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Designing withdrawal support services for antidepressant users: Patients' views on existing services and what they really need

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ABSTRACT

Background: Public Health England has recommended that services be put in place to support people who choose to withdraw from antidepressants because of a current gap. This study aims to explore the views of members of online withdrawal peer-support groups about existing healthcare and what additional support is needed.
Methods: The administrators of 15 online support groups for people stopping antidepressants were asked to advertise an online survey to their members. The survey, which was online from May 2021 to April 2022, was completed by 1276 people from 49 countries.
Results: 71% of respondents found their doctors' advice unhelpful (57% 'very unhelpful') regarding stopping an antidepressant; the main reasons being 'Recommended a reduction rate that was too quick for me', 'Not familiar enough with withdrawal symptoms to advise me' and 'Suggested stopping antidepressants would not cause withdrawal symptoms'. One in three did not seek advice from their prescriber when deciding whether to withdraw, with the main reasons being 'I felt they would not be supportive' (58%) and 'I felt that they didn't have the expertise to help me' (51%). The most common prescriber responses to those who did seek advice was 'Suggested a quick withdrawal schedule' (56%) and 'Not supportive and offered no guidance' (27%). The most common discontinuation periods recommended by doctors were one month (23%) and two weeks (19%). A range of potential professional services were rated 'very useful', most frequently: 'Access to smaller doses (e.g. tapering strips, liquid, smaller dose tablets) to ensure gradual reduction' (88%) and 'A health professional providing a personalised, flexible reduction plan' (79%).
Limitations: This was a convenience sample, which may have been biased towards people who took longer to withdraw, and experienced more withdrawal symptoms, than antidepressant users in general. Black and ethnic minority people, and people without access to the internet, were underrepresented.
Conclusions: Most participants reported their prescribers were unable to help them safely stop antidepressants, compelling them to turn to online peer-support groups instead. Our findings indicate, in keeping with previous studies, that clinicians require upskilling in safe tapering of antidepressants, and that patients need specialised services to help them stop safely.

1. Introduction

1.1. Antidepressant prescribing

Prescribing of antidepressants is high and increasing. Annual antidepressant prescribing in the U.K. has doubled in ten years (Iacobucci, 2019). A government enquiry found that 7.3 million adults (17% of the adult population) had been prescribed at least one prescription of antidepressants in 2017–2018 in England alone; with disproportionately high rates for women, older people and poorer people (Public Health England, 2019). In the USA, during 2015–2018, 13.2% of adults used antidepressants 'in the past 30 days', with higher use among women (17.7%), reaching 24.3% for women aged 60 and over (Brody and Gu, 2015). Similarly high prescription rates occur in other countries, including Australia, Belgium, Canada, Denmark, Finland, Iceland, Northern Ireland, Portugal, Sweden and Wales (OECD, 2017; Iacobucci,

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2019).

Increased prescribing is mostly due to longer periods of prescription, rather than to increases in new prescriptions (Kendrick, 2021). By 2011, half of AD users in England, about 3.5 million people, were taking ADs for longer than two years (Johnson et al., 2012). About half of AD users in the U.S. (about 18 million) take them for at least 5 years (Mojtabai and Olfson, 2014). Average duration has doubled since the mid-2000s in the U.K. (NHS 2018) and the U.S. (Mojtabai and Olfson, 2014). Although there is debate about the overall benefits of antidepressants ((Goldberg and Nasrallah, 2022; Horowitz and Wilcock, 2022; Kirsch et al., 2008; Moncrieff and Read, 2022; Munkholm et al., 2019; Ormel et al., 2020; Read and Moncrieff, 2022) and about the chemical imbalance theory that has been used to justify their use (Moncrieff et al., 2022), many commentators have suggested that they are over-prescribed (Byng, 2020; Kendrick, 2021; Wallis et al., 2021). In the U.K., 58% of patients taking ADs for more than two years did not meet criteria for any psychiatric diagnosis, and 'independent clinical assessments based upon diagnoses and other clinical data' indicated that 31% had no clear clinical reason for continued receipt of an antidepressant (Cruickshank et al., 2008), with similar rates in Australia (Ambresin et al., 2015) and the Netherlands (Eveleigh et al., 2014).

1.2. Withdrawal

One possible explanation for the ever-increasing prescribing rates is that people are having difficulty stopping the drugs (Eveleigh et al., 2018). Recent systematic reviews have revealed the severity and complexity of antidepressant withdrawal (Fava et al., 2018). The most recent review (Davies and Read, 2019) was undertaken for the All-Party Parliamentary Group for Prescribed Drug Dependence in the UK, to inform a government enquiry by Public Health England (2019). It found an average of 56% of people experienced withdrawal effects when trying to reduce or stop. The only four surveys where severity was assessed found that an average of 46% of people described their withdrawal symptoms as 'severe'. Of the ten studies reporting duration, seven found that a significant proportion of people experience withdrawal for weeks, months or, more rarely, several years.

