam)

Comments on overall helpfulness taking the positives and negatives into account included:

> *In collaboration with the other drugs it has been very helpful.* (Diazepam)
> *It works. I am not taking them because I am addicted to them. Ideally, I look forward to the day I come off them - even with the withdrawals. I sometimes still grit my teeth, but have been told that any drug can cause neuralgic problems for me now.* (Diazepam)

A number of respondents drew attention to the difficulty of stopping their drug, and indicated that they were wary of addiction. However, one respondent indicated that for her the benefits outweighed the potential problems, although it appeared to be a choice between bad and very bad:

> *Would not like to come off them… I have little quality of life with them. Without them it would be very poor quality, I still get extremely nervous and in a panic.* (Diazepam)
> *Diazepam has to be reduced very, very slowly and this time I will get it correct…* (Diazepam)

Attention was again drawn to the fact that the drugs were quick acting and that they could be taken as required:

> *Diazepam gives me instant relaxation but I want to get better without taking too much…* (Diazepam)
> *Helps me cope with the wobbly days. I don't take them all the time, only when required.* (Diazepam)

4.5 HYPNOTICS

Hypnotic drugs are also known as sleeping tablets and are very similar to anxiolytics in structure and effect: "Most anxiolytics ('sedatives') will induce sleep when given at night and most hypnotics will sedate when given during the day."[15]

Similar issues exist around withdrawal as seen with anxiolytic and it is recommended that wherever possible prescription should be for a short period.

Key findings

- Hypnotics were rated as helpful overall by 78% of respondents – a high rating.
- Hypnotics were the best rated drug group for symptom relief – 87% rating them helpful.
- Unwanted effects were reported by just under 40% while taking, and over 60% when trying to stop.
- The most commonly reported unwanted effect when taking a hypnotic was feeling drowsy. People reported experiencing sleep problems when they tried to stop taking them.

The main diagnostic categories for people prescribed hypnotics were depression, anxiety disorder, manic depression, and/or personality disorder.

15 British National Formulary 46, Bmjp/Pharm'l Press, September 2003

4.5.1 Symptom relief, unwanted effects when taking and stopping, and overall evaluation of hypnotics

Inspection of the following table reveals that half the prescriptions in this category were for Zopiclone, the other drugs only being prescribed to a handful of participants in this study. The low number of hypnotic prescriptions means that these figures should be treated with some caution.

The proportion of respondents reporting that their drug relieved their symptoms was high, more than eight out of ten. Three out of four respondents prescribed Zolpidem Tartrate reported unwanted effects when taking their drug, however, less than a third of respondents prescribed Zopiclone, Temazepam or Nitrazepam reported unwanted effects.

Unwanted effects when stopping a drug were reported by a higher proportion of respondents - more than three-quarters of those prescribed Temazepam, Zolpidem Tartrate, Nitrazepam, or Loprazolam. However, only a third of those prescribed Zopiclone, the most frequently prescribed drug, experienced withdrawal symptoms.

Overall evaluations, taking into account both the positive and negative aspects of these drugs indicated that more than three-quarters of respondents prescribed a hypnotic drug felt that they had been beneficial.

Table 4.40 Hypnotics: Symptom relief, unwanted effects when taking and stopping, and overall evaluation

Hypnotic	No.	%									
		Helpful for relieving symptoms			Unwanted effects when taking		Unwanted effects when stop*		How helpful overall		
		Helpful	Neither	Not helpful	Yes	No	Yes	No	Helpful	Neither	Not helpful
Zopiclone	12	83.3	8.3	8.3	27.3	72.7	33.3	66.7	81.8	27.3	9.1
Temazepam	4	75.0	-	25.0	25.0	75.0	100.0	-	75.0	25.0	-
Zolpidem Tartrate	4	100.0	-	-	75.0	25.0	75.0	25.0	75.0	25.0	-
Nitrazepam	3	100.0	-	-	33.3	-	100.0	-	66.7	-	-
Loprazolam	1	100.0	-	-	100.0	-	100.0	-	100.0	-	-
Total	24	86.9	4.3	8.7	39.1	52.2	63.2	36.8	78.3	43.5	8.6

*19 respondents, 72.9% had stopped taking a drug in this category.

