

DECISIONS WERE MADE ABOUT ME NOT WITH ME

A SAMH Research Report:
Treatment and Support
for Depression

ABOUT SAMH

Around since 1923, SAMH is Scotland's national mental health charity.

SAMH has represented the voice of people most affected by mental health problems in Scotland for more than 90 years.

Today, in over 60 communities we work with adults and young people providing mental health social care support, services in primary care, schools and further education, among others. These services together with our national programme work in See Me, respectme, suicide prevention and active living; inform our policy and campaign work to influence positive social change.

SAMH is dedicated to mental health and wellbeing for all: with a vision of a society where people are able to live their lives fully, regardless of present or past circumstances.

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EXECUTIVE SUMMARY

Given the prevalence of depression in Scotland, it is important that medical guidance is followed and that people are able to access treatment that is aligned with their preferences. Where there are barriers to shared decision making and accessing treatments, these need to be identified and addressed.

SAMH undertook this research to find out about people's experiences of being involved in decisions about treatment and support for depression, in order to establish barriers to people's participation. We also wanted to know if the treatment people were given was aligned with their preferences and if the prescribing processes reflected the advice in National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN) and NHS Education for Scotland (NES) guidance.

This work builds on and updates research that SAMH undertook in 2012, which summarised the experiences of a group of people who took medication for mental ill-health.¹ In this new report, we decided to specifically focus on depression due its prevalence, and in acknowledgement of the fact that people's experiences of being prescribed treatment can vary depending on their mental health problem.



Almost half of respondents (48%) were not referred to a psychological therapy

Key Findings

In total, 281 people completed the survey and 12 people took part in focus groups. The research found that almost half of respondents (48%) were not referred to a psychological therapy. Additionally almost half of respondents who were prescribed an antidepressant (49%) were not referred to a psychological therapy, despite medical guidance advising that antidepressants should be prescribed alongside a psychological therapy.² Most respondents (68%) had been treated for depression for over two years.

The research found that respondents who were happier with their level of involvement in decision making about their treatment and support were more likely to be satisfied with their treatment. This is important because we know that people who have higher levels of treatment satisfaction are more likely to benefit from it.³ However, over a third of respondents to SAMH's survey (36%) were unhappy with their level of involvement.

The findings give some insight into the barriers to involvement in decision making. For example, 46% of respondents were not given treatment options; almost a third (32%) did not feel well informed; and around a quarter (24%) did not feel like their doctor understood them.

This data aligns with the most frequently discussed barriers in focus groups and in the survey's free text boxes, which included: lack of treatment options, particularly psychological therapies; lack of information about different treatment options; GP time constraints; and the symptoms of depression.

A significant number of respondents (91%) had been prescribed antidepressants, but this is not surprising given that respondents and participants were all receiving support for depression. It is also important to note that the context of respondents' prescriptions is not known. There could be many reasons for not referring someone to a psychological therapy, including personal preference. Moreover, while there has been a steady increase in antidepressant use,⁴ this is not necessarily due to an increase in prevalence of depression but to a number of factors, in particular an increase in long-term prescribing aligned with medical guidance.⁵

SAMH is making a number of recommendations based on the experiences of the people who took part in the report including:

- 1** The Scottish Government to review the psychological therapies waiting time target, to establish why NHS boards continuously fail to meet it.
- 2** The Scottish Government to undertake a review of psychological therapy provision across Scotland, to establish if people have access to the full range of evidence-based therapies as outlined in the NHS Scotland Psychological Therapy Matrix.⁶
- 3** Integration Joint Boards (IJB), which have oversight of community mental health services, to commission a range of psychosocial services to support people experiencing low to moderate levels of depression.

The full list of recommendations is outlined at the end of this report.

ABOUT DEPRESSION

DEPRESSION IN SCOTLAND

Depression is the third leading cause of disability in Scotland, behind heart disease and back pain,⁷ and is the leading cause of disability globally.⁸ There has been a steady increase in the number of adults reporting symptoms of depression in Scotland, with 11% now reporting that they experience two or more symptoms, indicating moderate to severe depression.⁹ People living in the most deprived communities in Scotland are four times more likely to experience depression than people living in the most affluent communities.¹⁰

WHAT IS DEPRESSION?