Antidepressant withdrawal is characterised by many and varied symptoms, physical and emotional, that can appear days, weeks or even months after stopping antidepressants, and which can exceed the intensity of the problems for which the drugs were prescribed (Cosci and Chouinard, 2020; Davies and Read, 2019; Fava et al., 2018; Horowitz and Taylor, 2019; Jha et al., 2018). Many doctors remain unaware of this evidence and may not recognise that patients are presenting with withdrawal from the medications (Cosci and Chouinard, 2020; Davies et al., 2018; Hengartner and Plöderl, 2018) and may misdiagnose relapse of the original problem, such as depression, especially since withdrawal may manifest as psychological symptoms (Framer, 2021; Horowitz and Taylor, 2022; White et al., 2021). Two surveys of convenience samples of 867 (Read, 2020) and 1829 (Read et al., 2018) antidepressant users both found that less than 1% were told about withdrawal by the prescriber.

Public Health England (2019), in its report on 'Dependence and withdrawal associated with some prescribed medications: An evidence review' acknowledged the extent of problems withdrawing from antidepressants, and recommended "tiered services" and a helpline to assist people coming off antidepressants and other psychiatric drugs, and more accurate national guidelines. The Royal College of Psychiatrists published a new, evidence-based position statement (Iacobucci, 2019; Royal College of Psychiatrists, 2019) including that patients should be informed of "the potential in some people for severe and long-lasting withdrawal symptoms on and after stopping antidepressants". This should occur before prescribing as part of the informed consent process. The College also produced guidance on 'Stopping Antidepressants' which recommends that long-term antidepressants are stopped 'over a period of months or longer' and that the taper plan 'should allow you to reduce the dose at a rate that you find comfortable – as slowly as you need to avoid distressing withdrawal symptoms.'(Burn et al., 2020)

The UK's National Institute for Health and Care Excellence updated its guidelines (NICE 2022a) pointing out that:

> "- withdrawal can sometimes be more difficult, with symptoms lasting longer (in some cases several weeks, and occasionally several months)
>
> - withdrawal symptoms can sometimes be severe, particularly if the antidepressant medication is stopped suddenly."

In guidance on safe withdrawal of prescribed drugs of dependence, including antidepressants, published in April 2022 NICE says: "ensure the speed and duration of withdrawal is led by and agreed with the person taking the prescribed medication, ensuring that any withdrawal symptoms have resolved before making the next dose reduction" and "recognise that withdrawal [the process of discontinuation] may take weeks or months to complete successfully" (NICE 2022b)

1.3. Facebook groups

When they discover their doctor cannot help them withdraw safely, or mis-diagnose their withdrawal symptoms as relapse (Hengartner and Plöderl, 2018), tens of thousands turn to the internet (White et al., 2021).

Surviving Antidepressants, for example, has around 13,000 members and 6000 case reports, publicly accessible on the site, and receives about 750,000 visits to its site a month. Forum posts have been used to estimate longevity and prevalence of withdrawal from antidepressants (Stockmann et al., 2018) and instances of drug induced withdrawal anxiety and mood disorders (Belaise et al., 2012). Verbatim reports of severe withdrawal symptoms were reported in both studies.

A recent study followed 16 of these withdrawal Facebook groups for between five and 13 months (White et al., 2021). The groups had a total membership of over 67,000, predominantly female, increasing at about 25% annually. The most common reason for seeking out online support was failed clinician-led withdrawal attempts. The researchers concluded:

> "Further research should focus on the methods of support and tapering protocols used in these groups to enable improved, more informed support by clinicians. Much greater support from Governments and healthcare agencies is also needed, internationally, to fully address this issue."

The current study is, therefore, designed to learn from users of online peer-support groups to understand more about people's interactions with health services and their reasons for seeking online peer-support, so as to inform the provision of adequate services within the health system.

2. Methods

2.1. The survey

The survey was called the **'International Online Survey of Members of Peer Support Groups About Their Experiences of Withdrawing from Antidepressants'.** In the Participant Information section, on the first page, potential respondents were told:

> "The purpose is to understand the experience of coming off antidepressants so we can inform UK health services (and other health services around the world) what sort of services need to be provided. This is your opportunity to share your experience of coming off these medications and what you have learned in the process to help others going through similar experiences.
> We are interested in people around the world who have the following experiences.
> 1. You have stopped an antidepressant in the past

2. OR you are currently trying to stop an antidepressant with the help of an online peer support group
3. OR you tried to stop an antidepressant in the past and had to go back on the antidepressant and you are now seeking help to taper safely from an online peer support group.
You must be aged 18 years or older.
The survey is anonymous."

Besides demographics, the survey asked a range of questions (with yes/no, multiple choice, or Likert scale responses) covering: why the respondent had tried to withdraw; withdrawal symptoms experienced; the process of withdrawal – including speed of withdrawal, coping strategies, interactions with the prescriber, and role of the online support groups; and how useful a list of potential services would be. The current paper reports responses to questions about whether and why respondents sought advice from their prescriber about whether to stop, how the prescriber responded if asked for advice, and how helpful the respondents found that advice. It also reports on the question about the usefulness of various potential services.

2.2. Procedures

The administrators of 15 online support groups for people taking antidepressants (see Supplementary Table 1) were asked to advertise the survey to their members. Supplementary Table 1 also shows that the survey reached members of other online support groups. The survey was online for twelve months, from May 2021 to April 2022.

