THE UNIVERSITY of EDINBURGH

Medical Research Council

DEPRESSION DETECTIVES

Survey and Focus Group Analysis

Background Information

Depression Detectives was a user-led citizen science project that brought together people with lived experience of depression and University of Edinburgh researchers to co-produce research on depression. Citizen science projects invite the public to get involved in some way. User-led refers to allowing volunteers to set the agenda; they choose the questions that the project explores, and co-design and run a research project alongside the researchers.
For more information see https://blogs.ed.ac.uk/depressiondetectives/

A Facebook group was established with around one hundred members, who showed different levels of involvement in group discussions, polls, votes, and other contributions. Membership to the group required participants to either have lived experience of depression or work/volunteer regularly with people who do, to be at least 18, have a Facebook account and to not currently be experiencing a mental health crisis.

On the basis of their interests and experiences, and supported through Question and Answer sessions with researchers from various disciplines, participants developed a long list of potential research questions and voted on their favourite question, which was: “How does chronic depression/dysphoria differ from, say a single episode, or discrete episodes of reactive depression? Are there markers (biological, psychological, behavioural, and current or in a person's history, e.g. trauma) that distinguish them?" As this question was too big to be tackled in a small project, it was reformulated to: **"Do people report all episodes of depression to their GP? And if not, why not?"**
After discussing potential methodologies, the group divided the research into two main areas:
1) Data science research - looking at UK Biobank questionnaire and GP data (this will be reported as a separate document).
2) a survey and focus groups to find out about experiences of depression as episodes, to explore why people do or do not go to their GP with episodes of depression, and to find out where else they might seek help.

The focus groups had ten participants overall and were carried out in four Facebook discussion threads. Prior to the focus group, all participants had participated in the Facebook group Depression Detectives, where discussions were held on a wide variety of topics related to depression. All names of participants have been changed, some participants chose their own pseudonym, other names were created through an online name generator.

The survey was developed together with the group. 26 people filled in the survey. As the survey was carried out anonymously, it is unclear if focus groups and survey participants overlapped.

Episodes of depression

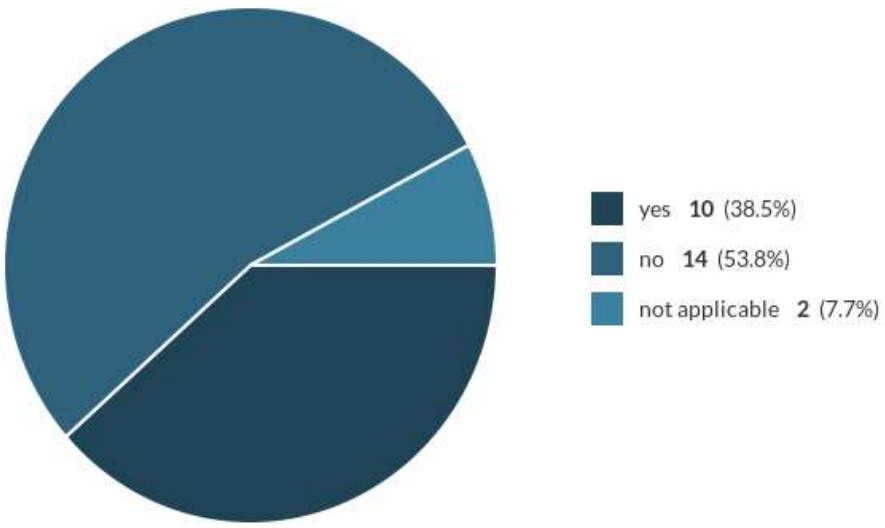
For many, the term “episode” is useful to describe a period of low-functioning or of particularly low mood.

> “The term episode would be a useful term to describe my experience of depression. I have experienced periods of particularly low mood which can feel uncontrollable.” (Craig)
>
> “I think about an episode as a time when I’ve had to have treatment (or should have had). I think of it as a long period (I’d say longer than a month) and where my depression is preventing me from functioning as I usually would at work and at home.” (Nadine)
>
> Episodes are “times when I ceased to function in the outside world and needed to take sick leave from university or work to recover. … I would say an episode is a time when I am aware that I am experiencing symptoms of low mood to the point that I am unable to pretend to the world that I am ok” (Anne)
>
> “When I think of an episode it’s a period of time from when I realise I’m sinking into depression/anxiety, through medication and to feeling it ‘lift’ and ending medication at the other side” (Alice)

The time between episodes is experienced by some as “being well” (Craig). For others, they feel never fully ’recovered’ before going back down again.

Figure 1

Do you feel like you fully recovered in between episodes?



Some people describe episodes as merging into each other and as having no “clear beginnings or ends” (survey comment).

For some people, the term episode implies something that will continue or recur, “very much like a soap opera or TV series has episodes and will be continued” (Jenni). This can elicit fear or hopelessness. Nadine replied to Jenni by saying “I don’t really want to think of it like a TV series!” (Nadine). Jenni also agrees that this view is not necessarily helpful: “I try very hard not to think too far ahead in terms of episodes but try and stay well one day at a time” (Jenni).

