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Identifying priorities for future research on reducing and stopping psychiatric medication: results of a James Lind Alliance priority-setting partnership

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ABSTRACT

Objective The objective of this study is to identify the top 10 research priorities on reducing and stopping psychiatric medication that reflect the perspectives and unmet needs of three key stakeholder groups (people with lived experience, family members/carers/supporters and healthcare professionals).

Methods A priority-setting partnership was conducted using the James Lind Alliance's seven-step process. This involved (1) creating an international Steering Group of key stakeholder representatives and (2) identifying potential partners; (3) gathering stakeholders' uncertainties about reducing and stopping psychiatric medication using an online survey and summarising the survey responses; (4) checking the summary questions against existing evidence and verifying uncertainties; (5) shortlisting the questions using a second online survey; (6) determining the top 10 research questions through a prioritisation workshop; and (7) disseminating the results.

Results A total of 3635 questions were collected in the initial survey from 884 respondents of which 32 questions were verified as uncertainties. These questions were then ranked in a second online survey by 526 respondents and the findings discussed in a final prioritisation workshop by 30 participants to produce the final top 10 list of research questions. These questions cover a range of areas including the most effective ways of safely reducing/stopping psychiatric medication and providing support to individuals undergoing the discontinuation process, as well as the best ways to educate healthcare professionals on this topic.

Conclusion The top 10 list of research priorities was produced through extensive engagement with key stakeholders and highlights important uncertainties and gaps in the existing evidence base that need to be addressed by future research.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study followed a robust and established methodology that is regarded as the gold standard in research priority-setting exercises.
⇒ This study has produced a top 10 list of research priorities on reducing and stopping psychiatric medication through extensive engagement with key stakeholders and addresses an important deficit in current practices of stakeholder engagement as involvement of people with lived experience of mental health challenges in research is not widespread, particularly in the early stages of research priority and agenda setting.
⇒ The list highlights important uncertainties and gaps in the existing evidence base on this topic that need to be addressed by future research.
⇒ The study was conducted entirely through English and the two surveys were only available in digital format which may have limited accessibility for certain groups and countries.

INTRODUCTION

The global consumption of psychiatric medication is increasing by 4% annually, with the greatest increase observed in antidepressant use.[1] In England, antidepressant prescriptions almost doubled over the last decade, from 47.3 million in 2011 to 85.6 million in 2022–2023.[2] Similar trends have been observed in prescribing rates of antipsychotics, gabapentinoids and mood stabilisers, while prescribing rates for benzodiazepine receptor agonists have been more variable across countries.[3–5] Longer prescription duration is one of the key driving factors for increased prescribing rates of psychiatric medication.[3]

These rising prescription trends have called into question the appropriateness of some long-term prescribing of psychiatric medication.[2 6] There is a substantial cohort of individuals looking to reduce and/or discontinue long-term use of psychiatric medication.[7 8] Reasons for wanting

to discontinue psychiatric medication include adverse effects, lack of perceived benefit, the desire to recapture personal autonomy and to live a life free of medication.[7–9] However, psychological and physical withdrawal symptoms from some of the above-mentioned drugs are a key barrier to successful discontinuation.[10 11] These symptoms can sometimes be mistaken for a return of an underlying condition or onset of a new health condition (ie, 'relapse').[11 12]

Despite the considerable cohort of individuals looking to discontinue psychiatric medication, there is a lack of high-quality evidence underpinning the process of reducing and stopping these medications.[13] While gradual dose reduction, that is, tapering is the recommended approach for discontinuing psychiatric medication, there are many uncertainties about the tapering process, which poses challenges both for people who are prescribed these medications or involved in their supply or administration.[13] There is a need for further research to establish an evidence base to support individuals and healthcare professionals in reducing and/or stopping psychiatric medication.

Traditionally, mental health research was solely conducted by the 'experts', that is, established researchers and healthcare professionals. This is now considered by many as a form of epistemic injustice, in which the perspectives of an individual diagnosed with a mental illness are wronged in their capacity as knower, by having their knowledge and expertise devalued in the knowledge production process.[14–16] More recently, there has been a shift in mental health towards a more participatory and collaborative model. This revised model advocates for a framework where experiential knowledge and the voice of the service user are central to treatment, research and policy-making processes.[15 16] In late 2023, a guidance document was jointly published by the WHO and United Nations which foregrounded a collaborative vision whereby individuals with mental health challenges can fully engage in their own recovery and participate in all areas of mental health, including mental health research.[17] The James Lind Alliance (JLA) developed a priority-setting partnership (PSP) process which has been in use for over 15 years and aligns with this new more modern, rights-based approach to mental health research.[18] The PSP process aims to identify and prioritise unanswered questions that is, 'evidence uncertainties', in specific conditions or areas of healthcare through working partnerships between key stakeholder groups.