4.5.2 What people said about hypnotics

Seven respondents reported that their drug enabled them to sleep well:

> *It was to help me sleep and I found it extremely effective.* (Temazepam)

However, some respondents indicated that although their drug had been helpful at first, the benefits had been short-lived:

> *Helpful at first…Once in my system, I feel they are not very helpful.* (Zolpidem Tartrate)

Commenting on unwanted effects eight respondents reported that their drug made them drowsy and that this lasted into the following day:

It leaves you feeling drowsy the next day. (Zolpidem Tartrate)
Felt drowsy the following day and could never wake up on the a.m. (Nitrazepam)

Two respondents reported having a dry mouth or 'bad' taste in their mouths and one reported perceptual changes:

I had perceptual changes - either positive or negative - depending on my mood when I took them. This only happens when I can't sleep after taking them. (Zolpidem Tartrate)
Bad taste in my mouth. (Zopiclone)

On stopping 11 respondents reported being unable to sleep and two reported feeling agitated:

Lost its affects and I could not sleep again and felt agitated. (Nitrazepam)

One respondent in considering the overall helpfulness of hypnotics reported having extreme difficulty stopping her drug, and suggested that other methods of support would have been preferable:

Was terrible coming off it, I was dependant on it. Would have preferred non-drug approaches to alleviating my sleeping problems instead of stuffing me full of addictive medicines. (Nitrazepam)

5 COMPARISON OF DRUG GROUPS

The following tables summarise findings by drug group. It should be noted that there can be considerable variation between different drugs within the same group and that different types of drug are prescribed for varying reasons. Also sample sizes between drug groups vary considerably.

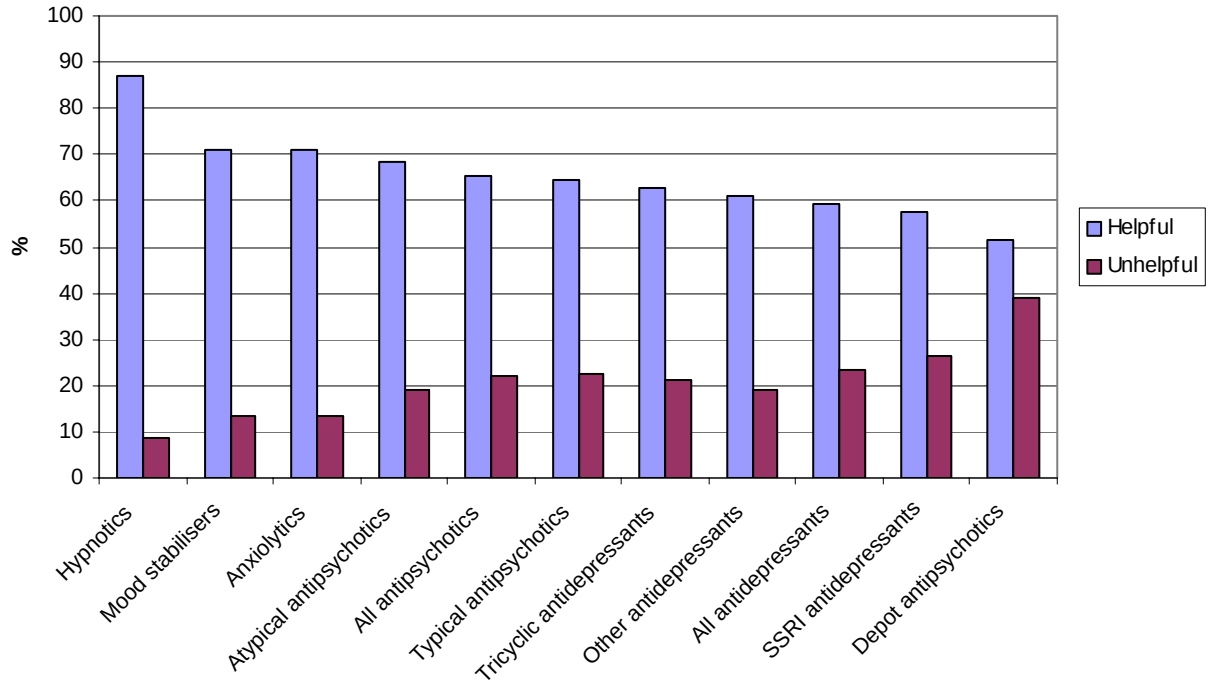
Hypnotics were rated helpful for symptom relief by the highest proportion of respondents (though the sample size was very small) followed by mood stabilisers and anxiolytics (both 71%). Antidepressants rated badly, in comparison, with the most commonly prescribed type, SSRIs, rated as helpful by just 57%. The group with the poorest rating was depot antipsychotic.

On average for all drug groups drugs were rated helpful by over 60% of respondents and unhelpful by one in five.