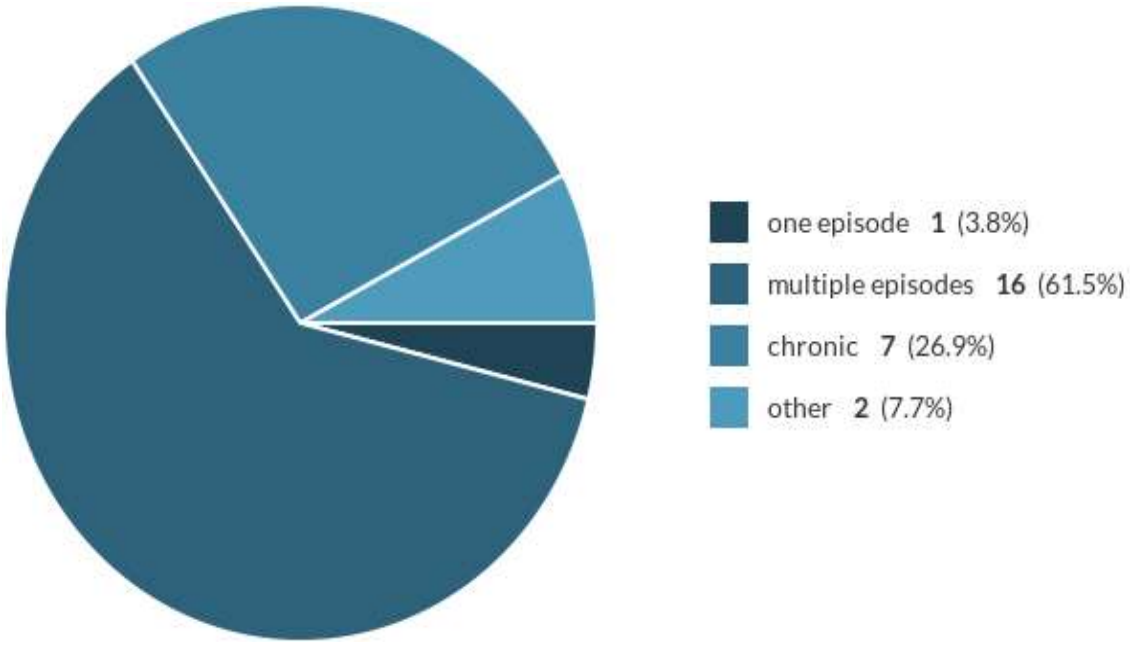
While some people have episodes of depression that they can clearly delineate, others describe difficulties in knowing when an episode begins or ends. Nadine says that “the way you would know I’m in an episode, is that I don’t think it’s an episode!” Often, others are needed to recognise the beginning of an episode. Also, the end of episodes might only be defined in retrospect.
For others, the frequent ups and downs of daily life make it hard to pin down the beginning or ends of episodes:

> “Retrospectively some periods of depression and anxiety do seem episodic (lasting weeks to months), but it can also be triggered by external factors so there's an almost constant up/down. I don't look back and think "that was a normal episode" in between an episode of depression.” (Catherine)

> “In between episodes, before I was cured, I used to be aware that my brain did not function healthily, in that I would ruminate on very negative thoughts which I couldn't escape, I heard judgmental voices in my head, I self-sabotaged everything I did etc etc etc, but I was able to appear normal and functional outside of my home and my mood wasn't too low. In summary, to me an episode is when I am incapable of functioning and doing my activities of daily living, but this is on a background of lifelong symptoms, so between episodes I was not healthy and questionnaires which ask questions which assume that you have in the past been mentally healthy are very difficult to answer accurately!” (Anne)

Not everybody experiences depression as episodic. For some, depression or dysphoria are chronic (figure 2).

Figure 2
Do you experience episodic or chronic depression?



For people who experience chronic depression, ongoing treatment might be required, and they feel that if depression is seen as something that comes and goes, this can lead to a lack of support and understanding.

> “that assumption means that depression is once again not being considered as a chronic condition which requires ongoing treatment/medication but instead simply comes and goes, and if that is how doctors assume depression occurs it is hardly surprising that people are often dismissed or not treated appropriately with a long-term view, because the thinking is "well you're going through a bit of a rough patch but it will get better in a few weeks/months, all we need to do is get you through this spell". My depression is not something that goes away if you just wait it out or treat it as you would an infection or a sprained ankle.” (Survey participant)

A lot of research focuses on improvement or healing of depressive symptoms through interventions. For this kind of research, “it is much easier if you are dealing with participants who are sometimes ill and sometimes well. I don't think medicine or the medical model is very good at dealing with chronic conditions (possibly why OCD is so under-researched)” (Diane, speaking about survey).

For people who have chronic depression or dysphoria, the term “episode” might still make sense for certain situations, for example periods of depression that were reactive and linked to an external event.

> "Episode" has made sense for me during periods where my depression has been triggered by something, but most of the time it is not “reactive” as such and feels more like existential distress” (Claudia)

In conclusion, “It's really clear from this that the concept of "episodes" of depression is not the only way to look at the condition. It's also striking that the majority of people aren't fully recovered in between episodes, which I think is something that isn't properly appreciated in the way society thinks about depression.” (Diane, speaking about survey)

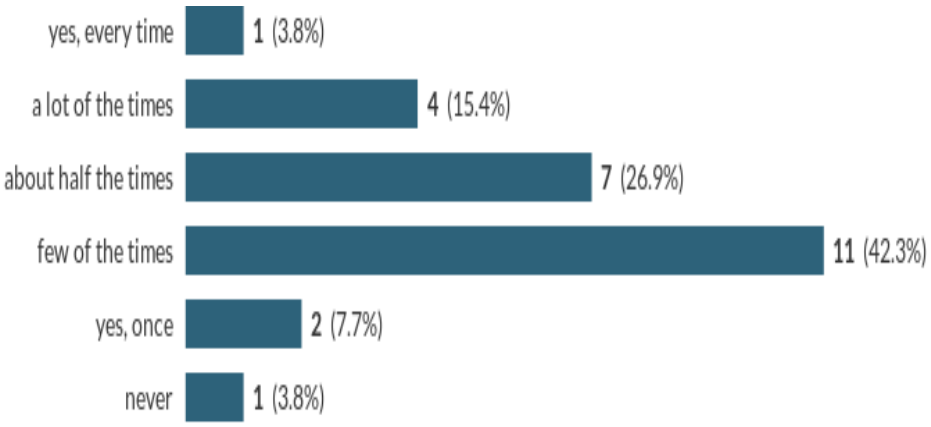
Help-seeking behaviour in people with depression

When do people with depression go to their GP?

