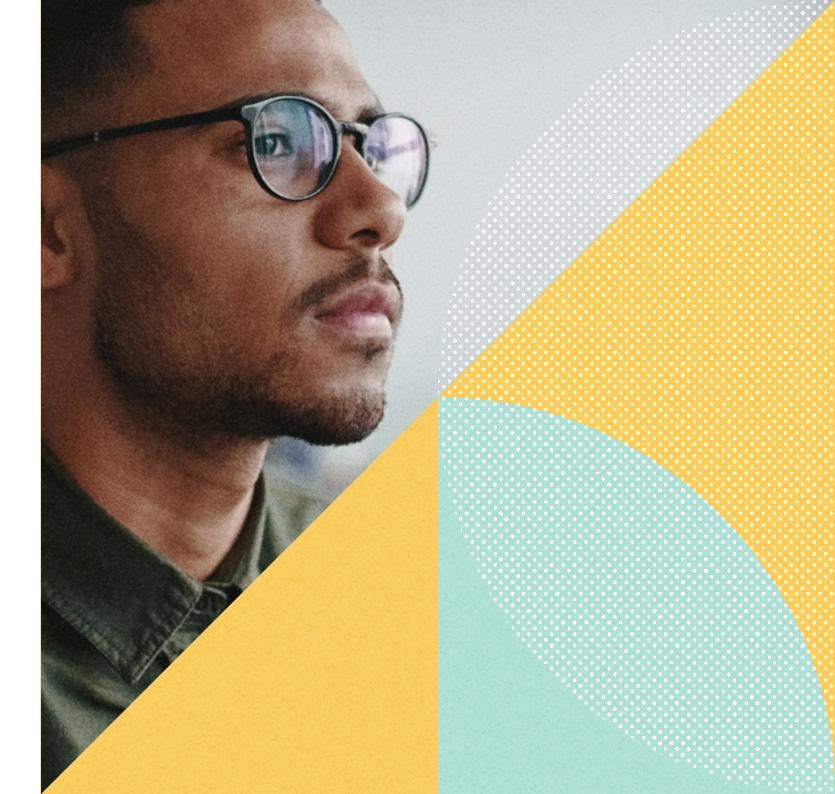


Bipolar Diagnosis Matters

"A light in the dark"
The early findings of the
Bipolar Commission –
October 2021



Let's talk at bipolaruk.org

Introduction

The Bipolar Commission was launched in March 2021 with two aims: to improve the quality of services and to dramatically reduce the rate of suicide for people living with bipolar in the UK.

To achieve this the Bipolar Commission brought together 22 Commissioners with academic, clinical, policy and lived-experience expertise to identify and review evidence on the current services and quality of life for people living with bipolar.

The Commissioners represent a broad cross-section of the bipolar professional and lived-experience community with a balance of ages, ethnicities, sexualities, gender and geographic locations. Professional experts include healthcare economists, academics, therapists and frontline clinicians including psychiatrists and GPs. More than half the Commissioners have direct lived experience, either living with bipolar themselves or with a close family member who has it.

The Commission is co-chaired by Professor Guy Goodwin, a senior research fellow at the University of Oxford, and Dr Clare Dolman, a patient participation lead at King's College London, who is herself living with bipolar. The secretariat has been provided by Bipolar UK.

The Commission research methodology has included a literature review, stakeholder and patient interviews and a series of comprehensive online surveys of the community. Compiled by our stakeholders, these surveys have been sent out to the bipolar community via our ecommunity, enewsletter and social media platforms. This means they are engaged with our services to some extent and may not be representative of the wider population/people with bipolar in general.

This first report sets the scene by informing us what bipolar is and what causes it and provides vital insights into patient experiences of getting a diagnosis.

The centre piece of the report is the first online survey which was completed by 2,458 people with a diagnosis of bipolar. Respondents were self-selected and more likely to be white British, female and graduates than the bipolar population as a whole (see appendix 1). This has been collated with qualitative interviews with academics, clinicians and people with lived experience. For the first time, we've asked thousands of people living with bipolar to tell us their story of diagnosis and provide a comprehensive dataset that can be used by researchers to improve our understanding of the pathway to a bipolar diagnosis from the patients' perspective.

The report's subtitle is "A light in the dark", which was a phrase used by a Commissioner with lived experience to describe getting a diagnosis. The findings shed a light on the lives of people living with bipolar who don't have a diagnosis, some of whom currently remain invisible to the health system. The report also aims to provide hope for the thousands of people struggling with bipolar who aren't getting appropriate support — the central message is that things really can get better.

The next phase of the Commission will look at services and treatment, physical health, women and bipolar, and the financial burden of living with bipolar. The full report is due to be published in spring 2022.

What is bipolar disorder?

Bipolar disorder is a severe mental illness characterised by extreme experiences of mood. These moods go far beyond most people's everyday experiences of feeling a bit down or happy.