Low mood and feeling down is not uncommon, and usually these feelings pass in due course. If feelings of low mood are interfering with a person's day-to-day life and don't go away after a couple of weeks, or if they come back over and over again for a few days at a time, it could be a sign that someone needs treatment or support for their depression.

In its mildest form, depression can mean just being in low spirits. It doesn't stop you leading your normal life, but makes everything harder to do and seem less worthwhile. At its most severe, major depression (clinical depression) can be life-threatening, because it can have serious detrimental effects on a person's overall health and cause suicidal feelings.

Depression varies from person to person and can happen for one or more reasons. Life events can trigger depression, like bereavement or moving schools, as can traumatic experiences like physical abuse. Sometimes physical health conditions may be the cause of

someone's depression, such as the menopause or low blood sugar. Depression can also be a side effect of a lot of different medicines. Occasionally someone may experience depression for no obvious reason.

For more information about depression, read SAMH's guide to [Understanding Depression](#)

ASSESSING DEPRESSION

There are clear guidelines for assessing people with depression from the National Institute for Health and Care Excellence (NICE).¹¹

NICE advises health care practitioners, like GPs, to not simply rely on a symptom count when diagnosing depression. Instead they should consider the degree to which the depression affects a person's day-to-day life. This is called 'functional impairment'.¹² This is important because it recognises that someone with fewer symptoms may find them very debilitating.

The guidance advises practitioners to explore how a person's depression may have changed as a result of other health conditions, past experience of treatment, living conditions and other factors. They are also advised to ask people directly about suicidal feelings.¹³

TREATMENT FOR DEPRESSION

There are various different treatment options available for depression. NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and NHS Education for Scotland (NES) all provide guidance on evidence-based treatment for depression.

For people with low level depression, which is sometimes called ‘sub-threshold symptoms’, the guidance advises an initial course of psychosocial therapy. There are different kinds of psychosocial therapy including guided self-help and physical activity programmes. For people who have low level to moderate depression, a high-intensity psychological therapy is recommended. This can include Cognitive Behavioural therapy (CBT), interpersonal therapy and behavioural activation among others.^{14, 15, 16}

If someone is experiencing moderate to severe depression, the guidance indicates that antidepressants can be used alongside a high-intensity psychological therapy. The guidance also indicates that antidepressants can be used for people with low level to moderate depression if psychosocial and psychological treatments have not worked.¹⁷

It’s important to note that, while antidepressant use has been steadily increasing,¹⁸ research has shown that this could be accounted for by a number of factors and is not necessarily due to an increase in prevalence of depression.^{19, 20} In particular, longer term prescribing means that there are increasing numbers of people using antidepressants.²¹ Moreover, while people should be able to access treatment aligned with their preference, NICE guidance advises continued use of antidepressants if they are found to be effective, especially for people with chronic or intermittent depression.²²

It should also be noted that antidepressants can be prescribed to treat other health conditions not related to mental ill-health.

SHARED DECISION MAKING

According to NICE guidance, a person’s preferences and priorities should influence the choice of treatment they are given, along with other factors.²³ The General Medical Council (GMC) provides guidance for practitioners on shared decision making, which emphasises the importance of working in partnership with a patient.²⁴

It advises practitioners to listen to patients; respect their views; discuss diagnosis, prognosis and treatment; and maximise opportunities for patient decision making. The GMC also advises practitioners that no single approach will suit every patient, or be appropriate in every circumstance.²⁵