2.3. Data analysis

The majority of the findings are quantitative and are presented descriptively without analysis. The relationship between the perceived helpfulness of the doctors' advice and age and level of education was tested by Spearman correlation coefficients and with gender and country by two-tailed t-tests. Responses to open questions, such as 'other' boxes after lists of possible responses were grouped into categories by one of the researchers and multiple examples provided, in Tables, for readers to assess the reliability of the categories.

3. Results

The survey was opened on 1806 occasions. 1523 people gave their consent to participate. Of these, 195 completed only the demographics, leaving 1330 people who answered at least some of the questions. 25 IP addresses were used more than once (21 twice, three thrice and one eight times). One of the pairs involved different responses so both were included for analysis. The other 33 duplicates were excluded, with either the most complete or most recent response retained. This left 1297 respondents. On the first occasion that respondents were asked to identify the antidepressant involved, 21 named a drug that was not an antidepressant and were excluded. The remaining 1276 were used in the analyses reported here.

Of these 1276 respondents, 967 (75.8%) completed the entire survey and 1027 (80.4%) completed 80% or more of the survey. I78 (13.9%), however, completed only 29% of the survey.

3.1. Sample characteristics

Sample characteristics are reported in Table 1. Although 49 countries were represented, approximately half of the respondents lived in the USA (34.6%) or the UK (18.7%). The majority were women (79.5%) and identified as 'white' (92.4%). The average age was 45.8 years.

Responses to 'Which online support group are you a member of' are summarised in Supplemental Table 1. The two groups most often cited were Surviving Antidepressants (28.2%) (www.surviginantidepressants.org) and Cymbalta Hurts Worse (21%) (www.facebook.com/groups/Cymbaltahurtsworse).

Table 1
Sociodemographic characteristics of the sample.

Characteristics		Proportion (%)
Nationality*	USA	34.6
	UK	18.7
	Germany	10.2
	Australia	8.3
	Canada	7.4
	Netherlands	3.1
	France	2.0
	Finland	1.7
	Ireland	1.4
	New Zealand	1.3
	Sweden	1.1
	Brazil	1.0
Ethnicity	White	92.4
	Asian	2.7
	Hispanic	1.7
	Black or African American	1.4
	Other	2.3
Gender[a]	Female	79.5
	Male	19.3
	Non-binary/third gender	1.2
Age[b]	Mean	45.8 years
	Range	18–85 years
Highest level of educational attainment	Postgraduate degree	28.6
	Undergraduate degree	34.1
	Only completed high school/ secondary school	33.7
	No completed high school/secondary school	3.5
Medication status[c]	'Come off antidepressant and were no longer taking it'	50.5
	'I have tried to stop an antidepressant and been unable to do so'	26.2
	'I am currently trying to stop an antidepressants'	50.7

*The following contributed between one and 11 respondents: Albania, Argentina, Austria, Bangladesh, Belgium, Denmark, Greece, Honduras, Hungary, Iceland, India, Indonesia, Iran, Israel, Italy, Japan, Kenya, Luxembourg, Malta, Mexico, Nepal, Nigeria, Norway, Pakistan, Poland, Portugal, Romania, Serbia, Singapore, South Africa, Spain, Sudan, Switzerland, Turkey, UAE, Uruguay and Zimbabwe.
[a] 5 'preferred not to say'.
[b] Excluding 25 who did not give their age.
[c] Some respondents fit into more than one category.

3.2. Diagnosis and opinion of treatment

When asked 'What was the main diagnosis your drug was prescribed for?', and given six options, most selected either Depression (751, 58.9%) or Anxiety (632, 49.5%) (many selected more than one). Numbers endorsing the six listed options, plus 'other' diagnoses or health issues reported by ten or more respondents, are listed in Table 2.

In response to the question 'Did the antidepressants help you with the problem they were prescribed for?' 628 (49.2%) ticked 'yes', 391 (30.6%) no, and 257 (20.1%) 'don't know/not sure'.

Was the doctor's advice helpful or unhelpful, overall?

Of the 741 who responded to the question 'Overall was the doctor's advice helpful or unhelpful?' 57.0% ticked 'very unhelpful', followed by 14.2% ticking 'moderately unhelpful', 14.2% 'neither helpful nor unhelpful/not sure', 8.5% 'moderately helpful' and 6.2% 'very helpful'. Spearman correlation coefficients found that degree of unhelpfulness was not significantly related to age ($r = 0.003$, $p = .93$) or level of education ($r = -0.013$, $p = .73$). T-tests found no significant differences in terms of gender ($t = 0.029$, $p = .98$) or country (USA vs the rest, $t = 0.87$, $p = .38$; UK vs the rest, $t = 0.11$, $p = .91$).

Why unhelpful?

Table 2
Diagnoses and health issues for which the antidepressants were prescribed.