This study aimed to identify the top 10 research priorities on reducing and stopping psychiatric medication that reflect the perspectives and unmet needs of three key stakeholder groups (people with lived experience of taking and/or stopping psychiatric medication, family members/carers/supporters and healthcare professionals) using a JLA PSP.

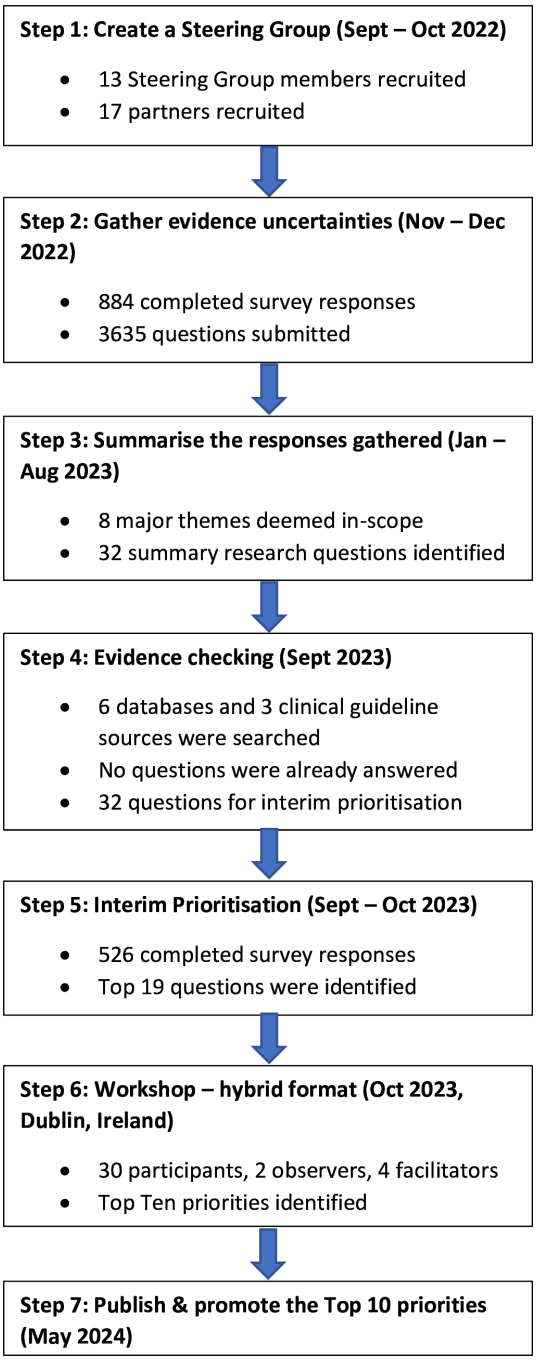

Figure 1 Overview of the James Lind Alliance priority-setting partnership process.

METHODS

This PSP followed the JLA's seven-step process (figure 1) and the published study protocol.[18 19] The REporting guideline for PRIority SEtting of health research was used to guide the reporting of this study.[20]

Step 1: establishing the steering group

A Steering Group was established to oversee and guide the PSP process, to discuss and agree the PSP's strategic orientation and scope, and to disseminate and publicise the online surveys.[18] The final Steering Group comprised 13 members from four countries (Ireland, Sweden, UK,

USA) representing different stakeholder groups: people with lived experience of taking and/or stopping psychiatric medication (n=4), family members and/or carers/supporters (n=2) and healthcare professionals (n=7). Several Steering Group members had dual roles (eg, healthcare professional with lived experience of psychiatric medication use/discontinuation). Steering Group meetings were conducted online to facilitate international representation and scheduled at regular intervals between September 2022 and December 2023 to maintain transparency and promote engagement. These meetings were chaired by a JLA Advisor (TG), and it was agreed at the outset that a minimum of three members each representing those with lived experience and those with clinical experience would need to be present to have a quorum. Steering Group members contributed their time on a voluntary basis.

The PSP's scope focused on reducing/stopping five classes of psychiatric medication: antidepressants, antipsychotics, benzodiazepine receptor agonists, gabapentinoids and mood stabilisers. As tapering is relevant irrespective of the clinical indication for which the medication is prescribed, the use of psychiatric medication for both mental and physical health conditions was considered within the PSP's scope.

Step 2: gathering evidence uncertainties (round 1 survey)

An anonymous online survey was conducted between 4 November and 31 December 2022 to capture research questions/uncertainties about reducing and stopping psychiatric medication from the three key stakeholder groups (described above). The survey was created in Qualtrics, reviewed by the Steering Group and piloted by representatives from each of the three key stakeholder groups. Pilot responses were not included in the final analysis.