ABOUT OUR RESEARCH

METHODOLOGY

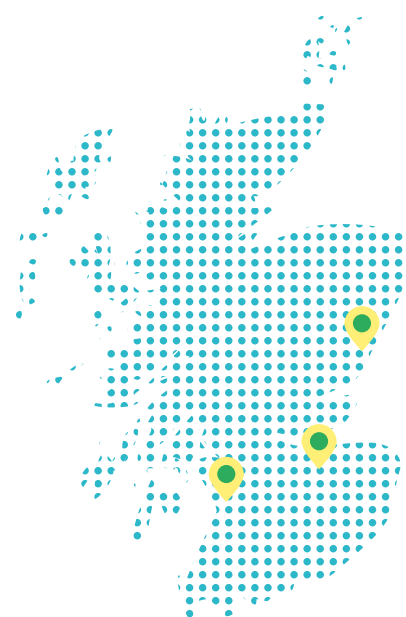
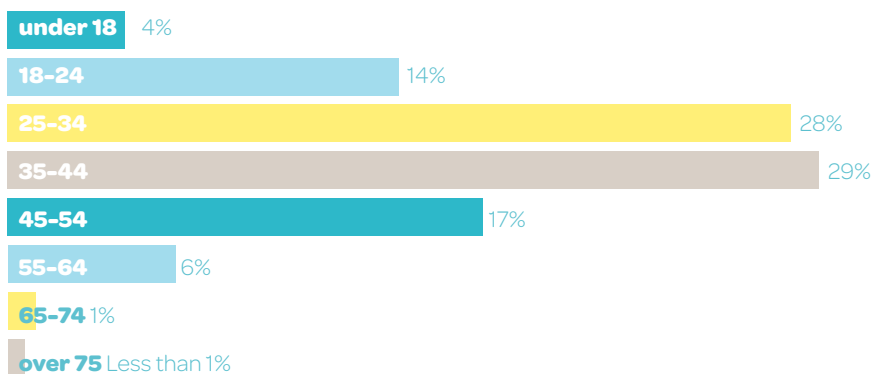
The research consisted of a survey that was publicised through SAMH's social media channels and mailing lists, as well as three focus groups with people that responded to the survey.*

There were 281 people who completed the survey.† Respondents had to be over 16 years old, living in Scotland and have received or been referred for treatment for depression within the last two years. The survey consisted of multiple choice and matrix questions, as well as free text boxes.

Respondents by Gender



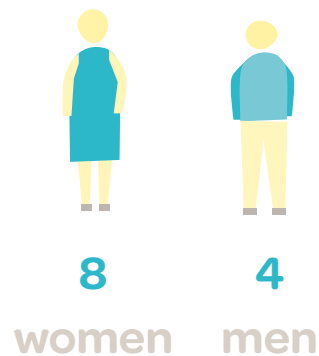
Respondents by Age Group



There were a total of

12
focus group
participants

across three focus groups held in Glasgow, Edinburgh and Aberdeen. The survey findings informed the discussion of the focus groups.



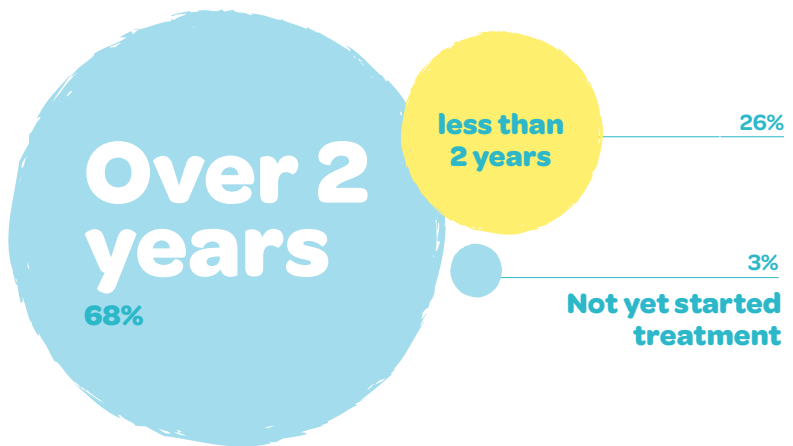
* Throughout this report, the term respondents refers to people who completed the survey and the term participants refers to people who attended the focus groups.

† In reporting the survey responses, percentages have been rounded to the nearest whole number.

OUR FINDINGS

TYPE AND DURATION OF TREATMENT

For how long have you been treated for depression?



Over the past two years, have you been **PRESCRIBED** or **REFERRED** to any of the following for your depression?

Antidepressants

91% of respondents indicated that they had been prescribed antidepressants

Psychological therapy

52% indicated that they had been referred to a psychological therapy

Mental Health specialist

40% indicated that they had been referred to a mental health specialist/psychiatrist

Individual or group CBT

37% indicated that they had been referred to individual or group CBT

Other

18% indicated 'other' for being prescribed or referred for treatment

Physical activity

7% indicated that they had been referred to a physical activity programme

Almost half of respondents (48%) were not referred to a psychological therapy.