Depression	751	58.9%
Anxiety	632	49.5%
Chronic Pain	172	13.5%
Social Anxiety Disorder	93	7.3%
Obsessive Compulsive Disorder	63	4.9%
Fibromyalgia [a]	52	4.1%
Insomnia/sleeping problems [a]	48	3.8%
Bipolar Disorder [a]	20	1.6%
PTSD [a]	17	1.3%
Menopause	15	1.2%
Panic attacks/Disorder [a]	13	1.0%
Postnatal Depression [a]	11	0.9%
Nerve Pain [a]	11	0.9%
Migraine [a]	10	0.8%
Eating Disorders [a]	10	0.8%

[a] Not one of the six diagnoses listed in the survey; reported by respondents under 'other diagnosis or health issue'.

The 72.1% (527) who found the advice unhelpful were asked why, given four options (see Table 3) and asked to identify 'other' reasons.

102 offered 'other' reasons, but many were repeats or elaborations of the four options. Explicitly 'other' reasons were: Rude or dismissive (8), More drugs (8), Told to stay on antidepressants (5), Told to alternate days (5) and No practical advice (4). One participant wrote:

I've consulted 3 GPs along the way, and all were a combination of shaming, dismissive, ill-informed or intent on convincing me that my own understanding of what was happening to me was wrong.

Did you seek advice?

Of the 1018 respondents who answered the question 'Did you seek advice from your prescriber (your GP, psychiatrist or other doctor) in the decision to stop your antidepressant?', 672 (66.0%) said 'yes' and 346 (34.0%) 'no'.

'If not, why not?'

The 364 who did not seek advice were asked why, and offered four options to choose from. The most common responses were 'I felt they would not be supportive' (58.2%) and 'I felt that they didn't have the expertise to help me' (51.1%). Far fewer endorsed 'I did not feel I needed to (19.5%) or 'I did not have time' (3.6%).

105 respondents offered one or more other reasons for not seeking advice. Reasons given by four or more respondents are listed, with examples, in Table 4.

'If yes, how did the doctor respond?'

The 672 who did seek advice from their prescriber were asked 'How did your doctor respond when you wanted to stop your drug?' and were given five possible responses, plus an 'other' box. Table 5 shows that more than half (55.6%) ticked 'Suggested a quick withdrawal schedule' and lists the frequencies with which the other options were endorsed. 20% felt their doctor was supportive. Some helpful responses are included in Table 6.

Table 3
Reasons doctors' advice was, overall, 'unhelpful'.[a]

'Recommended a reduction rate that was too quick for me'rowhead	450 (85.4%)
'Not familiar enough with withdrawal symptoms to advise me'rowhead	432 (82.0%)
'Suggested stopping antidepressants would not cause withdrawal symptoms'rowhead	308 (58.4%)
'They suggested I would relapse'rowhead	136 (25.8%)

[a] Respondents were able to give more than one answer to this question.

Table 4
'Other' reasons for not seeking advice from prescriber.

Previously taken off too fast	19	*'My doctor told me to go cold turkey'* *'Because she just wanted me to stop cold Turkey. She doesn't believe in withdrawal'* *'They are okay with me stopping, but don't believe in a slow taper'* *'I did not want them to control my dosing schedule and reduce my medication more quickly than i could handle'* *'I knew that after discussions with various doctors in the past that I would be told to come off far quicker than was safe'*
Doctors just want to switch, add or increase medications	16	*'My prescriber was against me withdrawing and I knew all he would do was prescribe more meds'* *'They only wanted to increase dose or change meds'* *'I had been on Anti depressants on and off for 25 years, when I was struggling with withdrawal I was only ever offered more anti depressants'*
Miscellaneous negative experiences with doctors	15	*'Lost confidence in my GP because he didn't tell my about side effects before starting mirtazepine'* *'GP gave me incorrect information'* *'They prescribed me medication that made me sicker than when I went to them'*
Doctor wants me to stay on antidepressant	13	*'I did not ask his advice - his advice would be to stay on the meds'* *'They told me, it is normal to take the medication for the rest of my life'* *'I am certain my Dr would want me to stay on cymbalta'*
Doctor's lack of knowledge	10	*'It was clear that they did not have helpful knowledge on the matter (based on past experiences)'* *'I think a lot of doctors have no idea! NO ONE explained the withdrawal symptoms to me, NO ONE told me how dependent you become'* *'I felt their knowledge was limited'*
Doctor does not believe/listen to me	7	*'Was not believed previously'* *'They refused to acknowledge my severe side effects were due to medication I was on'* *'They didn't take me seriously'*
Fear of being cut off	6	*'I was worried they would just cut me off and I wouldn't be able to taper'* *'I feared they would stop my prescription.'* *'When I told Dr I had reduced on my own from 120 mg Cymbalta to 20, he cut off my prescription'*
No relationship	6	*'I felt he truly didn't care for my well being!'* *'I don't have a doctor who really knows me or cares that much about me'*
Could not get appointment	4	*'I could not get an appt with my doctor & I couldnt wait any longer'*

Table 5
How did doctors respond when asked for advice?