Table 5.1 Symptom relief summary: Drug group

Drug group	Symptom relief		
	Number	Rated helpful	Rated unhelpful
Hypnotics	23	86.9	8.7
Mood stabilisers	170	71.2	13.5
Anxiolytics	59	71.2	13.6
Atypical antipsychotics	290	68.3	19.2
All antipsychotics	542	65.5	22.1
Typical antipsychotics	211	64.4	22.7
Tricyclic or related antidepressants	142	62.7	21.2
Other antidepressants	203	61.1	19.2
All antidepressants	727	59.4	23.3
SSRI antidepressants	369	57.5	26.3
MAOI antidepressants	13	53.8	23.1
Depot antipsychotics	41	51.3	39.0
All drug groups	**1521**	**63.9**	**21.2**

Figure 9: Symptom relief summary: Drug group



From Table 5.2 (over) we can see that most unwanted effects while taking a drug were recorded for antipsychotic drugs with between 66% (atypicals antipsychotics) and 70% (typical antipsychotics) of respondents recording issues. The drugs rated most positively were anxiolytics (35%) and hypnotics (39%).

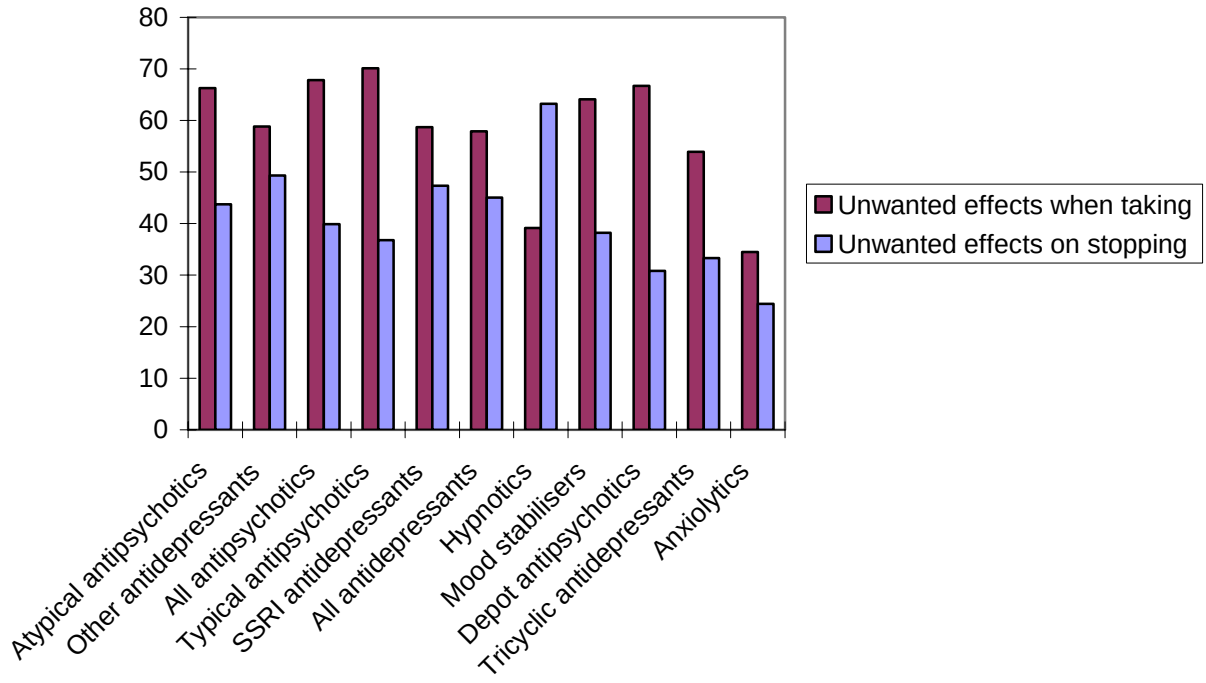
Reported levels of unwanted effects while taking a drug did not necessarily predicate a similar rating for unwanted effects when stopping. For example over 60% of people who stopped a hypnotic reported problems despite the fact that relatively few problems were reported by people when taking the drug. Similarly typical antipsychotics that had the poorest rating for unwanted effects whilst being taken, had a below average rating for unwanted effects when stopped.

By taking an average figure for unwanted effects while taking and stopping a drug it is interesting to note that the worst performing group was the newer atypical antipsychotics. The best performing drugs were the longer established, but less favoured, tricyclic or related antidepressants, MAOI antidepressants (though the sample was small) and anxiolytics.