The main section of the survey asked respondents to share their questions/uncertainties about reducing and stopping psychiatric medication as free-text responses with no word count limit. The survey also asked respondents to provide some brief demographic information in terms of stakeholder group, age, gender and country of origin. In cases where respondents could identify with more than one stakeholder group, they were asked to select the group that best reflected their questions/uncertainties about reducing and stopping psychiatric medication. For example, if a healthcare professional also had lived experience of discontinuing a psychiatric medication, and their questions stemmed from their lived experience as opposed to their clinical/professional experience, then they were advised to select 'people with lived experience of taking and/or stopping psychiatric medication' as their respondent group. The survey also included an optional free-text comments section for respondents to add any comments about reducing and/or stopping psychiatric medication. The survey link which was used in all dissemination activities directed individuals to the project website (www.tapersafer.org) where they could also access an information leaflet. A narrated video was also available on the website to overcome any literacy issues and improve equity of access. Before commencing the survey, respondents were asked to provide consent by confirming that they were ≥18 years old, represented one of the key stakeholder groups described above and agreed to complete the survey voluntarily. There were no geographical restrictions on participation.

The survey was promoted using a multistrand approach which included social media, newsletters and emails. Steering Group members and organisations that agreed to formally partner with, and promote, the PSP were asked to complete the survey and to share it with their networks to maximise the response rate. There are no formal target sample sizes for PSP surveys.[18] However, balanced representation of all stakeholder groups and diversity of respondents is desirable. Respondents' demographic profile was monitored on a weekly basis, primarily in terms of stakeholder group. Various strategies were implemented to enhance engagement from specific stakeholder groups, including targeted posts on Twitter and requesting assistance from specific organisations and groups in disseminating study information within their networks.

Step 3: summarising the responses gathered

This step involved reviewing round 1 responses, removing out-of-scope questions (ie, questions not directly related to tapering psychiatric medication), and creating a list of unique, researchable questions. Survey responses were exported into Microsoft Excel and analysed using template analysis to enable the creation of a list of codes ('template') representing the themes identified in the data, organised in a hierarchical structure.[21] Each respondent was assigned a unique response identifier (PSP001, PSP002, etc).

Preliminary coding was undertaken on a subset of 50 responses by the leading researchers (MB, CC, AH) to develop a provisional coding template. Once lower-order codes (level 2) were identified and defined, groups of similar codes were clustered and given a higher-order code title (level 1). Level 1 codes represented major themes. The provisional coding template was piloted on an additional 200 responses and modified on an iterative basis with input from the Steering Group. This group had oversight of the entire coding process and was sent the full dataset of coded responses to review to enhance rigour, credibility and transparency. Once the final coding template was agreed, it was applied to the full dataset by the lead researcher (MB). General queries that were not directly related to research or answerable through research (eg, how to take legal action against a prescriber) were coded under an out-of-scope code and excluded from the final analysis.

Most survey responses contained multiple questions/uncertainties and were not always written in the format of a research question. Once level 1 and level 2 coding were complete, responses were split into individual questions/

uncertainties and assigned a unique number which correlated to their response identifier. For example, if PSP001 submitted three questions, questions were split and named 1.1, 1.2 and 1.3 accordingly. Individual questions/uncertainties were grouped by major themes. In line with previous research, level 3 codes were created to facilitate the grouping of questions.[21]

Once levels 1–3 coding was completed, the coded data were converted into clear, indicative questions that were addressable by research using the PICO format (Patient, population, or problem; Intervention; Comparison or control; Outcome or objective) while retaining the sentiment of the original submission.[22] Similar questions were merged to minimise duplication and reduce the volume of data. Once formulated, the questions were reviewed by the Steering Group and refined to improve clarity.

Step 4: evidence checking

To verify that each indicative question had not previously been answered, relevant electronic databases (Medline, Embase, CINAHL, PsycINFO, Web of Science, Cochrane Database of Systematic Reviews) and organisational websites (National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network guidelines, Royal College of Psychiatrists) were searched for high-quality evidence (ie, systematic reviews, evidence-based guidelines) published within the last 3 years[18] using relevant keywords and search terms with input from an information retrieval specialist (GS).

All titles and abstracts were independently screened for inclusion by two researchers (MB and CC) in Covidence against inclusion criteria: systematic review or evidence-based guideline published within the last 3 years. Data were extracted by the lead researcher relating to the main aim/purpose of the reference source, as well as key results and author conclusions. This information was used to determine whether any of the summary questions had already been answered for any of the individual classes of psychiatric medication. Unless a reference source that addressed a summary question covered all classes of psychiatric medication, the question was considered only partially answered by existing evidence and retained as an existing uncertainty. To maintain transparency within the PSP process, a summary of the evidence-checking process findings linked to the list of unanswered summary questions was shared with the Steering Group for review before inclusion in the round 2 survey (step 5).