Almost half of respondents were not referred to a psychological therapy

It's important to note that there could be many reasons for not referring someone for psychological therapy, including a person's treatment preferences. However, the qualitative data from both the survey and the focus groups indicates that there are barriers to shared decision making and accessing non-pharmaceutical treatments for depression.

Additionally, 49% of respondents who had been prescribed antidepressants had not been referred for psychological therapy. We know that when someone is prescribed antidepressants, NICE guidance advises that they should either have already received psychological therapy or also be referred for psychological therapy.

In comparison to psychological therapies and other non-pharmaceutical treatments, there was a high level of antidepressant prescription among respondents (91%). This was the case for people who had been treated for less than two years and for those who had been treated for more than two years.

FEELING INVOLVED

Over a third (36%) of respondents were unhappy with their level of involvement in decision making about treatment for their depression.

Our research found that respondents who were happier with their level of involvement in decision making were more likely to be satisfied with the treatment prescribed for their depression. This is an important finding, because we know that people who are more satisfied with the treatment they are receiving are more likely to benefit from that treatment.²⁶

Increased involvement could therefore be a very tangible way of helping people to benefit from treatment for depression.

Only 45% of respondents to our survey indicated that they were happy with their level of involvement in decision making about treatment for their depression. It's clear, therefore, that in a lot of circumstances people's involvement could be improved.

TREATMENT OPTIONS

46% of respondents were not given different options for treatment and support for their depression.

Our research supports findings that people are not always offered treatment options when seeking support for their mental health.²⁷ In the case of our research this was specific to treatment and support for depression. This is despite 90% of respondents indicating that professionals should not be making decisions about treatment without asking how the person feels about it.

Not only is this concerning given that the NICE and GMC guidance is explicit about discussing treatment options,^{28,29} but it is also counterproductive. We know that the more choices a patient is able to make, from the type of treatment to when and where they receive it, the more likely they are to benefit from treatment.³⁰ Specifically, our research shows that being given options was considered by some to be an important part of patient involvement:

'I think that comes from the patient being allowed to talk and the other person listening, and having options there, and having realistic options [...]'
(Focus group participant)

'[...] there are loads of things that have been kind of helpful to treat depression and other mental illnesses, so I think you should be offered options and the pros and cons of all of them [...]'

(Focus group participant)

Not being given treatment options was associated with feelings of fear and anxiety, and seen as a barrier to shared decision making by some respondents and participants. There is an indication that where options were not offered, people were accepting treatment that was potentially not aligned with their preferences.

'I think there's a fear of just being told this is it, if you don't choose this then there's not another option.'

(Focus group participant)

'I would have liked to be offered different options but the GP decided the best option for me without discussing other options.'

(Survey respondent)

It was frequently indicated that antidepressants were used as a first line therapy, with little to no other options presented at this stage. The experience of being prescribed antidepressants as a first line therapy was often associated with feelings of being dismissed and not listened to, in particular when the person wanted to try other treatment options.

'Was not given any choice nor was there any discussion when initially consulted GP – was put straight onto antidepressants. Feel I should have been asked if I wanted support, not just thrown a prescription.'

(Survey respondent)



Almost a third of respondents (32%) did not feel well-informed about their treatment.

'He was very quick to prescribe me antidepressants, even though it was the first time he met me.'

(Survey respondent)

However, it's important to note that there were respondents and participants who acknowledged that their knowledge of antidepressants was limited and that being more informed would have made them feel more comfortable about being prescribed medication.

There was also acknowledgment from some respondents and participants that primary care practitioners, in particular GPs, experience barriers in providing people with different treatment options. Barriers that were frequently highlighted included not having services to refer people to and long waiting times for non-pharmaceutical treatments, both of which had a direct effect on some respondents' and participants' experience of seeking support.³¹

'The GP needs to be the kind of director, but they need to have people to direct to, I think that's part of the problem.'

(Focus group participant)

'They refused to put me on the waiting list for counselling as they said with the waiting list in my area there was no point.'

(Survey respondent)

'Requesting specific types of services resulted in the GP essentially telling me that most services were overwhelmed, and to just be grateful that I got anything at all.'