Suggested a quick withdrawal schedule	374 (55.6%)
Not supportive and provided no guidance	183 (27.2%)
They were supportive and tried to help	134 (19.9%)
Suggested I stopped the medication abruptly (in one day)	105 (15.6%)
Helped me to plan a gradual withdrawal schedule and guided me through it	61 (9.1%)

155 reported 'other' responses from doctors. Responses reported by more than five participants are listed in Table 6, with examples.

What time period did the doctors recommend.

Respondents were asked 'If your prescriber provided advice on how

Table 6
'Other' responses from doctors when asked for advice.

MIXED	43	Examples
Supportive but uniformed	15	*'Listened but didn't provide helpful guidance'* *'Psychiatrist did their best and had the best intentions, but unfortunately were completely ignorant and therefore unable to help'* *'He did try his best, think he just did not know better. Feel sorry for him'* *'Supportive but provided no proper guidance'*
Some helpful, others not	6	*'The first prescriber suggested a quick withdrawal schedule, the second helped me plan a gradual schedule'* *'My regular doctor always talked me out of it for years. One day they put me with the nurse practitioner and I told her I wanted to stop and she was so supportive. And gave me the plan'*
Miscellaneous	22	*'Was told to take my time. No specifics, plans, dosage, or withdrawal information provided'* *'He went more slowly than he wanted to because I wanted it that way but he wasn't willing to order liquid or do bead counting or anything I learned in support groups'* *'They were hesitant for the first couple of times that I asked, then they eventually agreed to a taper advised and monitored by them'* *'Would support it but recommended staying on it'*
More or new medications	27	*'Tried to get me to go on another anti-depressant'* *'Tried to add valium to the mix, i.e the opposite of what I went to talk to him about'* *'Adding another med to help with withdrawals'* *'Switched me to fluoxetine as thought it would be easier to come off and then they said to stop when I had severe reactions. They assumed it was the new medication but It was withdrawal'* *'Tried to increase my dose instead'* *'Increased dose, added more meds'*
Told to withdraw too fast	26	*'I had one doctor tell me on the day that I just reached* 75 mg *to drop to 37.5, take that for 2 weeks and then stop'* *'I was advised I could reduce over a period of 3 days to a week at most!'* *'Was on* 100 mg *told to half, did for 6 weeks, then told to stop abruptly'* *'Suggested I reduce by 50% and review in one month'* *'Doctor thought I was better, no longer needed to take paroxetine. "just stop taking it" '* *'It was agreed I stop 3 meds at once, I was actively suicidal'*
Unhelpful - miscellaneous	16	*'My psychiatrist told me he no longer wanted to see me when I told him. No advice was given. Just insults. I asked for help once and he would not help me. Just told me withdrawal doesn't happen'* *'GP did not seem to know that people in withdrawal could suffer for years as a result. Did not sense that he understood what I was going through; not empathic; clueless'* *'GP gave incorrect advice … more than once. He didn't seem interested at all'*
Helpful - miscellaneous	14	*'GP has been completely open-minded and great at taking my experiences seriously'* *'After I pointed out it would take years, told me they would prescribe the liquid needed if that's what i was comfortable with'* *'Just let me work out my own taper rate'* *'I said I would like to reduce by 5% of the beads inside the capsule as per the support group recommendation, my GP was very supportive of this approach'* *'My doctor is the one who suggested getting off meds in the first place'*
Told to keep taking the medications	14	*'They said I should take the meds for a longer time as I was just a "depressive type" '* *'I saw the same psychiatrist between 2002(?) and 2013, every six months, and pretty much every visit to him I said I wanted to stop Seroxat and every time he said 'wait another six months'.'* *'Was of the opinion that i should remain taking them.*
Alternate days	13	*'Just told me to do every other day'* *'Told me to take full dose one day and less dose the other day'* *'Told me to take* 20 mg *every other day for a week (I think) then* 10 mg *every other day, then stop'*
Withdrawal effects denied	11	*'He didn't believe me when I told him they were withdrawals'* *'He denied totally there would be any withdrawal issues even when I explained what happened to my partner'* *'Withdrawal symptoms were simply denied'* *'Told me withdrawal from antidepressants doesn't exist'*
Told it's a relapse	8	*'I changed doctor because he didn't believe me and said I feel worse because of my mental illness'* *'Told me that the symptoms that I knew were side effects were in fact a relapse of the original problems'*

to withdraw, over what time period did they recommend you reduce your medication to zero?', followed by nine possible responses. The responses of the 582 endorsing one or more of the nine options are listed in Table 7. The most common period recommended by doctors was one month, followed by two weeks.

Twenty eight respondents gave 'other' answers to this question, the most common being reductions measured by dosage rather than, or as well as, by time, mostly involving large and/or speedy reductions (see Table 8).

The complexity of some of the participants' responses, not always evident from the shorter quotes in Table 8, is exemplified by the following:

> 'My latest GP has been completely open-minded and great at taking my experiences seriously. However, ALL the psychiatrists I have seen since 2013 have been dismissive to various degrees. Some say things like 'you're on a sub-therapeutic dose of Seroxat, no wonder your depressed.' Another one advised me to stop cold-turkey and take diazepam for three months (I declined). Another told me 'you can't believe all you read on the internet' when I told her about NICE reviewing the guidelines about antidepressant withdrawal. The worst one aggressively said I had 'adjustment disorder' and refused to acknowledge that Seroxat withdrawal was a factor. Nurses are similar – I have probably encountered 20 different psychiatric nurses and only three of them have taken my experiences seriously. … I could not bring myself to get pregnant while taking this hideous drug, so thanks to Seroxat I have probably missed out on one of my lifelong dreams.'