Step 5: interim prioritisation (round 2 survey)

A second anonymous online survey was conducted between 14 September and 16 October 2023 to identify which of the unanswered summary questions were considered most important by the key stakeholder groups. Similar to round 1, the survey was created in Qualtrics, reviewed by the Steering Group and piloted by representatives from each of the three key stakeholder groups. Pilot responses were not included in the final analysis.

The main component of the survey comprised two parts. Part 1 asked respondents to review the full list of summary questions and shortlist those that they felt were most important. Part 2 asked respondents to review their shortlisted questions and select up to 10 questions from that list. The same processes for dissemination, monitoring engagement and obtaining consent were used as per round 1. Individuals could respond to the survey irrespective of whether they completed the previous survey. Similar to the round 1 survey, in cases where respondents could identify with more than one stakeholder group, they were asked to select the group that best reflected their questions/uncertainties about reducing and stopping psychiatric medication. The response data were analysed in Microsoft Excel using descriptive summary statistics. Using the demographic information submitted by respondents, responses were grouped for each stakeholder group, and the questions were ranked based on the frequency with which they had been selected. This enabled the ranked priorities across the different stakeholder groups to be compared and contrasted. Once the analysis was complete, the Steering Group reviewed the findings and the 19 most highly ranked questions across the three key stakeholder groups were taken forward to the final workshop (step 6).

Step 6: workshop (final prioritisation)

A final prioritisation workshop was held in Trinity College Dublin in October 2023 to prioritise through consensus the most highly ranked questions about reducing and stopping psychiatric medication from the round 2 survey. This 1-day workshop was held as a hybrid event to enable participants to join remotely from any location and enhance international representation. Workshop participants (n=30) consisted of representatives from each of the three key stakeholder groups from six countries (Belgium, Canada, Ireland, Sweden, UK and US). They were identified through two processes. First, the round 2 survey respondents could express their interest in participating in the workshop through a dedicated email address. Second, all Steering Group members were invited to attend and asked to nominate other individuals within their networks. The response obtained exceeded expectations. Workshop participants were purposively selected to achieve a representation of voices, genders and nationalities. Workshop participants contributed their time on a voluntary basis; however, travel and accommodation were reimbursed for those attending the workshop in person.

The workshop was facilitated by two JLA advisors and two JLA-trained facilitators who chaired the small group sessions. Prior to the workshop, participants were provided with the list of 19 shortlisted questions and asked to select their top three and bottom three questions. An adapted Nominal Group Technique was used to make decisions and ensure that all participants' opinions were considered.[18] The workshop involved three small group sessions during which participants completed several ranking exercises. In the first session, participants

were split into four groups, balanced according to participant background, and asked to share their top three and bottom three priorities. Similarities and differences between the individual rankings were documented. During the second session, each group was tasked with ranking all 19 shortlisted questions in order of priority. Questions were assigned to gold, silver and bronze categories and then ordered within each category to assign a score to each question. A combined rank was calculated by arithmetic averaging of the individual group rankings and shared with the entire group of participants. For the final small group session, participants were split into three groups and groupings were revised to ensure that participants were exposed to different stakeholders and perspectives. During this session, each group started with the combined ranking, and was given the opportunity to revise this as they wished. The rankings from each group were again collated using Microsoft Excel. The workshop concluded with a whole group plenary discussion to review and reflect on the final top 10 priorities.

Patient and public involvement

People with lived experience of taking and/or stopping psychiatric medication and family members and/or carers/supporters were involved as equal members of the Steering Group members and had a key role in all stages of this research (design, conduct, reporting and dissemination plans). People with lived experience of taking and/or stopping psychiatric medication and family members and/or carers/supporters were also involved in deciding on the top 10 priorities at the final workshop.

RESULTS

Step 2: gathering evidence uncertainties (round 1 survey)

There were 884 responses to the survey containing at least one question/uncertainty. All three stakeholder groups were represented in the responses: people with lived experience of taking and/or stopping psychiatric medication (69%), healthcare professionals (21%), family members/carers/supporters (10%). Most respondents resided in the US (42%), UK (21%) and Ireland (10%) with the remainder spread across Europe (13%), Canada (6%), Oceania (5%), Africa (<1%), Asia (2%) and Latin America (<1%). Full details of respondents' demographics are reported in table 1.

Step 3: summarising the responses gathered

Round 1 respondents submitted 3635 individual questions/uncertainties. These were reviewed in consultation with the Steering Group and out-of-scope questions (n=1458) were removed, leaving 2177 questions (figure 1).