Most people go to their GP only a few of the times they experience depression (figure 3). Only one participant went to see their doctor with every episode they had.

Figure 3.

Frequency of approaching the GP with episodes of depression



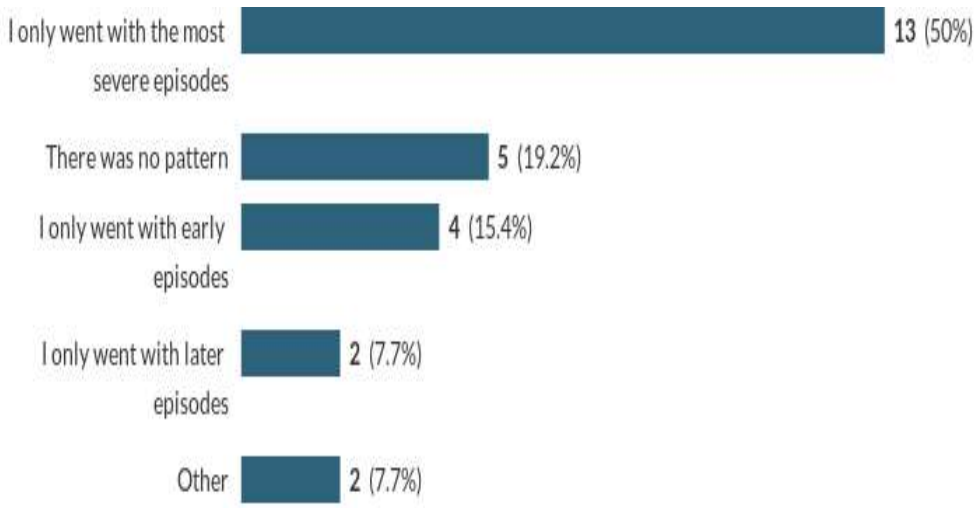
Participants often choose to see their GP (or psychiatrist or psychiatric nurse if they have been assigned to them) if other techniques do not work or if they are losing faith that they would ever get better. The focus groups showed that despair, not coping, and not knowing what else to do, were motivations for many.

> "I go to my GP when I feel desperate, and don't know what else to do / have worked through all other things I know how to make it better." (Anne)

The survey (see figure 4) shows that most participants only went to their GP with their most severe episodes, some only went with early episodes, some did not see a clear pattern, and a few only went with later episodes.

Figure 4.

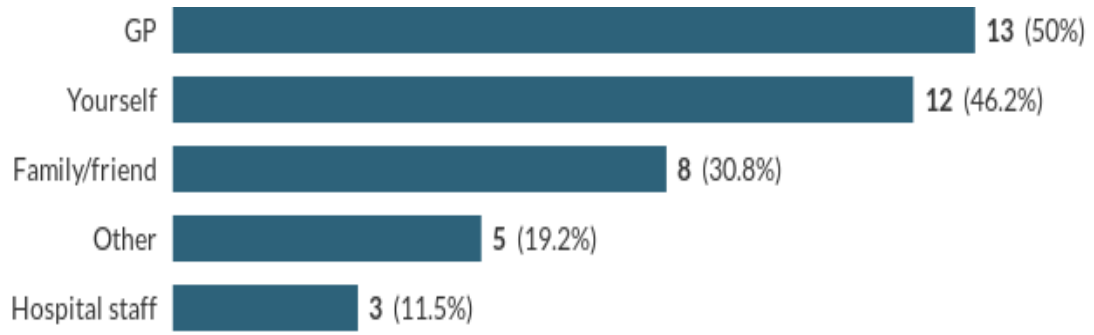
Pattern of approaching primary care with depression



Around half of the survey participants were supported during their first experience of depression by their GP, half managed it by themselves, a third also had support from friends and family, and some were looked after by counsellors or other support staff (figure 5).

Figure 5.

Management of FIRST experience of depression



In the focus groups, some people also said that GPs are often the only option that people know about, or that going to the GPs fulfils the function to sign them off work when they are depressed.

> "I've only been to my GP during periods when my depression is interfering with my ability to work. It's been out of necessity as I become unable to function and need to be signed off work." (Claudia)

Making appointments with the GP – the role of receptionists

Sometimes, to make an appointment, people need encouragement from others (for example their parents, partner, etc.). Making an appointment can feel like "crossing the rubicon" (Wendy). Receptionists might be the first people that people with depression talk to, and therefore play a very important role. Unfortunately, some experience reception staff as abrupt, as they are under time pressure, which has affected some participants' confidence around making appointments. Another issue is patients being asked why they want to see a GP, and many finding that difficult to answer. Rosie said that this made her "feel paranoid and coerced into revealing stuff." Sometimes, receptionists made people also feel like they might be wasting doctors' time:

> "Some just let me make an appointment, others would ask why I wanted to see a doctor and made me feel very uncomfortable about requesting to see a very busy GP for something so seemingly trivial when there were people waiting who had real illnesses!" (Anne)

Many participants thought that they had to be specific and make it sound serious enough to be seen by a doctor. Others worry that mental health issues are often understated, and that people who might not try to make it serious might not get an appointment. The focus groups also revealed that people had worries around confidentiality. One patient overheard a receptionist talking about them on the phone, which made them feel uncomfortable, others felt uncomfortable when they had to talk about their mental health in a crowded reception area, where they might be overheard by other patients.