(Survey respondent)

It is important to note that there were mixed feelings and experiences about being offered treatment options. There were respondents and participants who

felt that medical professionals know best and should be strongly guiding decisions, rather than presenting lots of different options. This was particularly the case for people who knew that their symptoms were preventing them from being able to make a fully informed decision if presented with options.

'[My psychiatrist said] "You could stay on the one you're on or you could try this one, which is a really old-fashioned drug and it has really high rates of overdose and suicide, but it might be better than what you're on. Do you want to make that decision? I'll leave that with you for a month"... I need direction from someone. I can't make that decision. So even when you are sort of given those balances it's kind of a catch 22, neither are very good.'

(Focus group participant)



FEELING INFORMED

Almost a third of respondents (32%) did not feel well-informed about their treatment.

We know that people often feel like they are not given enough information about treatment, particularly the side effects of medication.³² The lack of information and discussion around side effects is worrying, when we know that peoples' experience of side effects for mental ill-health is high.³³ The qualitative data from our research supports this finding, with respondents and participants frequently describing negative experiences of side effects from antidepressants and not having been informed about them.

'Being on so many, the side effects can be quite different, and the doctors never ever mention the side effects apart from saying 'oh this new shiny pill has less side effects', they never actually talk you through what you might expect and what's normal and what's not.'

(Focus group participant)

Similarly, respondents and participants frequently indicated that they were not well informed about the difficulties of withdrawing from antidepressants, and that there was little support when it came to de-prescribing and managing withdrawal symptoms. Participants in the focus groups indicated that knowing more about withdrawal would have helped to inform decisions about treatment.



Almost a quarter of respondents (24%) did not feel like their doctor understood them.

'[...] we need to know before we take them the side effects and if you want to come off them, really how bad the withdrawal process is.'

(Focus group participant)

'They never tell you what coming off it's going to be like; they just don't talk about that. Or they say oh take two weeks to come off it, and if you've been on antidepressants for two years, that's not long enough. Nobody tells you that!'

(Focus group participant)

Some respondents and participants also indicated that they wanted more information about what different non-pharmaceutical therapies there are and what they entail. This supports findings from other research, which shows that people often don't know what kind of therapy they are receiving or what it entails.^{34, 35} Data on the type of non-pharmaceutical therapies that people are referred to is not provided by the NHS and there is very little evidence on the extent of psychosocial prescribing.

'[...] what type of therapies are available in [local health board area], and what the differences are, what the referral pathways are, whether it needs to go from the GP to the community healthcare team to someone else to make an assessment...yeah, those are factors which have definitely had an impact for me.'

(Focus group participant)

Our research indicates that there could be two barriers to feeling informed: lack of confidence and not actively being given information.

Over a third of respondents (34%) indicated that they did not feel confident asking questions and 44% had questions that they wanted to ask but didn't. Sometimes the symptoms of depression were felt to hamper someone's ability to ask questions, as was mental health stigma. Respondents and participants also frequently indicated that having a conversation about depression when first seeking support is more difficult and, correspondingly, that experience in engaging with health care professionals increases a person's confidence.

'I think a lot of the time, especially from my own perspective, [I] feel really timid or uneasy asking certain questions in case you are looked down on, or not taken seriously. I for one, found it incredibly difficult to speak to a doctor the first time I went'

(Survey respondent)

'[...] certainly when I was at my very, very lowest, I couldn't have discussed with them because I didn't have the vocabulary at that time.'

(Focus group participant)

'I ask questions, I suggest things because they're not the 'great I am' to me because I'm used to working with doctors.'

(Focus group participant)

In terms of being given information, a third of respondents (33%) did not feel like their treatment was explained to them, while over a third (36%) did not feel like their prescriber made sure that they understood the treatment. Respondents and focus group participants were very clear about what information was lacking and what information they would like to receive.

This included information about the side effects of medication, referral pathways, waiting times for non-pharmaceutical treatment, and withdrawal symptoms of medication.

Some participants felt like the preconceptions they had about depression and treatment for depression, in particular antidepressants, could have been more readily challenged by practitioners. It was indicated that this would have helped them to make more informed decisions about treatment.

'When you're on it, on the dose, they don't tell you beforehand, which would help you make a more informed decision about OK, I can't drive on that type of medication, or I wouldn't be able to concentrate at work, or you know, that's going to impact kind of my sexual relationship or whatever... we need to know before we take them the side effects and if you want to come off them, really how bad the withdrawal process is.'