The in-scope questions were then coded into the framework generating eight themes (level 1 codes): (1) tapering aids/supports; (2) tapering process; (3) post-taper; (4) withdrawal symptoms and adverse effects; (5) accountability/responsibility; (6) acknowledgement/recognition of problems/issues; (7)

Table 1 Demographic characterises of respondents to the round 1 and round 2 surveys

	Round 1 survey	Round 2 survey
	N (%)	N (%)
Total respondents	884	526
Gender		
Male	232 (26%)	143 (27%)
Female	629 (71%)	371 (71%)
Non-binary	21 (2%)	11 (2%)
Did not specify	2 (<1%)	1 (<1%)
Stakeholder group		
Person with lived experience	609 (69%)	343 (65%)
Family member, friend, carer, supporter	86 (10%)	32 (6%)
Healthcare professional	186 (21%)	151 (29%)
Other	3 (<1%)	0
Healthcare professional group		
General practitioner/primary care physician	11 (6%)	7 (5%)
Nurse	47 (25%)	66 (44%)
Pharmacist	22 (12%)	23 (15%)
Psychiatrist	64 (34%)	17 (11%)
Psychologist/psychotherapist/counsellor	24 (13%)	17 (11%)
Social worker	5 (3%)	4 (3%)
Specialist physician	4 (2%)	1 (<1%)
Occupational therapist	0	7 (5%)
Other	9 (5%)	9 (6%)
Age range (years)		
18–24	22 (2%)	7 (1%)
25–34	88 (10%)	67 (13%)
35–44	164 (19%)	120 (23%)
45–54	195 (22%)	127 (24%)
55–64	236 (27%)	129 25%)
65–74	137 (15%)	62 (12%)
75–84	39 (4%)	14 (3%)
>85	2 (<1%)	0
Did not specify	1 (<1%)	0
Country of origin		
USA	371 (42%)	156 (30%)
UK	188 (21%)	147 (28%)
Ireland	88 (10%)	79 (15%)
Canada	49 (6%)	35 (7%)
Oceania	41 (5%)	36 (7%)
Europe	118 (13%)	44 (8%)
Latin America	7 (<1%)	7 (1%)
Africa	5 (<1%)	2 (<1%)
Asia	15 (2%)	9 (2%)
Did not specify	2 (<1%)	11 (2%)

Table 2 Overview of process of iterative review and refinement of summary questions following round 1 survey

Theme	Number of summary questions per round of review			
	Prereview	Review 1	Review 2	Review 3
1. Tapering aids and supports	18	8	7	6
2. Tapering process	23	17	8	8
3. Post-taper	12	7	4	4
4. Withdrawal symptoms and adverse effects	11	9	7	5
5. Accountability	14	8	3	2
6. Acknowledgement of issues	17	4	3	3
7. Communication and decision-making	7	6	3	3
8. Healthcare professional	3	1	1	1
Total number of questions	**105**	**60**	**36**	**32**

communication/decision-making; and (8) healthcare professional knowledge/training. Examples of questions linked to each of these themes are provided in online supplemental table 1.

Once coding was complete, the coded data were converted into researchable summary questions. Submitted questions were reviewed for similarity, combined and rephrased to create summary questions. Initially, there were 105 summary questions. These questions underwent three rounds of review and refinement involving the Steering Group (table 2). This included exclusion, merging and/or rewording of questions. After the review, 32 'indicative questions' (online supplemental table 2) were taken forward to the evidence check (step 4).

Step 4: evidence checking

Following the evidence review (online supplemental table 3), all 32 questions were considered as 'verified uncertainties' and were entered into the round 2 survey (step 5) for prioritisation.

Step 5: interim prioritisation (round 2 survey)

In total, 526 respondents completed the survey. The respondent profile was broadly similar to round 1 in terms of stakeholder group and geographical location. Full details of respondents' demographics are reported in table 1.

The ranked order of each question is outlined across each stakeholder group in table 3. In consultation with the Steering Group, the 19 highest ranked questions across the stakeholder groups were taken forward to the final prioritisation workshop (step 6) (online supplemental table 4).

Step 6: final prioritisation workshop

Thirty individuals representing each of the key stakeholder groups took part in the final prioritisation workshop: people with lived experience of taking and/or stopping psychiatric medication (n=10), family members/carers/supporters (n=4) and healthcare professionals (n=16). Most participants attended in person (n=21).