Table 5.2 Unwanted effects summary: Drug group

Drug group	Unwanted effects				Average
	When taking		When stopped		
	Number	%	Number	%	
Atypical antipsychotics	288	66.3	190	43.7	55.0
Other antidepressants	204	58.8	136	49.3	54.1
All antipsychotics	541	67.8	376	39.9	53.9
Typical antipsychotics	211	70.1	160	36.8	53.5
SSRI antidepressants	370	58.7	275	47.3	53.0
All antidepressants	728	57.9	516	45.0	51.5
Hypnotics	23	39.1	19	63.2	51.2
Mood stabilisers	170	64.1	102	38.2	51.2
Depot antipsychotics	42	66.7	26	30.8	48.8
Tricyclic or related antidepressants	141	53.9	99	33.3	43.6
MAOI antidepressants	13	61.5	6	16.7	39.1
Anxiolytics	58	34.5	45	24.4	29.5
All drug groups	**1520**	**60.9**	**1058**	**41.9**	**51.4**

Figure 10: Unwanted effects summary: Drug group

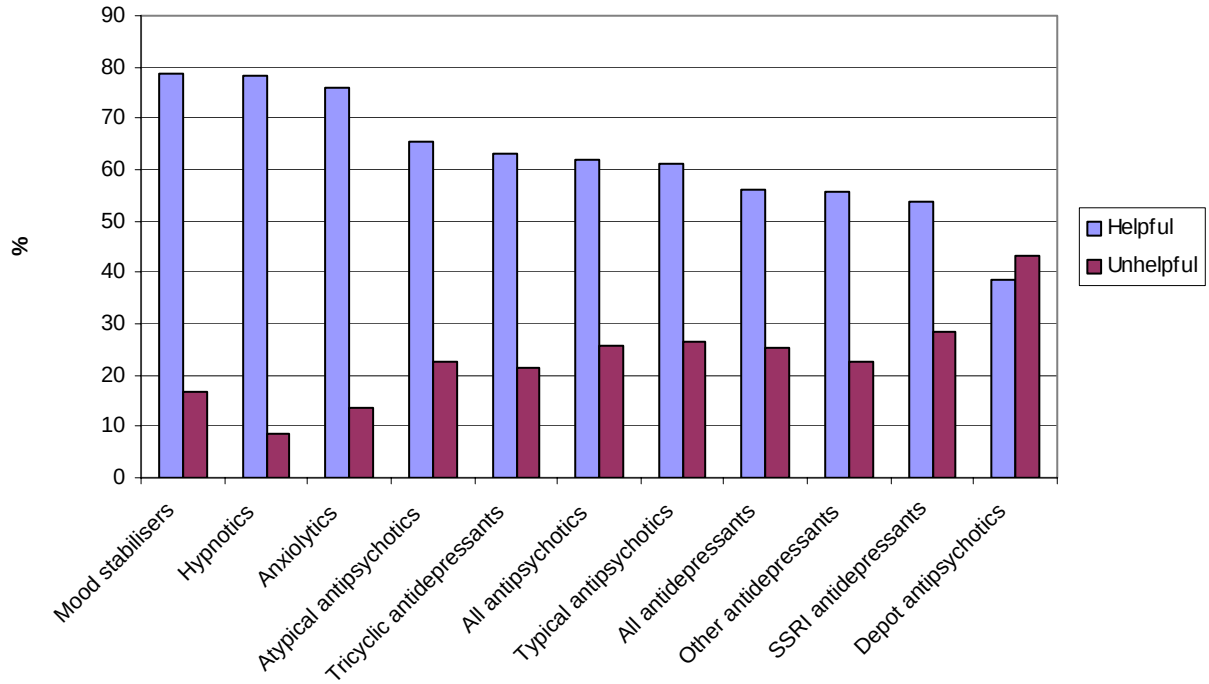


The drug group rated as most helpful overall, taking the positive and negatives into account, was mood stabilisers, rated helpful by just under 80% of respondents, closely followed by hypnotics (though again the sample size was very small). SSRI antidepressants, the most commonly prescribed drug group in this survey and nationally, performed badly with just over half of respondents rating them as helpful overall. The only group rated more poorly were depot antipsychotics (see Table 5.3, over).

Table 5.3 Overall helpfulness summary: Drug group

Drug group	Overall		
	Number	Rated helpful	Rated unhelpful
Mood stabilisers	167	78.8	16.8
Hypnotics	23	78.3	8.6
Anxiolytics	58	75.9	13.8
Atypical antipsychotics	287	65.5	22.7
Tricyclic or related antidepressants	141	63.1	21.3
All antipsychotics	535	61.9	25.6
Typical antipsychotics	209	61.3	26.3
All antidepressants	722	56.2	25.2
Other antidepressants	204	55.9	22.6
MAOI antidepressants	13	53.8	23.1
SSRI antidepressants	364	53.8	28.5
Depot antipsychotics	39	38.4	43.3
All drug groups	**1505**	**60.8**	**23.5**

Figure 11: Overall helpfulness summary: Drug group



6. CONCLUSION

Quite often, surveys of this kind are held to be unrepresentative because it is suspected that people with negative views are more likely to participate. However, in this survey, over half of respondents told us they found their drugs helpful overall, and for some drugs this figure climbed to nearly 80%. At the same time we found that many people experienced unwanted effects. We are very pleased that we did manage to get a broad sample of opinion.