(Focus group participant)

'I didn't want pills because I had heard bad stuff about them. But if the GP had challenged my frankly anecdotal evidence about pills I would have been more inclined to give them a try...'

(Survey respondent)

'The length of waiting lists, if it's a talking therapy, and be upfront about it straight at the beginning so that you're not at home by yourself and you receive the letter that says there's a 30 week wait for some specific therapy.'

(Focus group participant)

THE THERAPEUTIC RELATIONSHIP

Almost a quarter of respondents (24%) did not feel like their doctor understood them.

When consulting on its guidance for shared decision making, GMC found that practitioners are mindful of the fact that there is an inherent imbalance in the patient/doctor relationship; although decisions are expected to be shared, the responsibility for those decisions is not felt to be shared.³⁶ This can often lead to defensive practice, with practitioners giving lengthy lists of side effects and detailing all possible risks.³⁷

Our research shows that respondents also experienced this imbalanced relationship, with almost a quarter of respondents not feeling understood and over a third not feeling confident asking questions. This is despite the fact that the majority of respondents felt that doctors should not make decisions about treatment for depression without asking how the person feels about it.

It was evident from the qualitative feedback that the relationship between the prescribing doctor and the person seeking support has an effect on how involved someone felt in deciding the treatment for their depression. The relationships experienced by respondents and participants were very mixed. Positive experiences were associated with feeling heard and feeling like someone cared, while negative experiences were associated with feeling dismissed and not listened to.

'...she cared, and she acted like she cared because she wanted to know my story, she wanted me to come back and tell her how I'd got on with my treatment and how the medication was affecting me and stuff like that.'

(Focus group participant)

'The first time I went, it was almost, you could feel almost as if you're there just for the sick line, to get off work for three or four weeks, and that's how I felt, and that's how I felt I was treated, rather than actually listening to my story and how I'd been feeling for a prolonged period of time.'

(Focus group participant)

Some participants and respondents acknowledge that the symptoms of depression can be a barrier to engaging with a doctor. Other also highlighted that doctors themselves experience barriers in building positive relationships with patients, primarily due to time pressures.

'I think it depends what state your mind's in at the time because if you're in the depression, it's very hard to think rationally or coherently, and to involve yourself in the conversation in a sort of meaningful way [...]'

(Focus group participant)

'It all comes to the time again, you've got five minutes and then it's like "right that's you", and then you come out and you're like "I didn't really say what I wanted to say or how I'm really feeling", it just frustrates you.'

(Focus group participant)



CONCLUSION

- Our research demonstrates the importance of involving people in decisions about treatment and support for depression, with increased feelings of involvement associated with increased feelings of treatment satisfaction.
- However, the research also identified various barriers to supported decision making for people with depression. These barriers included a lack of psychological therapies and other treatment options; short appointment times; the symptoms of depression; and a lack of information about medication.
- Moreover, respondents and participants indicated that the relationship with the doctor had a direct effect on whether their experience was negative or positive. One of the strongest themes that came through was that people with depression want to be heard when they seek support.

RECOMMENDATIONS

SAMH is calling for:

- 1** The Scottish Government to review the psychological therapies waiting time target, to establish why NHS boards continuously fail to meet it.
- 2** The Scottish Government to undertake a review of psychological therapy provision across Scotland, to establish if people have access to the full range of evidence-based therapies as outlined in the NHS Scotland Psychological Therapy Matrix.³⁸
- 3** Integration Joint Boards (IJB), which have oversight of community mental health services, to commission a range of psychosocial services to support people experiencing low to moderate levels of depression.
- 4** SIGN to develop evidence-based guidance for practitioners on supporting withdrawal from antidepressants.
- 5** The Medicines and Healthcare products Regulatory Agency to review the Patient Information Leaflets for all medicines used in the treatment of depression, to ensure that the information contained in the leaflet reflects peoples' experience of side effects and withdrawal symptoms.
- 6** The development of best practice guidance for active monitoring of people with depression, in partnership with people who have experience of depression.
- 7** The development of guidance on shared decision making for people with mental health problems, including suicidal thoughts, in partnership with people who have experience of seeking support for their mental health.

ENDNOTES

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