The top 10 priorities were agreed with workshop participants and are listed in table 4. The remaining priorities are listed in online supplemental table 5. The two highest ranked questions focused on the most effective ways of safely reducing/stopping psychiatric medication and providing support to individuals undergoing the discontinuation process. Another question asked about the best ways to educate healthcare professionals about reducing and stopping psychiatric medication. Other questions

Table 3 Ranked order of questions from round 2 survey

Ranked order	People with lived experience	Family members/carers/supporters	Healthcare professionals
1	Q9	Q3	Q3
2	Q32	Q32	Q16
3	Q3	Q9, Q23	Q32
4	Q16	Q4*, Q25, Q28	Q6, Q25
5	Q28	Q2, Q26	Q9
6	Q26	Q22	Q7
7	Q19	Q6, Q14, Q18, Q24	Q31
8	Q15	Q12, Q15, Q16, Q31	Q4*

*Due to a high level of overlap/similarity between Q3 and Q4, the Steering Group agreed to exclude Q4 and retain Q3.

Table 4 Top 10 priorities for reducing and stopping psychiatric medication

Final ranking (after workshop)	Question
1	What is the most effective way to safely reduce and stop psychiatric medication in terms of tapering approach, rate of taper and duration of taper? What individual service user characteristics (eg, age, gender, pregnancy, other medical conditions/diseases) and drug characteristics (eg, medication type, duration of treatment, use of other medication) determine these?
2	What are the most effective ways to provide support to individuals who are reducing and stopping psychiatric medication? These may include, but are not limited to, family/peer support, educational support, financial support, psychological support, and healthcare support.
3	What are the best ways to educate current and future healthcare professionals about reducing and stopping psychiatric medication in terms of the tapering process, associated risks/difficulties, withdrawal symptoms and supporting shared decision-making? What is the impact of education on clinical practice?
4	What are the views and experiences of individuals who have reduced/stopped psychiatric medication or are currently reducing/stopping psychiatric medication on the tapering process and accessing tapering support?
5	What are the views and experiences of service users, family members/carers and healthcare professionals around shared decision-making in relation to starting and stopping psychiatric medication? This includes informed consent. How can the process of implementing shared decision-making be improved when starting and stopping psychiatric medication? What factors influence this process?
6	What are the positive and negative long-term consequences of reducing and stopping psychiatric medication on an individual's physical and mental health status? For individuals who experience negative consequences, what are the best ways to manage these difficulties? Negative consequences may include withdrawal symptoms, relapse and protracted withdrawal syndromes.
7	What are the perspectives of key stakeholders on the professional, ethical and legal responsibilities of healthcare professionals and/or the pharmaceutical industry in relation to reducing and stopping psychiatric medication? Stakeholders include service users, family members/carers and healthcare professionals. What are the best ways to enact these responsibilities?
8	Which factors influence the prevalence, duration and severity of withdrawal effects that appear during or after reducing and stopping psychiatric medication? What is the best way to control these factors and reduce an individual's risk of developing withdrawal effects or relapsing?
9	How best can the withdrawal symptoms that appear during or after reducing and stopping psychiatric medication be identified and differentiated from other causes (eg, relapse/return of underlying condition, distress)?
10	What are the barriers and enablers to reducing and stopping psychiatric medication? These may include, but are not limited to, the service user, the healthcare professional, family and society.

focused on understanding barriers and enablers to reducing and stopping psychiatric medication, and the views and experiences of those who had reduced/stopped or were currently doing so. Questions also asked about the perspectives of key stakeholders on shared decision-making, as well as the professional, ethical and legal responsibilities of healthcare professionals and the pharmaceutical industry in relation to reducing and stopping psychiatric medication. Other questions focused on the consequences (positive and negative) of reducing and stopping psychiatric medication on an individual's physical and mental health, as well as understanding the withdrawal symptoms.

DISCUSSION

This study has produced a top 10 list of research priorities on reducing and stopping psychiatric medication through extensive engagement with key stakeholders representing people with lived experience of taking and/or stopping psychiatric medication, family members/carers/supporters and healthcare professionals. The list highlights important uncertainties and gaps in the existing evidence base on this topic that need to be addressed by future research. To our knowledge, this is the first JLA PSP to focus on psychiatric medication. The process by which these priorities have been developed also addresses an important deficit in current practices of stakeholder engagement as involvement of people with lived experience of mental health challenges in research is not widespread, particularly in the early stages of research priority and agenda setting.[23] For example, a survey commissioned by the International Alliance of Mental Health Research Funders found that most involvement of people with lived experience in health research has traditionally taken place at the level of feedback and information giving (ie, 'consultation' stages).[24] Consequently, people with lived experience of mental health challenges report difficulties in sharing their

views and influencing the research agenda.[23] A hallmark of the JLA approach is the representation of all stakeholder groups throughout the priority-setting process. Equitable involvement of different stakeholders has been shown to facilitate the process of setting research priorities by developing a more holistic understanding of the 'unknown unknowns'.[25]

The highest ranked question focused on the most effective ways of safely reducing/stopping psychiatric medication. This is a long-standing issue that has not been answered by previous research. To date, there is no standard approach on how best to taper which has created many uncertainties regarding the tapering process.[26] Studies have shown that the rate of taper is typically based on prescribers' clinical experience as opposed to high-quality empirical evidence.[13] Key organisations in the UK, such as the Royal College of Psychiatrists and the NICE, recognise the importance of gradual dosage reduction at a rate that is tailored to the individual.[27] There is a pressing need for further comprehensive research to establish an evidence base to support individuals looking to reduce and/or stop psychiatric medication.