Table 7
Doctors' advice on time period for withdrawal process.

One day	55 (9.4%)
One week	36 (6.2%)
Two weeks	112 (19.2%)
One month	135 (23.2%)
Two months	82 (14.1%)
3–6 months	78 (13.4%)
6 months - 1 year	16 (2.7%)
Longer than 1 year	15 (2.6%)
At a rate you could tolerate	53 (9.1%)

Table 8
'Other' advice about speed of withdrawal.

By dosage	19	*'3 days ie* 40 mg 20 mg 10 mg 0 mg *escitalopram'* *'3 weeks.* 90 mg, 60 mg, 30 mg, *zero. Cymbalta.'* *'5–6* months 75 mg *each month - 6 weeks'* *'From* 60 mg *to* 30 mg *in one day, then* 30 mg*/day for 4 weeks and then* 0 mg*'* *'Withdrawing at* 10 mg *reductions would you believe it?'* *'Was at* 60 mg *he suggested* 30 mg, *I pushed up to* 40 mg. *After that experience I lost trust and concealed my taper'* *'One GP halved my dose and gave me a script for beta blockers to counter the ensuing anxiety'* *'I should halve the dose for 14 days and then stop the drug altogether.'*
Alternating	7	*'To take a cymbalta every second day'* *'Skipping doses, no time period provided'* *'Only cold turkey, or alternating days as you reduce it (which I cant even imagine going through now as doing it properly is so hard already)'* *'I have seen various doctors over the years when trying to stop taking duloxetine. All gave the same advise of taking every other day for a week, then take every 3rd day, etc'*
No need; drug tapers itself	2	*'Advised to just stop as it "tapers itself".'*

3.3. Recommendations for changes to services

Between 941 and 1011 participants responded to the questions about the usefulness of eight specific professional services, on a three point scale ('How useful would the following professional services (eg in the NHS in UK or elsewhere around the world) be, or would have been?'). All eight were thought to be 'very useful' by the majority of respondents, with the most useful being 'access to smaller doses (88% 'very useful'), 'a personalised, flexible reduction plan (79%) and 'regular follow-up to monitor reductions' (72%) (see Table 9).

Table 10 lists the additional suggestions made by at least five of the 107 respondents who suggested 'other' useful services. Educating doctors about withdrawal symptoms and how to support gradual tapering was the most commonly made recommendation. Examples of each of the nine suggestions are provided.

Table 9
Responses to 'How useful would the following professional services be'?

	n	Very useful	Somewhat useful	Not useful
Access to smaller doses (e.g. tapering strips, liquid, smaller dose tablets) to ensure gradual reduction	955	837 (87.6%)	68(7.1%)	50 (5.2%)
A health professional providing a personalised, flexible reduction plan	1011	800 (79.1%)	128(12.7%)	83 (8.2%)
Regular follow-up to monitor reductions	953	688 (72.2%)	201(21.1%)	64 (6.7%)
Online support group supervised by a professional	928	628 (67.7%)	209(22.5%)	91 (9.8%)
Telephone/online, video/online chat help line	949	622 (65.5%)	247(26.0%)	80 (8.4%)
Individual therapy/counselling	941	616 (65.5%)	236(25.1%)	89 (9.4%)
Support/education for carers and/or families	919	568 (61.9%)	243(26.4%)	108 (11.7%)
In person professionally supervised support group	924	533 (57.7%)	265(28.7%)	126 (13.6%)
Other[a]	107			

[a] See Table 10.

Table 10
What other professional services would be useful?

Education of doctors	35	'Doctors do not know how to taper patients. They need to be completely re-educated on this' 'Professional training on withdrawal and withdrawal symptoms' 'Professionals education in the need for slow tapering and long term effects of withdrawal symptoms' 'For drs to not ignore withdrawal symptoms or put it down to original illness returning - more education needed'
Other professions/ treatments: Nutrition(ist)/Diet (ician) 5 Physical therapy/ Massage 3 Pharmacist 3 Vitamins/ Supplements 2 Mental health/ Counsellor 2	18	'Hands on physical therapy or massage to relieve tense muscles/pain/anxiety' 'Collaborative approach between GP, specialist and holistic practitioners such as dietitian and accupuncturist' 'Databases of compounding pharmacy's who are willing to make the medications at lower doses and who will ship anywhere' 'Referral to an educated mental health practitioner at the point of prescribing to talk through potential side-effects, and tapering/withdrawal information'.
Information/ explanation	7	'Clear explanation about withdrawal syndromes' 'Short easy to read directory, q&a or something so I knew I wasn't only one and that I wasn't going mad or going to die'
Improved initial prescribing	7	'Not to be prescribed before warning patients about the risk they are about to take if they start ADs' 'Being given accurate information before taking medicine' 'not prescribing antidepressants to everyone in every little crisis'
Acknowledgement	7	'acknowledgement of what you are going through is real, a real diagnosis of withdrawal syndrome, having your experience count' 'Plain acknowledgement of the condition' 'To be told that was I was going through was normal'
Public/employer education	7	'Public lack of understanding from work/family/ friends/medical profession made this whole journey much harder than it needed to be' 'Make withdrawal more public all over the world' 'Educational materials to provide to employers so they can understand the symptoms and how they interrupt life'
Detox centre	6	'A place where withdrawal patients can live and are being taken care of as long as they need it' 'A safe place to be away from work and home with 24/7 support' 'A specific detox/addiction center for antideppresive medication and other brain altering drugs'
Peer support	6	'Peer tapering support group'