Often, appointments cannot be made as fast as needed. Jenni comments: “It's the slowness of the service that bothers me.”

Some have found that emergency appointments were available, but that it is hard to wait for a week for an appointment if things are difficult:

> “there was a gap in the support and treatment of MH crises. I can make an appointment to see my GP in a week or so, or I can go the 24 hour mental health crisis unit immediately if I feel suicidal, but there is nothing in the in between space of "I don't quite feel suicidal but almost and I'm in a complete state and I can't calm down and my heart is pounding like it’s going to burst out of my chest". I do now have propranolol prescribed which can help that a bit, but for years that was when I felt most scared and alone and did not know where to turn” (Catherine)

More research is needed to find out if receptionists pointing to support outside the doctor’s practice, such as helplines, would be helpful to bridge these waiting times, or if this would be experienced as dismissive.

A further area that participants highlighted is the importance that if depression appointments are missed, a new appointment should be offered rather than expecting patients to ask for a new one themselves. People with depression often do not have enough energy, strength or motivation to seek help, therefore not getting in touch can be symptomatic of the problem, rather than an expression of non-compliance.

> “I guess they assume if things haven't improved you'll come back, but it's often so hard to make contact if you're depressed that this assumption is going to be wrong quite a lot of the time.” (Nadine)

> “I really did not have the energy to keep pushing for appointments and just wanted to crawl under a rock and stay there. (...) The medical establishment is very dismissive of people who cancel appointments and they are very quick to label people as non-compliant, but actually these things can be symptomatic of the problem! A bit of curiosity, compassion and empathy wouldn't go amiss sometimes...” (Anne)

Why did people with depression sometimes not see a doctor?

There are a diverse range of reasons for not going to the GP with depression. In the survey development discussions, the participants developed a long list of possible reasons why they have not gone to their doctor. Many felt held back by thinking their depression was not serious enough to justify going to the doctor and worries about wasting their time, being ashamed about not being able to cope, feeling uncomfortable talking about their feelings. Some did not want to be diagnosed, particularly around early episodes, as they did not want to name their experience “depression” or be told to have a life-long severe illness, or thought that what they experienced was not a medically treatable illness.

> "I hadn't been diagnosed with depression by a doctor yet, and I really didn't want to be, as both my parents struggled with depression...I didn't want to think I'd have as severe and long lasting an illness as them, as I'd seen how horrible it was for them." (Anne)

Some also worried that what was going on for them was their own fault, and that it came down to a lack of character or discipline, rather than an illness. For others, not going to the GP was related to the expectations and previous experiences with doctors, who only offered very limited time for

listening and exploring patients' needs, and only offered limited treatment options. The discussion in the focus group showed that this was particularly relevant for those for whom medication was not a preferred choice of treatment.

> "there was no point in going to the GP once I had decided I didn't want drug treatment. Also it is impossible to gain anything useful from a doctor who has 7 minutes to talk to you and that is never going to help to sort out a life-long, very complex problem when they are unable to refer me on to someone who can take the time to unpick it all properly." (Anne)

Some also did not have the energy at times to seek help. Further reasons are listed in table 1.

Table 1.

Reasons for not going to the GP with depression

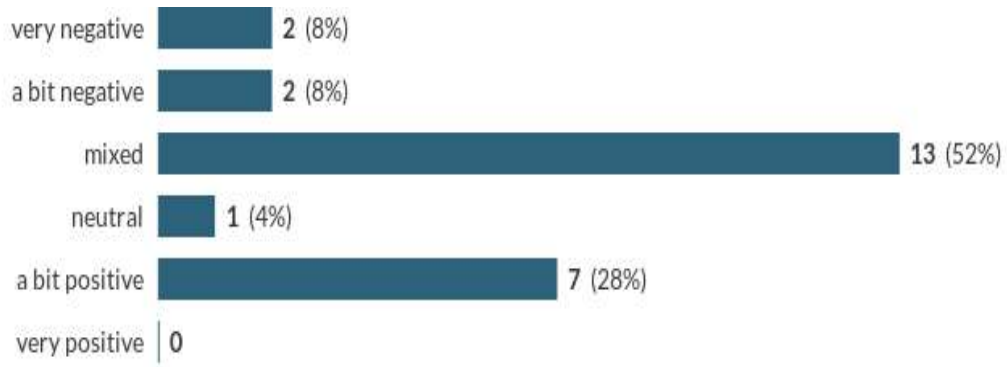
Reason for not going to the GP	Number of Participants
Didn't think I was depressed 'enough' to justify going to doctor	18
I just thought what I felt was part of who I am, rather than it being an illness	15
Hoped it would pass by itself	12
I did not feel worth bothering the GP (initially or repeatedly); I feared being classed as a time waster or to be seen as a burden	12
I did not believe that the GP would be helpful, because the GP would not be able to give me enough time to explore what is going on and what I need	11
I did not believe that the GP would be helpful, because I thought other options not on offer from GP would be more useful	11
I was ashamed about not being able to cope	11
I am worried about being prescribed medication, as I don't think they will treat the root of the problems	11
I did not have the energy to seek help	10
I felt very uncomfortable talking about my feelings or struggles	9
I did not believe that the GP would be helpful, because I had negative past experience with GPs who was unhelpful	9
I didn't feel any hope that anything could make it better, at the time	9
I am worried about being prescribed medication, as I worried about side-effects	8
I was worried about work implications	8
I didn't want 'mental illness' on my medical records	8
I felt it was related to a situation in my life at the time (e.g., grief) and would pass	7
I did not know that I was depressed, that what I was feeling is depression, and that a GP could help with what I am experiencing	7
I did not want to admit something was wrong or an episode is starting	7
I didn't feel worthy of medical treatment and getting better	7
I was worried about pressures /cultural/ family perceptions/ stigma	7
I did not believe that the GP would be helpful, because I thought they will only offer drugs and nothing else	6
I did not believe that the GP would be helpful, because I felt too vulnerable	6