It is clear from our survey that people's experience of individual drugs can vary wildly and that finding the right drug can be largely a question of trial and error. Psychiatry (including psychopharmacology) is a practical and theoretical discipline and not an exact science. It is not clear, for example, why certain treatments are effective. This and the fact that psychiatric drugs target mood and behaviour, and affect the conscious mind, means that their effects on individuals are more unpredictable than most of their counterparts for physical illness. It is also clear from our research that many of the people surveyed experienced debilitating, and often severe, unwanted effects as a result of taking or stopping a drug.

For these reasons it is vitally important that service users enjoy an open relationship with the person responsible for making the prescription. They should be treated as equal and complementary partners in the prescription process whereever possible. Findings from part one of this report show that this is often not the case.

Without access to information the value of psychiatric drugs is severely limited. This was summed up by an Executive of leading psychiatric drugs manufacturer Eli Lilly:

"It is always worth remembering that a medicine is a chemical plus information – when to take, with what, what to avoid, what to expect etc. Without the information the chemical is not a medicine and is at best useless and at worst dangerous."[16]

In considering the prescription experience a third of respondents in our survey reported that there had been no discussion of the drug being prescribed. A similar proportion of respondents said that they did not feel able to ask questions of the person making the prescription.

It is, of course, important to bear in mind that in some situations service users may feel too unwell to take a full part in the decision making process and may be quite happy to leave decisions to professionals. However, throughout the report there is a fairly consistent group of about 25% who are clearly unhappy with the prescription process and/or the effect of their drug.

Service users are often highly knowledgeable about psychiatric drugs but we came across numerous examples where opinion seemed to be unreasonably discounted. The fact that a third of those who disagreed with their doctor were very unhappy with the extent to which their opinion was considered suggests that there is a lot of room for improvement. Because someone may be unwell at the point of prescription does not mean that they do not have a legitimate opinion and valuable personal experience to call upon when it comes to decisions around drugs.

As a membership and information organisation we often hear stories of inconsistent and variable practice between different health professionals and this report confirms our anecdotal experience. For some respondents issues around drugs were clearly discussed in an open and honest manner and decisions reached collaboratively. For others the reverse was clearly true – too often it was clear that professionals did not value or invite the service users opinion. We have no doubt that an essential component of any successful treatment is the quality relationship between the person providing the treatment and the person receiving it.

16 Stephen Whitehead, former Corporate Affairs Director for Eli Lilly Europe, quoted in Pharmaceutical Marketing, February 2000

One of the more interesting findings, in relation to respondents experience of different drugs, is that the newer antidepressants and antipsychotics, although more expensive, either do not do better overall than the older drugs, or at best only perform marginally better.

Sexual problems are commonly reported in our survey – but people find it difficult to talk about these, and even if the subject is raised, people's concerns can be dismissed or trivialised.

Many people also complained that they were not told in advance about the risk of unwanted effects or the nature and severity that these can have. Similarly people were not told about potential problems with stopping. This is a serious problem given the severity of some reported unwanted effects. Without proper knowledge of the risks as well as anticipated benefits it is not possible to say that informed consent is being given when drugs are being prescribed.

Depot antipsychotics did particularly badly - they were the only group of drugs for which overall negative views were higher than overall positive views.

One of the most noticeable aspects of this research was, given the frequency of negative and unwanted effects, how positively many drugs were rated. There seemed to be no clear correlation between unwanted effects and helpfulness – some of the drugs rated most positively overall had some of the poorest ratings in terms of unwanted effects (for example Lithium Carbonate/Citrate). Similarly respondents frequently followed positve ratings on individual drugs, on, for example, how helpful a drug was for symptom relief, with very negative comments, when prompted to elaborate on their experience.

The message seems to be that respondents, in the main, value psychiatric drugs and see them as an important part of their treatment. Equally clear though, is that respondents had very serious concerns, both about the the extent to which they were involved in the prescription process and about negative or unwanted effects. These findings are perhaps confirmed by a recent survey that found that the number one priority for a large sample of service users was 'medication with less adverse side effects.'[17]

From comments it was clear that some respondents appeared to be scared of the consequences of stopping, or reducing the dosage of, their drugs. It was also clear that many people had been taking one or a range of different drugs over a very long period of time. Both of these points raise concerns, expressed by SAMH in the past, about the extent to which some service users appear, to some extent, to be 'maintained' through the use of drugs at an 'acceptable' level of health with insufficient regard for a 'plan of recovery.'