Linked to this question about the most effective ways of safely reducing/stopping psychiatric medication is the question about what the most effective ways are to support individuals undergoing the discontinuation process. The prioritisation of this question highlights a fundamental shift in the recognition of the potential challenges of discontinuing psychiatric medication and associated withdrawal symptoms, which were previously underacknowledged. For many years, guidelines described antidepressant withdrawal symptoms as mild and self-limiting, typically lasting only 1–2 weeks.[28] Only in recent years have professional bodies and prescribing guidelines acknowledged that a proportion of individuals taking psychiatric medication, such as antidepressants, may experience significant withdrawal symptoms following discontinuation.[27 28] Although gradual dosage reduction is a core feature of many interventions, there is less robust evidence about additional measures such as psychological support.[29 30] In addition to this, the availability of dedicated withdrawal services is lacking.[31] In the absence of empirical evidence, individuals are increasingly turning to online sources, such as discussion fora and peer support groups, for guidance and support while tapering psychiatric medication.[32]

Another key question asked about the best ways to educate healthcare professionals about reducing and stopping psychiatric medication. Previous research has highlighted important perceived deficits in healthcare professionals' knowledge of psychiatric medication and tapering approaches.[33] This aligns with the views and reported experiences of people taking psychiatric medication.[34] For example, a survey of members of an online discussion forum, who have stopped or tried to stop antidepressant use, found that 71% of respondents (n=906/1276) felt their doctors' advice regarding stopping an antidepressant was unhelpful.[35] Reasons included their doctor recommended an abrupt taper and/or were unfamiliar with the concept of withdrawal. Similar findings were reported by another survey involving antidepressant users in which 64% (n=205/319) of respondents reported receiving a lack of information about the potential for withdrawal symptoms from their doctor and 40% were advised to withdraw from their medication rapidly.[36] Gaps in healthcare professionals' knowledge and training may create barriers to the safe discontinuation of psychiatric medication. According to this survey, the most frequently cited recommendation for future withdrawal services was to improve healthcare professionals' knowledge.[36]

Other questions focused on the consequences of reducing and stopping psychiatric medication on an individual's physical and mental health, as well as understanding the withdrawal symptoms, and key stakeholders' perspectives on shared decision-making. Various adverse effects are associated with the use and discontinuation of different psychiatric medications, about which individuals have reported not being informed before starting.[37] According to the WHO, shared decision-making and informed consent are crucial to the provision of person-centred and recovery-oriented care.[17] Service users have reported challenges in having their autonomy and choice respected and being involved in decisions around their medication.[38] This does not align with a rights-based, recovery-oriented approach to mental healthcare that seeks to promote open discussion about medication.[17] Another related area of importance was the professional, ethical and legal responsibilities of healthcare professionals and the pharmaceutical industry in relation to reducing and stopping psychiatric medication. This has not been examined by previous research.

Although the PSP's key output was the top 10 list of research priorities, it is important to note that several other shortlisted questions were discussed at length during the final prioritisation workshop. These questions may also provide a useful starting point for future research on reducing and stopping psychiatric medication. For example, the question about improving the availability of psychiatric medication in formulations and dosage ranges that facilitate the tapering process was deemed a key uncertainty among many survey respondents and workshop participants. There is currently a lack of evidence informing clinicians or individuals as to what extent existing marketed formulations of psychiatric medication, which primarily consist of oral solid dosage forms (ie, tablets, capsules, oral liquids/drops) can be further manipulated (eg, split/crushed/diluted) to achieve smaller doses with due consideration to the physicochemical properties of individual medication and their formulations. Consequently, many individuals attempting dosage reduction use do-it-yourself methods that are shared online or through peer support forms that involve crushing tablets and making liquid preparations.[11 32] The accuracy, efficacy and safety of these approaches have not been evaluated. Tapering strips, consisting of psychiatric

medication packaged into pouches of individual daily doses, have been developed in the Netherlands to enable gradual dosage reduction.[39] However, as in the Netherlands, tapering strips are not widely available or accessible on public health schemes via existing reimbursement mechanisms. This is therefore an important area for future research, but ultimately, the stakeholder collaboration determined that other questions about the tapering process were of higher priority.