I didn't want to make depression more real by giving it a name or saying it aloud	6
I am worried about being prescribed medication, as I don't like taking medication	6
I am worried about being prescribed medication, as I worried about having to take it forever or being dependent	6
I was worried about being seen as someone to be pitied	5
I felt having mental health issues was shameful	5
I am worried about being prescribed medication, as I previously tried them and found them ineffective	5
I would have needed someone else to tell me to go or to make an appointment for me	4
I did not believe that the GP would be helpful, because consulting with a GP had caused me more pain before	4
I did not believe that the GP would be helpful, because I did not have a regular GP that I trust	4
I felt it was a natural process and wanted to allow my depression to run its course	4
Other reasons*	3
it was difficult to make an appointment as talking to the receptionist was hard	2
I did not believe that the GP would be helpful, because of what I heard from others or thought would happen	2
I did not believe that the GP would be helpful, because I could not choose which doctor to see, and didn't want to speak with the one that was given to me	2
I did not believe that the GP would be helpful, because the doctor seemed so different to me, I wasn't sure if we could relate to each other and the doctor would understand	1

The survey shows that participants would mostly characterise their experiences with GPs, when they contacted them about depression, as mixed (figure 6). Some characterised them as mainly a bit or very negative, some characterised them as a bit positive. Nobody said that their experience was very positive.

Figure 6.

Quality of experience of going to the GP with depression



What is required for positive experiences with GPs?

Participants with positive experiences in primary care had GPs with a non-judgemental attitude, who took their patient seriously and offered attentive listening and a helpful, supportive and pragmatic approach.

> “what really helped from my GP was the fact that I felt believed, they were supportive and non-judgmental” (Craig)

Overall, many participants had positive experiences, which needs to be kept in mind while we focus on what can be improved in primary care. Jenni commented that “most do an excellent job.”

It is important that GPs are not dismissive or make people feel like they are wasting their time. Not feeling taken seriously enough was even the case when a participant disclosed suicidality, which made them feel that an actual suicide attempt might be necessary to be taken seriously enough to be referred to psychiatry.

> "One GP said, 'you just have to pull yourself up by the bootstraps like everyone else does'. (...)
>
> I concluded then, and still somewhat believe now, that some GPs won’t actually believe you have serious depression until you commit suicide, which kind of defeats the purpose of the idea of being able to go to them for help in the first place!” (Nadine)

A similar experience was described by somebody in the survey:

> “I have had bad experiences of being dismissed and told it wasnt that bad and I just needed to buck up because I could still read out a sentence when asked to despite not being able to concentrate enough to do simple calculations needed for work and being afraid I might kill myself” (Survey participant)

The risk assessment around suicide felt inadequate or upsetting for many clients.

> “the first one [GP] was terrible, asking me very specific questions in lots of different variations on a theme of whether or not I would get out of the way if a bus were hurtling towards me or whether I would step into the path of a bus, then prescribing a week of SSRIs and that was the end of it” (Anne)

Anne also commented that people might not share all information when asked about risk or that this might change, which makes continuous care important.

> “They have no way of knowing who is high risk for hurting or neglecting themselves or their children in these situations so I'm pretty unimpressed that no one followed it up when I had to cancel the appointment.” (Anne)

Participants gave a mixture of reasons why doctors were limited in giving what was needed: Some said that GPs did not seem to have enough training in mental health regarding what to offer or how to listen, and that poor quality care is mostly a structural problem of limited resources that give doctors too little time for each client, and that restricts treatment to medication and, sometimes, CBT. The medical model of depression often did not focus enough on the importance of depressed people’s needs for empathy, which many participants spoke about. Without having more time, the opportunity for a doctor to show empathy is limited. This issue of limited time becomes intensified if patients do not have access to a continuous GP:

> "the GP who sees you often doesn't know you at all. They are trying to keep appointment times short, and minimise time between appointments, it's clear to me that many times I've seen a GP (for mental health or other things) they have not read any of my notes before I go in, so they don't know any history unless I think to tell them (and they should be the ones deciding what is relevant in my history, not me!) I think it's asking the impossible of GPs to manage mental illness well without giving them more time to become familiar with the patient and their history. **I do think there are some GPs who are simply prejudiced about mental illness, but I think the main problem is the overall system they work in.**" (Nadine)

Again, the issue that is stressed is that the experience of insufficient care is not because of the inadequacy of individual doctors, but because of structural problems within the health system, which does not allow more time or continuity. Many argued that more adequate mental healthcare funding would be the most important first step to make a difference. Some also pointed out the relevance of taking physical health into account when doing an assessment and treating patients (e.g., treatment for anaemia).