Our research shows that because a drug type is newer, or currently favoured, does not necessarily mean that it will be preferred by service users. This is perhaps most clearly demonstrated by the fact that newer SSRI type antidepressants rated more poorly than older, cheaper, tricyclic or tricyclic related drugs, on all measures. Similarly we found little difference between ratings for newer atypical antipsychotics and older typical antipsychotics. We also found very high approval ratings for anxiolytics and hypnotics - drugs considered to be problematic, whose prescription is discouraged.

In line with wider SAMH policy on ensuring access to a range of appropriate treatments and services we believe that people should also have access to a range of drugs and be allowed to play an active part in deciding which drugs are best suited to them and how they are used.

We are very concerned that SSRI antidepressants rated so poorly in our survey, particularly given the massive increase seen recently in their prescription in Scotland. Prescriptions have

17 Just one per cent: The experiences of people using mental health services, Rethink, 2003

increased by just under 80% in the last five years and concerns have been widely reported that, in some circumstances, these drugs may be inappropriately prescribed where people present to their GP with symptoms of mild depression, possibly related to stressful life events.

The fact that 28% of survey respondents described SSRIs as unhelpful overall is concerning. We are also concerned by the reported frequency and severity of some unwanted effects. A sizeable minority experienced severe problems both when taking and stopping SSRIs. These included reports of suicidal and self-harming behaviour, bouts of rage, 'psychotic' feelings and anxiety.

Our research has given a fascinating view of issues around prescription and drug performance. We hope that this report will be a spur for further investigation and research, particularly approaches that are based on user's own experiences of psychiatric treatments and services.

We strongly believe that an open and honest relationship between the person making the prescription and the service user can only lead to improved treatment outcomes and enhance the prospects of recovery. We hope that this report contributes towards that understanding.

7. RECOMMENDATIONS

1. Given the current lack of faith in much of the research evidence for drugs, because so much research is controlled and funded by the pharmaceutical industry, the Government should consider establishing an independent body to perform clinical trials. Fees from pharmaceutical companies would fund this new body. Payment of a fee to cover the cost of research would be a precondition for obtaining a licence to market a drug. The advantage of this approach would be that the industry would still finance the tests, but the tests would be seen as much more objective and neutral. This additional rigour and credibility would benefit both consumers and producers.

2. Although the need would continue for traditional RCTs in 'controlled' conditions to establish 'efficacy', there is also a need for RCTs in more naturalistic settings with ordinary, less carefully selected populations of patients. These so called 'effectiveness' studies would provide better information on how these drugs performed in normal situations.

3. There needs to be improved mechanisms for direct reporting of unwanted effects. The Yellow Card system is discredited and should be replaced with a system of reports to an independent monitor. Results of the direct reporting pilot, being run in some English regions through NHS Direct, must be carefully considered. Whatever the outcome of that pilot it is important that thought be given to how to ensure health professionals take account of direct reports of unwanted effects.

4. Given the negative results for depots antipsychotics, (they were the only drug group to have an overall negative rating) consideration should be given to creating greater legal protections around their use and the option of using other methods of delivery should be kept under continual review in all cases.

5. People need to be able to access a wide range of drugs – no drug effects appear to be uniform. Budgetary considerations should not prevent people accessing the drugs that they find most helpful.

6. Whilst our survey shows that in many cases people do feel that doctors listen and decision making is joint, there are also many cases where people are unhappy and feel excluded. Without full information on risks as well as benefits people are being given treatment without informed consent. This issue needs to be addressed specifically in both training and in the setting and monitoring of clinical standards. It may also benefit from further research.

7. Drugs regarded as problematic may still be helpful, for example, anxiolytics. Provided people are making an informed choice, and the risk of addiction is guarded against, they should not be prevented from accessing drugs that also carry risks.

8. We recommend the introduction of good practice guidelines on the prescription of psychiatric drugs. These guidelines should ensure that, every time a new or different psychiatric drug is prescribed, there is a full and frank discussion on all relevant aspects of the drug, and its part in a wider treatment plan, to ensure that informed consent is given by the service user. This would include discussion of:

    a. How long someone might need to wait for the drug to take effect and how long they may need to take it.
    b. What unwanted effects they might experience with a realistic and honest discussion of how common unwanted effects are and potential severity.

c. How easy or difficult it would be to withdraw from, or reduce the dosage of, the drug.
d. A plan for timely review of the drugs effectiveness, unwanted effects and appropriate dosage.
e. What to do if the service user has concerns about any aspect of their drug treatment, including effectiveness, unwanted effects and issues around withdrawal.
f. What support would be available at withdrawal.
g. What impact the drug could have on other aspects of their lives, for example, ability to drive or maintain employment.