4. Discussion

4.1. Current medical services for stopping antidepressants

Respondents reported that clinicians were ill-informed about withdrawal and safe tapering, with 82% of patients reporting that the clinician was not familiar with withdrawal symptoms and almost 60% reporting that their GP denied that stopping antidepressants could cause withdrawal symptoms. One-third did not seek help from their doctor to stop their antidepressant, half of whom felt that prescribers lacked expertise in how to safely stop. Some respondents indicated that this impression was formed by past experience where they had been told to stop abruptly or informed that there was no such thing as withdrawal. Some respondents reported that this lack of faith in their prescribers was based on other evidence of a lack of knowledge regarding the effects of antidepressants – for example, not informing them of withdrawal effects or other side effects when starting.

A recent survey of UK GPs reflected this lack of understanding of

withdrawal, with only 29% feeling their knowledge of withdrawal was sufficient and only 1 in 6 feeling that they were able to distinguish between withdrawal effects and relapse (Read et al., 2020). Another study found that UK health professionals report that the focus in their medical education was on prescribing but not in the "coming-off part"; and that they lack confidence in how to stop antidepressants, skills and access to useful information (Bowers et al., 2019). Some respondents in the current study indicated that prescribers were more interested in adding, increasing or switching medication than stopping medications.

4.2. Clinicians' recommendations about speed of tapering

When advice was sought from prescribers, more than 70% of respondents felt their doctors' advice on how to stop antidepressants was unhelpful, mostly because they recommended tapering too quickly. The advice given for tapering speed shows that most prescribers recommended tapering over one month or less.

This advice is consistent with advice given in most guidelines for stopping antidepressants around the world (Sørensen et al., 2022). For example, until 2022, the NICE guidelines in England recommended "gradually reduce the dose, normally over a 4-week period". A recent RCT involving discontinuation of antidepressants over 4–8 weeks found that 48% dropped out early, with elevated withdrawal symptoms in those that remained, for at least six months afterwards (Lewis et al., 2021), suggesting that this rate of taper may be too fast to be tolerable for many patients (Horowitz and Moncrieff, 2021; NICE 2022a). Other studies have reported that patients were unable to tolerate tapering of antidepressants over 4 weeks, with most requiring months to do so (Bockting et al., 2018). The current survey confirms that this rate of tapering is intolerable for most patients, compelling them to seek advice from peer-support services online, as found in other accounts of tapering with clinicians (Guy et al., 2020; Public Health England, 2019; White et al., 2021).

Recently updated NICE guidance on this topic is an improvement, recommending individualised reduction at a rate the patient can tolerate, and taking 'weeks or months' (NICE, 2022a; NICE 2022b), however it has been criticised for lacking practical detail meaning it will be difficult to implement in clinical practice and therefore unlikely to ameliorate present problems (Burns, 2022).

4.3. Responses to patients

One theme in this survey was the lack of belief doctors applied to patients' reported experiences. This response has been noted in various inquiries into the health system, for example in England, relating to implantation of vaginal meshes, use of valproate in pregnancy, and hormone pregnancy tests, where the healthcare system was found to be "unresponsive" and "defensive" (Haskell, 2020). The same dismissive response has been directed towards people reporting post-SSRI sexual dysfunction (Healy et al., 2019). This suggests a power imbalance between doctors and patients. This also likely indicates the pervasive effect of misleading information by drug manufacturers, reproduced in official guidelines, that "discontinuation" symptoms from antidepressants are "mild and brief" and that they are therefore relatively easy to stop (Davies and Read, 2019; Massabki and Abi-Jaoude, 2020).

This survey also suggests some reasons why clinicians' ignorance about the trouble patients have in coming off antidepressants persists. A third of patients did not approach clinicians to ask for advice on stopping and when they did the results were mostly unhelpful, leading patients to seek advice online. This suggests that clinicians were not made aware of the trouble that patients were experiencing because patients took their concerns elsewhere (White et al., 2021). Additionally, when some patients reported withdrawal effects to their clinicians the clinicians did not believe the patients and instead perceived it as relapse of a mental health condition, whereby ignorance of the category of withdrawal perpetuates itself.