> "my mental health has never been looked at holistically, only ever as a set of symptoms at a specific point in time (the appointment)." (Catherine)

Those who shared that they have had negative experiences with GPs felt that this affected patients' mental health negatively, additionally to the already existing problem:

> "My issues with primary care has been the attitude of some of the GPs themselves who may be dismissive and make you feel you are wasting their time. Their abruptness, especially if it's a mental health issue, can make the difference in outcome for the patient, potentially adding to the patient's low mood/anxiety or stability on the day." (Jenni)

For Nadine, the effect was not short-lived but stayed with her and created terror about potentially seeing somebody similar in the future, which might be influencing her health-seeking behaviour:

> "That one negative experience always stays with me though, I am terrified of having to see someone who is similar in the future." (Nadine)

Therefore, better training or monitoring of GPs' bedside manner and listening skills might also be an important step to avoid such experiences.

Some participants mentioned requesting a different GP, with whom they had better experiences. It might therefore be helpful to support people in making choices in whom they want to see—a further role that the reception staff could play.

Participants also said that they felt that more continuous professional development in mental health was needed for GPs so that they could point them to a wider range of options that might be helpful. This could also help to assess people with mental health issues better and develop a more comprehensive treatment plan. However, most participants felt that there are systemic barriers in the way for GPs to act as the gatekeepers they are supposed to be, because they do not have enough time to assess people well and do not have enough options that they can offer regarding treatment.

> "I think GPs could, if trained properly about what options there are and given enough time to get to know a patient and talk with them in a consultation, I do think they could act as the point of contact, and refer to counselling or a specialist when needed, and manage milder cases themselves. But I don't think they are currently given the chance to do that well enough." (Nadine)

> "I feel mental health issues are a speciality service much like diabetes or even cancer and it would not be expected that the G.P. could manage the latter two illnesses, especially at the

> outset or any ongoing issues with the illness. G.P.s are the gatekeepers of health services and whilst they have a certain amount of training in all health and speciality services, I'm not sure whether that equips them to successfully treat seriously ill mental health patients." (Jenni)

Anne formulated an ideal as to how primary care for depression could work: A rapid-access GP clinic would refer people presenting with depression on to a GP or nurse with specialist training in depression to do a thorough assessment and to develop a personalised treatment plan that is relevant to their situation. Ideally, patients could weigh up options themselves or be supported in decision-making if they are too depressed to make decisions by being compassionately guided through the options, which could include talking therapies (more than 6 sessions), social interventions, access to a dietitian, exercise classes, social support groups, etc. The assessment would also involve looking at underlying causes of a person's depression such as toxic relationship or work issues, and treatment plans would offer support to change these external problems. Regular follow ups would also be important.

Some participants also pointed to the need to signpost to recommended counsellors or to directories; particularly considering that depression involves low energy, help to find additional support would be appreciated.

Treatment options

Participants often criticised the lack of options that are on offer by primary care. Medication is commonly offered, sometimes a short course of CBT, and rarely other therapeutic support, be it through psychologists, psychotherapists, counsellors, or others.

a) Medication

Many participants who went to their GP about their depression were only offered medication. While some were content with this, others felt that medication only dealt with current symptoms and did not go to the root of the problem.

> "My experience is that doctors prescribe antidepressants all too readily and use them as a sticking plaster" (Claudia)

Holistic care or longer-term support were missing for many. For some, this was the reason why they did not approach their GP for later episodes:

> "I have only ever been offered SSRIs by the GP. I do not find these useful as they are like taking paracetamol - they take the edge off the pain if I'm lucky, but do nothing to address the underlying cause. I gave up on them long ago because they are not helpful. (…)
> Over the years, I have always organised my own therapy because I knew that my GP wasn't going to offer me talking therapy so there was no point in going to the GP once I had decided I didn't want drug treatment. Also it is impossible to gain anything useful from a doctor who has 7 minutes to talk to you and that is never going to help to sort out a life-long, very complex problem when they are unable to refer me on to someone who can take the time to unpick it all properly. (…) medication can allow you to make changes through

> working in the psychological and social issues that along with biology have all worked together to cause the depression. (…) It may be that GPs can only offer the pills but that is not going to make best use of those pills, just taking them and not working on underlying issues too.
>
> I am convinced that I would not have done any of these things had I depended upon my GP for treatment and agreed to just continue on SSRIs with no other therapeutic options, which is what multiple GPs have offered, and so I would have been doomed to continue with my previous pattern of episodic relapses and slow remissions while being on sick leave in alternate years. ” (Anne)

Anne’s comment shows that this participant did not only find the offered options of primary care unhelpful, but thinks that they would have stopped her from finding a cure to her depression.

Claudia described that she felt pressured to take medication, as they thought that not taking them was interpreted as not doing enough to change the situation, or as the depression not being serious enough.

> I have previously felt pressure to take antidepressants by bosses and GPs. If I don’t take medication but need to be signed off, I worry people think I am somehow not trying, or I worry that people think I can’t be that bad, because if I was, I’d take medication. I have now done some reading about the evidence/lack of evidence for antidepressants and vow never to be talked into taking them ever again.” (Catherine)

As we can see from this quote, it took Claudia time to gather knowledge and confidence to be able to resist the expectation from others about taking medication.