While the prioritisation of research uncertainties was the principle objective of the PSP, it also sought to enhance and strengthen the manner in which research questions are identified. By engaging key stakeholders in a meaningful and structured way in jointly identifying research priorities, the PSP process enabled the coproduction of research priorities.[25 40] Coproduction has been widely advocated as a means of valuing and respecting knowledge from different sources and stakeholders, and thus promoting inclusive research practices and strengthening research impact.[40] In this sense, the PSP process aligns with more modern, rights-based approach to mental health research.[41]

A key strength of this study was the robustness of the JLA PSP methodology which has been used internationally across a range of healthcare domains and is regarded as the gold standard in research priority-setting exercises.[42] The research prioritisation process was further strengthened through extensive engagement with the three key stakeholder groups across the Steering Group members, survey respondents and workshop attendees. The involvement of a diverse and international mix of stakeholders with varying demographics at every step of the process gives the resultant priorities legitimacy. Moreover, the high level of interest and engagement with the study, as evidenced by the volume of responses submitted to both the round 1 and 2 surveys, adds to the credibility of the findings as the study captured uncertainties/questions from hundreds of individuals worldwide.

A limitation of this study was that it was conducted entirely through English and the two surveys were only available in digital format due to resource and logistical constraints. This may have limited accessibility for certain groups and countries where English is not widely spoken. Furthermore, in consultation with the Steering Group, it was decided not to capture information on the ethnicity of survey respondents as this information would not have contributed directly to the selection of the top 10 list of research priorities. It must also be noted that the round 1 survey submissions primarily consisted of free-text responses. Despite efforts to minimise interpretative bias while coding, the subjective nature of coding qualitative data always creates a potential for bias. However, the Steering Group had oversight of the entire coding process and were sent the coded responses to review to enhance rigour, credibility and transparency of the coding process.

CONCLUSION

This PSP has produced a top 10 list of research priorities on reducing and stopping psychiatric medication through extensive engagement with key stakeholders representing people with lived experience of taking and/or stopping psychiatric medication, family members, carers/supporters and healthcare professionals. The list highlights important uncertainties and gaps in the existing evidence base on this topic that should be addressed by future research. This top 10 list of research priorities is relevant to research funding agencies and could help to guide future research and deliver responsive and strategic allocation of research resources, with a view to improving the future health and well-being of individuals who are taking psychiatric medication.

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Competing interests Cathal Cadogan (CC) sits on the Board of Directors for the Alliance for Benzodiazepine Best Practices; a not-for-profit organisation with the mission to inform evidence-based improvements in the use of benzodiazepines and Z-drugs. Anne Cody (AC) works at the Health Research Board, who part-funded the process The grant did not contain any expectation or condition of

being included in the Steering Group. Adele Framer (AF) is the founder of Survivin gAntidepressants.org which is an online community of volunteers providing peer support for tapering all psychiatric drugs and their withdrawal syndromes. AF sit on the Board of Directors for International Institute for Psychiatric Drug Withdrawal a not-for-profit organisation which supports research and practice-based knowledge that will facilitate safe reduction of and withdrawal from psychiatric drugs and is President of the Psychotropic Deprescribing Council. Mark Horowitz (MH) is a collaborating investigator on the RELEASE and RELEASE+ trials in Australia evaluating hyperbolic tapering of antidepressants against tapering as usual. MH has received honoraria for lectures about deprescribing from several NHS Trusts, and universities in the US and the UK. MH is a co-founder of and consultant to Outro Health digital clinic which aims to help patients in the US to help stop no longer needed antidepressant treatment. Christy Huff (CH) is the Medical Director of the Benzodiazepine Information Coalition, a not-for-profit organisation with the mission of educating about the potential adverse effects of benzodiazepines taken as prescribed. Nicole Lamberson (NL) is a Medical Board Member of the Benzodiazepine Information Coalition, a not-for-profit organisation with the mission of educating about the potential adverse effects of benzodiazepines taken as prescribed. NL is cofounder of the Inner Compass Initiative's The Withdrawal Project, a not-for-profit organisation which seeks to help people make more informed choices about psychiatric diagnoses and drugs and build community with like-minded others thinking critically about today's mental health industry. NL is an Associate Member of the International Institute for Psychiatric Drug Withdrawal, a not-for-profit organisation which supports research and practice-based knowledge that will facilitate safe reduction of and withdrawal from psychiatric drugs. Luke Montagu (LM) is cofounder of the Council for Evidence-based Psychiatry which seeks to communicate evidence of the potentially harmful effects of psychiatric drugs to the people and institutions in the UK that can make a difference. All other authors declare no competing interests.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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