

Scottish Association for Mental Health (SAMH)

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Major new report on psychiatric drugs from SAMH prompts calls for better independent monitoring of drugs

The Scottish Association for Mental Health (SAMH), Scotland's leading mental health charity, today released the results of the first Scotland wide survey of psychiatric drugs. This unique piece of research asked the experts – people with experience of taking the drugs how they felt about the drugs themselves and the prescription process.

### Key points

- 60% of people found their drugs helpful overall. However, the same percentage of people also reported experiencing unwanted effects, ranging in severity. Half of all respondents had at some point disagreed with their doctor about medication, and of these, nearly half (44%), were not happy and felt that their opinion had not been considered.
- SSRIs, the most common type of antidepressant, performed badly compared to other drug groups –they did not do as well as older types of antidepressant. Moreover, serious concerns emerge about unwanted effects, like suicidal thoughts and actions, feelings of violence and self-harming.
- People's experience of drugs can vary enormously- the same drug was described by one person as having "saved my life", and by another person as "a living nightmare".
- Although many people were happy about their participation in medication decisions, a
  sizeable minority consistently said they were unhappy with the extent to which they
  were able to raise concerns or the extent to which they felt listened to when they did.
- This was a unique large scale study, the first of its type in Scotland 750 participants were included (with over 1,500 individual reports on drugs).

## What SAMH is calling for

- There needs to be improved mechanisms for direct reporting of unwanted effects, with a new system of reporting to an independent monitor.
- The Government should consider establishing an independent body to perform clinical trials, so that tests would be seen as much more objective and neutral.
- There should be new good practice guidelines on the prescription of psychiatric drugs, ensuring there is 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.



Shona Barcus, Chief Executive of SAMH said:

"This research is the first of its kind ever to be carried out in Scotland. Apart from anything else, it has highlighted how complex an issue the whole business of drug treatment in mental health is. Individual experiences of the same drug varied enormously – it was not uncommon for a drug to be viewed by some recipients as having 'saved their lives' yet to be considered by others to have made them feel 'suicidal'

"The current evidence used to support certain drugs is very limited. It is based on short-term use in a select population. Our research, by directly asking people who have been prescribed the drugs about the impact these actually have on their lives contributes crucial new evidence and it is clear that this type of information must be collected as a matter of course in the future.

"As a result of our findings, we are now calling for a system where unwanted effects can be directly reported to an independent monitor."

#### COMMENTS FROM THE REPORT

1 People's experience of the same drug can be dramatically different

The following quotes were from survey respondents, commenting on the antidepressant Paroxetine (Seroxat):

[I] want it banned, nobody is interested, Panic attacks make my life hell.

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.

Excellent mood uplifter, particularly initially upon taking this drug.

Could have saved my life.

2 We came across a broad range of unwanted effects

Many people taking newer atypical antipsychotic medication reported weight gain, in some cases severe:

Made me increase in weight - I went from ten to fifteen stones and seven pounds in one month. This depressed me more... (Quetiapine - antipsychotic)

Weight gain, went from seven and a half stone to seventeen and a half stone in seven months! (Olanzapine - antipsychotic)

Sexual problems are a common unwanted effect from psychiatric drugs. This can come as an unwanted surprise.



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 (Seroxat) - antidepressant)

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 - antipsychotic)

3 Some people taking commonly prescribed antidepressants reported severe problems, when taking and stopping them, which they ascribed to the drug

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)

If I stopped taking it for more than two days, I had symptoms similar to labyrinthitus – dizzy, any noise unbearable, nauseous. Awful, wouldn't wish it on my worst enemy. (Sertraline)

Out of just over 400 comments from people who had stopped taking an SSRI type antidepressant, ten people specifically mentioned suicidal thoughts and acts, others mentioned self-harming:

Waves of crying for about two weeks, then hyperactive - agitated, extremely depressed/suicidal. (Venlafaxine)

Felt suicidal which I had never done previously either on or off this drug. (Sertraline)

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))

4 Experience of prescription was highly variable

We recorded many examples of good practice in prescription:

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.

Others had a less positive experience

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 opinion was completely ignored and the debilitating side effects were dismissed.



Many issues were identified around stopping drugs. We identified good practice:

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.

But a significant minority felt disempowered and excluded. Threats were not uncommon.

My old consultant told me he would refuse to be my consultant if I stopped the medication.

I was told I would (not might) get ill and relapse. Possible sectioning was hinted at if I persisted in requesting to stop.

The report also looks at anxiolytics and mood stabilisers. The full report is available from SAMH (cost £10) or alternatively can be downloaded free of charge from the SAMH website: <a href="https://www.samh.org.uk">www.samh.org.uk</a>

#### **ENDS**

#### **NOTES TO EDITORS**

- 1. The Scottish Association for Mental Health is Scotland's leading mental health organisation. As well as campaigning and providing information, SAMH delivers community care services throughout Scotland.
- 2. The two year study of people's experience of psychiatric drugs was funded by the Community Fund, and involved focus groups held across Scotland and a detailed Scotland-wide survey. The project was assisted by an advisory committee representing professional and user views.
- 3. The Report "All you need to know?" is being launched on Wednesday 7<sup>th</sup> April at 10am at the Radisson SAS Hotel, 301 Argyle Street, Glasgow, G2 8DL
- 4. 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. Spending on antidepressants in Scotland is 40% higher per head than in England. (Source: ISD Scotland).
- 5. Newer 'atypical' antipsychotic drugs cost, on average, 17 times as much as their older equivalents. (Source: Quality Improvement Scotland).
- For further information on this news release contact Richard Norris, SAMH Director of Policy, on 0141 568 7000 or 07803 235089 or Simon Bradstreet, Policy & Information Manager, 0141 568 7023 or 07971 892872.