Claudia points out that being prescribed medication leads to reinforcing stigma, as it gives the message that one is “defective”:

> “I think medicalisation of distress only adds to stigma as it reinforces the message that the individual seeking help is defective.” (Claudia)

b) CBT

Sometimes, doctors offered CBT to participants with depression. While some found this helpful, others saw potential caveats. Some participants experienced CBT, similarly to medication, as helping to manage symptoms or giving people “a few ideas for managing the exhaustion” (Anne), instead of going to the roots of problems and helping to create lasting changes. Others argued that the person delivering CBT influenced the experienced:

> “My experiences of CBT within the NHS have been one positive and one negative - with the negative experience it felt like the counsellor was just trying to fit me/my experiences into easily solvable tick-boxes” (Catherine).
>
> “I told the psychologist that sometimes the depressed mood just got worse for no apparent reason, I couldn’t identify a conscious thought behind it. She just kept saying ‘there must have been a thought!’ so I felt I was failing. But another clinical psychologist who I was referred to at a later date (another GP in the practice recommended a private one and I was desperate) said, of course there isn’t always a ‘thought’ and although that is how you do CBT, the trainee had been wrong as mood variations aren’t always triggered by a specific conscious thought” (Nadine)

Both participants felt that their individual experiences were not acknowledged as such, but that they were expected to fit into the CBT model. There was a sense of not being heard and even of failing, when one's thoughts did not fit into preconceived patterns.

c) Counselling

Few people were offered help beyond medication or CBT through their doctor. Yet many seemed to feel that the NHS should offer easier and quicker access and more choice and variety of counselling and support:

> "In an ideal world the NHS would supply more choice and variety of counselling support as well as quicker and easier access." (Jenni).

> "I feel that my GP had limited resources and tools at their fingertips so if I was thinking about what could have been different then I would say the opportunity to have counselling or being signposted to the BACP counselling directory … I would have liked access to counselling. I paid for this myself and have found an excellent counsellor but some signposting towards reputable counsellors would have saved some time and effort when I didn't feel like I had much in the tank. Talking therapy with the right counsellor is great and I was lucky enough to be able to pay for it myself - I feel that the level of support that I received should be available to everyone, regardless of their means." (Craig)

There was a lot of agreement in the focus group on this theme, and people agreed that "a lot of the problem is funding limiting resources." (Nadine) Jenni argued: "I don't feel mental health services are cohesive enough or adequately funded and resourced enough to offer a therapeutic service."

Many people spoke about counselling as helpful, but Nadine also pointed out that, for her, it was not sufficient on its own.

Some people paid for private counselling, and others persisted and were eventually given access to a clinical psychologist or psychiatrist, yet this seemed to be rare:

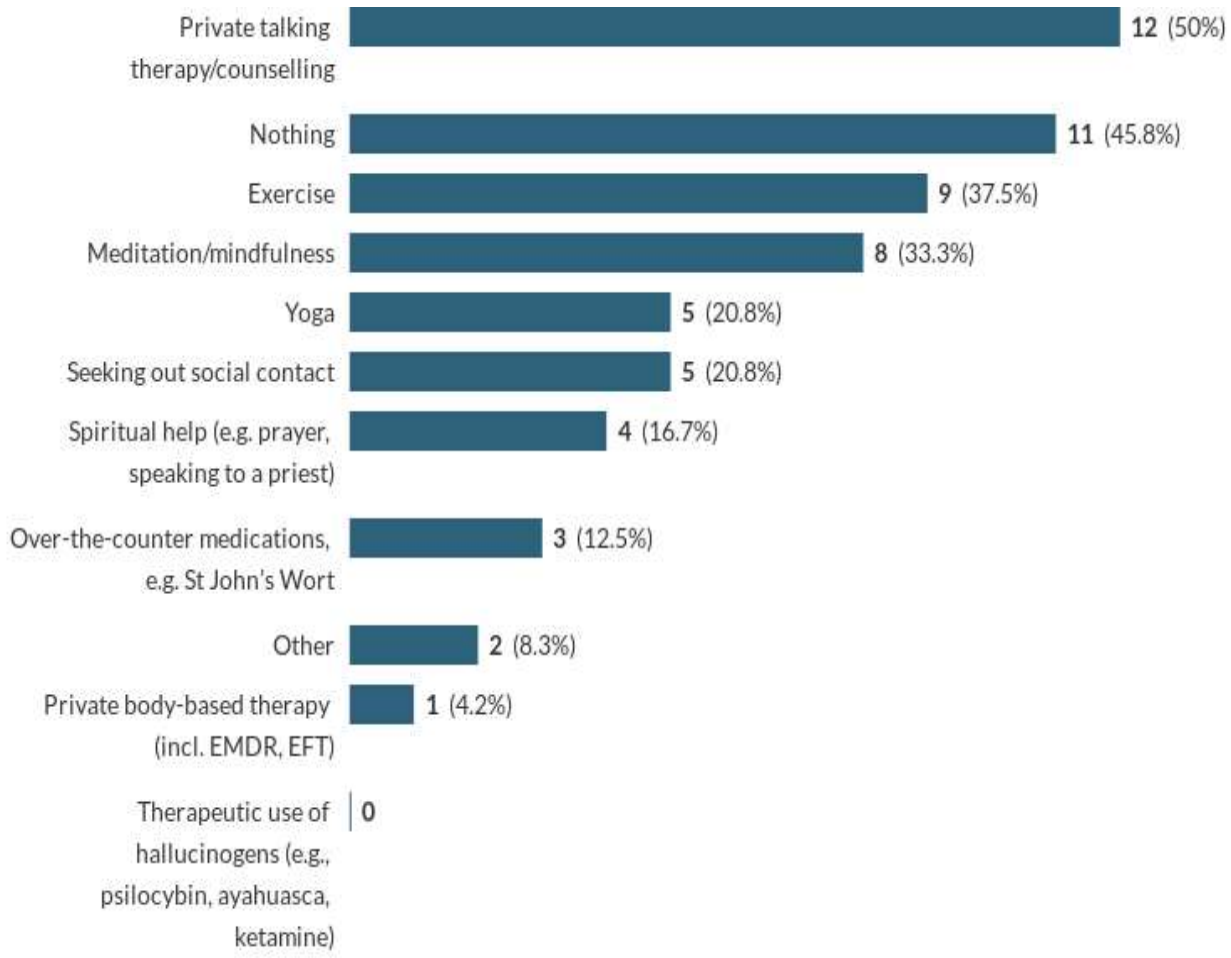
> "Things seem much more hopeful long term, once I got to a good clinical psychologist for mindfulness based cognitive therapy and later for compassion focussed therapy, and to a psychiatrist who unlike most GPs didn't try to take me off medication for the sake of it, despite a history of relapse every time I come off. The medication I am currently on is not prescribed by GPs at the high dose the psychiatrist can do, or at last they would only do so on the advice of a psychiatrist." (Nadine)