These guidelines should be developed in collaboration with service users and complemented by user-led training for prescribing doctors, aimed at raising awareness of the users experience and the importance of proper consultation and involvement in decisions around drugs. We realise that is in some cases this practice is being followed but we are worried that existing information provision around drugs is often inadequate, (for example, discussion around how long someone might need to take a drug) or inappropriate (for example, the daunting, and often ignored, Patient Information Leaflet).

9. We recommend further research into the following topics:

a. The impact of long-term psychiatric drug use upon the prospects of recovery.
b. The relationship between the quality of partnership between service user and the person making the prescription, and perceived effectiveness of drug.
c. Further investigation into what written information people receive with a drug.
d. Effectiveness of drugs when given under compulsion as opposed to taken on a voluntary basis.
e. User based research on the connection between doseage levels, efficacy, and unwanted effects.
f. Further quantitative and qualitative research into severe unwanted effects when taking and stopping SSRI and SNRI antidepressants.
g. A user-based survey into the availability and effectiveness of non-drug treatments.

APPENDIX 1: METHODOLOGY

The Advisory Group

The first stage, prior to undertaking the research itself, was to select an advisory group whose role it would be to oversee and review the various tasks involved in the project and generally to steer it in the right direction. Members of the advisory group were chosen to achieve a balance of skills and experience. A majority of group members had experience of using psychiatric drugs themselves.

The Advisory Group attended meetings and gave guidance and comments throughout the process of producing this report. We would like to acknowledge our gratitude to members of the Advisory Group for their commitment and enthusiasm, particularly those members from out with SAMH who gave freely of their own time and knowledge.

Advisory Group membership

Richard Norris, Director of Policy, Scottish Association for Mental Health.

Professor Robert Hunter, Consultant Psychiatrist and Director of Research and Development, Greater Glasgow Primary Care NHS Trust.

Fiona Tall, Head of Services, Scottish Association for Mental Health.

Karen Fraser, Principal Pharmacist - Mental Health, Ailsa Hospital, Ayr.

Richard Anderson, Director, Lanarkshire Association for Mental Health.

Laurence Wilson, formerly Development Worker, Mental Health Network Greater Glasgow.

Simon Bradstreet, Policy and Information Manager, Scottish Association for Mental Health.

Anne Mathie, Information Officer, Scottish Association for Mental Health.

Mark Raeburn, Information Officer, Scottish Association for Mental Health.

Literature survey

An extensive literature survey of all relevant material was undertaken to find out what studies had been carried out previously in this area. We also met with Alison Cobb of MIND to discuss their Yellow Card survey.

Focus groups

It was decided to use focus groups to gather information for use in constructing the survey form. This was felt to be an ideal method to explore diversity of opinion and experience. The groups drew upon respondents' attitudes, feelings, experiences and reactions in a way that would not have been feasible using other methods. The use of focus groups also enabled us to gather a larger amount of information in a shorter period of time than would have been the case if other methods had been used, e.g. individual interviews.

Each group was made up, as far as was possible, of a reasonable gender and age spread, and with representatives from ethnic minority service users. People with a range of psychiatric conditions were included so that information was gathered about as wide a variety of drugs as

possible. Participants were also selected who had experience of using psychiatric drugs and who were comfortable about expressing their views. Each group was made up of approximately 12 mental health service users. Two members of the project team also attended to introduce the project and to take notes.

As it was a nation-wide study, groups were organised in different geographical locations throughout the country to take account of possible variations in the quality of care. Focus groups were organised by:

- Mental Health Network (Greater Glasgow)
- The Lanarkshire Association for Mental Health
- Highland Users Group
- Reach Healthy Living Project

Our thanks to these organisations for their assistance.

The survey form

A postal survey was chosen because the target sample population was known to be dispersed over a large area and because of the relatively low cost of a mail survey. We also felt that because some of the topics discussed were sensitive that people might feel more ready to give information in an anonymous survey form than they would using other methods.

Issues identified by the focus groups were used to design the form, which respondents were later asked to complete. The form contained closed questions (for example, tick boxes) as well as open questions where the respondent could write answers in a space on the form.

A pilot study of the survey was undertaken at SAMH's Glasgow North Project, with ten service users. As a result of this pilot further changes were made to the form.