4.4. Changes to services

Patients provided their invaluable views on what service characteristics would have been useful in the healthcare system in order to help them more safely come off antidepressants. Many of the main requests related to practical steps to help them taper off their medication in a manner allowing gradual reductions of dose by small amounts over a period that was long enough to keep their withdrawal symptoms to tolerable levels, consistent with more recent guidance (Burn et al., 2020; Framer, 2021; Horowitz and Taylor, 2019, 2021; NICE 2022a). Notably, the top request (88% 'very useful') was for access to means to make small doses e.g. with liquids or compounded medications, such as 'tapering strips' (Groot and van Os, 2021). Patients make this request because for almost all antidepressants the size of currently available tablets makes it impossible to taper down in a gradual manner as recommended by the latest guidance (Burn et al., 2020; Horowitz and Taylor, 2019).

In the new guidelines on safe withdrawal from medications (NICE 2022b) including antidepressants, there is no explicit mention of access to liquid versions of medication or compounded small dose tablets like 'tapering strips', which makes its advice to institute 'proportionate' tapering of antidepressants (a simple approximation to hyperbolic tapering) difficult to implement in practice (Horowitz and Taylor, 2019). There is mention of 'liquids' in the stopping antidepressant section of the new Depression guidelines (NICE, 2022a). However, there is a lack of wide availability of liquids in primary care formularies because policies focus on short-term cost minimisation, missing the significant long-term potential benefits, financial and human, of enabling people to discontinue medication.

Other requests from patients included a request for well-informed health professionals able to oversee a personalised and flexible reduction scheme, and monitor reductions carefully, supplemented by peer support groups and access to a help line – either in telephone, video or online form. These requests suggest that current clinical practice does not provide the individualised, flexible reductions suggested by current guidelines. Implementing these guidelines requires upskilling of prescribers, establishment of dedicated staff within existing primary care practices to be able to provide close follow-up and support for patients stopping their medications. Perhaps it would be even more effective to establish dedicated, integrated deprescribing services with specialised staff trained for stopping psychiatric medications including antidepressants (Cooper et al., 2023). A telephone help-line or website would seem to be essential, alongside these upskilled or newly established services.

4.5. Strengths and limitations

In some regards the population surveyed is probably not representative of the wider population of people using antidepressants. Drug studies with randomised or more representative samples have not addressed the issues covered by our survey, a tendency which we hope may soon change. Our participants were a self-selected group who had sought out online advice and may therefore represent a group that is more affected by withdrawal symptoms on average, or shrewder in accessing information on the internet, and therefore able to make sense of alternative sources of information. People with an overall negative experience of antidepressants may have been particularly attracted to our survey. However, in response to the question 'Did the antidepressants help you with the problem they were prescribed for?', 49.2% responded 'yes', 20.1% said 'don't know/not sure' and 30.6% said 'no', which compares favourably with outcomes of drug trials using randomised samples. Participants tended to be highly educated (almost 30% with post-graduate degrees). However, the group of people accessing information about how to stop their antidepressant online is not a small group of people – there are tens of thousands of such patients, growing by 30% a year. (White et al., 2021). The study indicates the need for services for people who cannot access online support so easily. The study

sample was predominantly white (92%) and female (72%). This gender representation reflects the wider use of antidepressants, but black, Asian and other minority ethnic groups were clearly underrepresented.

The categorising of the qualitative responses (Tables 4, 6, 8 and 10) was a subjective process. This can be evaluated, to some extent, by reading the multiple examples of each category.

5. Conclusion

According to our sample, of over 1200 antidepressant users, and other related studies, current health systems are not well-equipped to help people stop antidepressants safely, and poorly informed doctors recommended tapers that are too rapid and cause patients substantial problems, compelling them to seek help online. It seems that medical education and medical systems are more geared towards prescribing medications than stopping them. This harms patients. There needs to be clearer, detailed guidelines on how to safely stop antidepressants, and system-wide upskilling of clinical staff, including the establishment of specialised services to deliver this care. The key components of these services include clinicians who are well-informed to deliver safe tapering, access to formulations of medication (e.g. liquids or compounded medication), adequate resources for monitoring and adjusting patients' tapers and acknowledgement of the significant suffering withdrawal can cause. Patients' concerns regarding their health must be taken seriously, which is perhaps inhibited by pervasive corporate messaging, and the effects thereof on official guidelines and doctors' knowledge.

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Author statement

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Contributors

MAH, JR and JM designed the study and wrote the survey. JR obtained ethical approval, programmed the survey, performed data analysis. JR and MAH wrote sections of the first draft of the paper, and all authors contributed to revising the final manuscript.

Declaration of competing interest

JR has no conflicts of interest. MAH is a Collaborating Investigator on the NHMRC-funded RELEASE trial in Australia investigating supported, hyperbolic tapering of antidepressants and a co-founder of Outro Health, a digital clinic helping people who wish to stop long-term antidepressant medication in Canada and the US using supported, hyperbolic tapering. JM is a co-investigator on a National Institute of Health Research (NIHR) funded study exploring methods of antidepressant discontinuation (REDUCE), a Collaborating Investigator on the RELEASE trial and Chief Investigator on the NIHR funded research programme on antipsychotic reduction (RADAR). She collects royalties from five books on psychiatric drugs.

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Appendix A. Supplementary data

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