d) Other treatment options

The survey showed that half the participants have not tried out depression treatments beyond what was offered through primary care, and half have tried private counselling/psychotherapy (figure 7). Many also used exercise and/or mindfulness/meditation. Some used yoga, seeking out social contact, and spiritual help.

Figure 7.

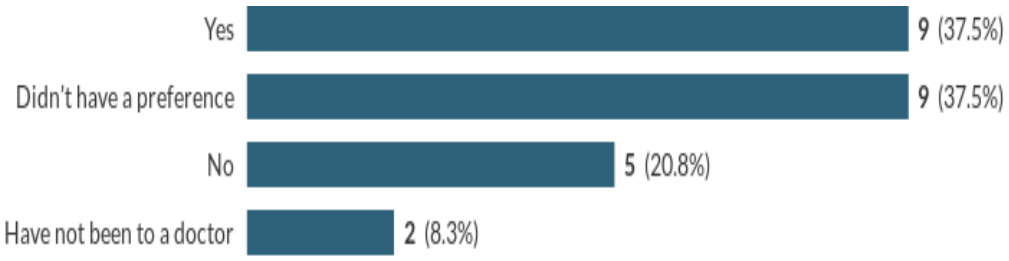
Alternatives to going to the GP with depression



Nearly 40% of the survey participants preferred these options, equally many had no preference, and around 20% did not prefer these options compared to going to the doctor.

Figure 8.

Are alternative options (see previous question) preferred, compared to going to the doctor?



Reasons for this that were mentioned in the free text of the survey were that these options, particularly counselling, often offered more time to help identify “the root of the problem, rather than just applying an emotional sticking plaster”; helped participants “to grow rather than just cope”; or to help the participant to understand her depression and “understanding that it is an illness and not just who I am.” Self-help literature was found helpful for one survey participant to address underlying childhood trauma, which enabled the participant to feel they had cured themselves. Other options were perceived as “more holistic,” more flexible (“easy to do myself in my own time on my own terms”).

Survey participants had mixed views on what to do for future episodes of depression. Many would go to the GP, or others would mix this with other options, and others “will only seek help from a Dr if it becomes too difficult to manage or I need time off work”. Some said they would seek private counselling or would try to access help through employment.

Other comments around future episodes were to overcome the “reluctance to admit” that a person has a problem; “lifestyle changes” to help to prevent future episodes; “trying to catch episodes early” before they spiral down; use yoga and meditation; psychedelic-assisted therapy; “Remember that I had been there before and remind myself I improved by using some of the tools I had learned”.

Somebody also said that they would not know what to do, and somebody else said “deal with this on my own or kill myself”.

Why did people regret not having gone to the GP?

Half of the participants have regretted not going to the GP, half had no regrets about this.

The survey did not address why people have regrets, but cross-tabulating the items of the survey gives us an indication as to how people with and without regrets differ.

The biggest difference for those who did not have regrets is that they seem to have found an alternative strategy that they prefer or find helpful as dealing with their depression, compared to going to the GP.

Participants were also asked if they ever had regrets about not going to their GP about episodes of depression. Most participants who prefer alternatives to what the GP offers have no regrets. On the other hand, those who do not prefer alternatives have never had regrets. Not having regrets is correlated with negative experiences with the GP and negative attitudes towards medication or towards the medical model of depression.

As table 2 shows, people who regret not having gone to the GP with some episodes, more often generally have had better experiences with GPs than those without regrets. Regrets are correlated with feeling held back by fear of making depression more real by naming it, by shame about not being able to cope, and by worries about cultural pressures, family perceptions and stigma.

Table 2.

Difference in responses from people who have regrets about not going to the GP with depression

	Percentage of people with regrets who chose this answer	Percentage of people with NO regrets who chose this answer
Experience with GP was · very negative · a bit negative · mixed · neutral · a bit positive · very positive	 4% 0% 27% 4% 15% 0%	 4% 8% 23% 0% 8% 0%
I was worried about pressures/ cultural /family perceptions/ stigma	14%	6%
I was worried about being prescribed medication as I don't like taking medication	2%	11%
I was worried about being prescribed medication as I don't think they will treat the root of the problem	9%	16%
I was worried about being prescribed medication as I previously tried them and found them ineffective	0%	11%
I did not believe that the GP would be helpful because the GP would not be able to give me enough time to explore what is going on and what I need	5%	13%
I did not believe that the GP would be helpful because I thought other options not on offer from GP would be more useful	6%	11%
I was ashamed about not being able to cope	11%	4%
I didn't want to make depression more real by giving it a name or saying it aloud	12%	2%
I did NOT prefer alternative forms of treatment compared to going to the doctor	19%	0%

Limitations

The numbers of participants is not large enough to generalise the findings. The self-selection of participants might mean that certain forms of depression or conceptualisations of depression are either over-represented or excluded. The rules about participation in the group will also have an impact on the results - for safeguarding reasons people who were currently in crisis were excluded.

For more information see https://blogs.ed.ac.uk/depressiondetectives/