A copy of the survey form is available on request.

Survey form distribution

10,000 survey forms were distributed through SAMH networks including SAMH projects, member organisations and user groups. Forms were also distributed through SAMH magazine, The Point.

The survey was also promoted through advertising in The Big Issue, and other media news coverage.

The survey form could also be completed online at the SAMH website.

Survey forms were distributed and returned between January and May 2003. The total number of forms returned was 1,012. The number of printed returns was 931 (92%); the number of website returns was 81 (8%). Of these, 756 had been prescribed a new or different psychiatric drug in the previous three years and were therefore considered as part of the research. A further 186 forms were returned by people who had not been prescribed a new or different drug in the last three years (many of whom had returned a form in order to obtain a copy of the summary report).

Analysis

A database was developed in MS Access for recording the information returned. Once all the data had been recorded the psychiatric drugs were coded using the codes from The British National Formulary.[18]

The only exception to BNF drug groupings in this report is the use of the word 'typical' to describe older antipsychotic medications.

Initial statistical analysis of the data was carried out by Dr Pauline Banks, Depute Director, The Strathclyde Centre for Disability Research, University of Glasgow with additional analysis carried out by SAMH. SPSS and MS Access were used to analyse data.

Limitations and biases

The survey was of people who had taken a new or different psychiatric drug within the last three years. This group of people was chosen because we were interested primarily in people's recent experience of psychiatric drugs. However, this resulted in a significant number of people who returned a form - 21% in our survey - being excluded from the research even though they may have been taking psychiatric drugs for many years.

There is a bias in the sample population towards people using secondary care. This is because a majority of the survey forms were distributed to people using voluntary sector services, or involved in mental health user networks, and people in these groups are more likely to be using secondary care services.

Many survey respondents were taking a number of drugs and in some cases it may have been difficult for them to isolate the positive and negative effects of individual drugs.

Funding

Financial support for the survey was kindly provided by the Community Fund as a major part of a two-year psychiatric drugs information project.

18 British National Formulary 46, Bmjp/Pharm'l Press, September 2003

APPENDIX 2: SOURCES OF HELP AND INFORMATION

If you are currently taking a psychiatric drug, or think you might be getting a prescription in the future then we hope that this report provides valuable information. However, it should be remembered that we all react differently to medication; so don't be put off seeking help because of some of the comments in this report. Very many people who returned forms said they found medication helpful.

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

SAMH Information Service

The SAMH Information Service offers information on a range of mental health issues including psychiatric drug treatments, services, benefits and legal advice. Monday to Friday from 2.00pm to 4.30pm,

Tel: 0141 568 7000
Email: enquire@samh.org.uk
Web: www.samh.org.uk

Norfolk Mental Health Care Trust

Good quality pharmacy medicine information website.
Web: www.nmhct.nhs.uk/pharmacy

CSM Scotland – Centre for Adverse Reactions to Drugs Scotland

CSM Scotland is a joint venture between the Medicines Control Agency (MHRA) and the Scottish Executive. It aims to increase and improve the quality of adverse drug reaction reporting in Scotland using the Yellow Card Scheme. Yellow Cards can be completed online by health professionals but not directly by service users.

Tel: 0131 242 2919
Email: CSMScotland@luht.scot.nhs.uk
Web: www.show.scot.nhs.uk/CSMScotland

Medicines and Healthcare products Regulatory Agency (MHRA)

The MHRA are the Executive Agency of the Department of Health, They are responsible for protecting and promoting public health and patient safety by ensuring that medicines, healthcare products and medical equipment meet appropriate standards of safety, quality, performance and effectiveness, and that they are used safely.

Tel: 020 7084 2000 (weekdays 0900 -1700), 020-7210 3000 (other times)
Email: info@mhra.gsi.gov.uk
Web: www.mhra.gov.uk

APRIL – Adverse Psychiatric Reactions Information Link

APRIL raises awareness of, and catalogues, adverse psychiatric drug reactions to all medications.
Web: www.april.org.uk

Mental Welfare Commission for Scotland

The Commission has the responsibility for protecting the welfare of people with mental disorder in Scotland, and is accountable to the Scottish Executive and Parliament.

Tel: 0131 222 6111
Email: enquiries@mwscot.org.uk
Web: www.mwscot.org.uk

NHS 24

24 hour NHS health advice service. Currently available in Grampian, Highland, Greater Glasgow, Ayrshire and Arran and Fife and will be available to the rest of Scotland by the end of 2004.

Tel: 0800 22 44 88

Samaritans

Available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair.

Tel: 08457 90 90 90