Bipolar disorder was originally called manic depression. The term was coined by German psychiatrist Emil Kraepelin in 1896 to describe a combination of 'mania' and 'melancholia' symptoms that had been observed from as far back as Greek and Roman times.

The name was changed to bipolar disorder in 1980 by the American Psychiatric Association in their Diagnostic and Statistical Manual of Mental Disorders (DSM). This was because the term manic depression resulted in people living with the condition being described as 'maniacs', which was thought to be stigmatising.

To explain the condition to people who have never met someone with bipolar, Bipolar UK uses a mood scale which ranks mood from 0-10, with 0 being low and 10 being high (see overleaf).

For anyone without bipolar, on their worst day they will only experience a 'feeling down' low of 4, and on their best day a 'feeling happy' high of 6. For people living with bipolar, their range of emotions is much wider. They can experience a 0, which is deep depression with recurring suicidal thoughts. At the opposite end of the spectrum, they can experience a 10, which is an extreme manic high where people experience psychosis and hallucinations, completely losing touch with reality.

When someone living with bipolar goes above a 6 or below a 4, they are said to be relapsing. The more often someone with bipolar relapses the more likely they are to relapse again. A key focus for the Bipolar Commission is to identity the specific support and treatments that enable people with bipolar to maintain a balanced mood. We also aim to find out whether or not they are getting this support and treatment and, if they're not, to ask why not. Most importantly we want to find out what can be changed to ensure that they do.

Relapsing is a term recognised within the community, but a growing number of academics, clinicians and members of the community are uncomfortable with the word as it can imply blame. For instance, we would rarely describe the return of cancer as a relapse. The Bipolar Commission uses the term relapse because it's a commonly recognised term. We want to stress though that no judgement is meant by it whatsoever.

While the mood scale is a very useful tool to help people understand the extreme range of emotions people with bipolar can experience it does have its limitations, oversimplifying a highly complex condition. For example, sometimes people with bipolar can go into what's known as a 'mixed state', where they experience symptoms of mania and depression at the same time. They can also experience 'rapid cycling' or 'ultra rapid cycling' where their emotions change in quick succession.

Figure 1: Bipolar UK Mood Scale

Mood Scale Numbers Total loss of judgement, exorbitant spending, religious delusions and hallucinations 10 MANIA Lost touch with reality, incoherent, no sleep, paranoid and vindictive, reckless behaviour 9 Inflated self-esteem, rapid thoughts and speech, counter-productive simultaneous tasks Very productive, everything to excess (phone calls, writing, smoking, tea), charming and talkative Self-esteem good, optimistic, sociable, and articulate, good decisions, need less sleep and get work done 6 BALANCED Mood in balance, no symptoms of depression or mania 5 MOOD Slight withdrawal from social situations, concentration less than usual, slight agitation Feelings of panic and anxiety, concentration difficult and memory poor, some comfort in routine 3 DEPRESSION Slow thinking, no appetite, need to be alone, sleep excessive or difficult, everything a struggle Feelings of hopelessness and guilt, thoughts of suicide, little movement, impossible to do anything SEVERE DEPRESSION Recurring suicidal thoughts, no way out, no movement, everything is bleak and it will always be like this 0

What's it like living with bipolar?

Some people with bipolar can live a 'normal' life with a relatively stable mood for weeks, months or even years at a time. But both a manic high and depressive low moods can be incredibly destructive.

Mania can result in reckless spending and impulsive decisionmaking, hyper sexualisation and rapid uncontrollable thought patterns. It can also lead to psychosis where someone experiences hallucinations, extreme paranoia and delusions.

Severe depression is also debilitating. It can result in low energy, apathy, not leaving the house for days, weeks or months at a time, not carrying out basic self-care and, tragically, sometimes suicide.

Studies suggest having bipolar increases the risk of suicide by 20 fold¹. A Delphi exercise² conducted by the Bipolar Commission found that at least 5% of all suicides in the UK were by people with a bipolar diagnosis. However the true figure is thought to be significantly higher due to the fact that not everyone with bipolar has a diagnosis.

I was 17 and still at school when I first experienced a slide over a number of weeks into depression, then deeper down to a point where my thinking became fixated on self-destruction. In this state, my mind seemed to focus exclusively on ways to take my life with an exhausting drip, drip, drip of repetitive suicidal thoughts. JC

When someone becomes so unwell that they become a danger to themselves and those around them they are forcibly detained under the Mental Health Act (1983) which is known as 'sectioning'.

Mania and sectioning are terrifying and traumatic experiences for everyone involved. Some experiences are so traumatic that people living with bipolar are often unable to recollect them.

I was working in New York when it became clear something was wrong. My long hours were bizarre (I felt physically sick on the weekends if I couldn't make calls), I woke up several times a night to check emails, and there was a famous episode of me madly banging on the door of the New York office at 6am to be let in to make calls to Europe only to be called by an exasperated colleague that if I had arrived two minutes beforehand I would have set off the security alarm in the entire skyscraper. I felt that I was on some sort of cosmic mission to be fulfilled by my profession. Everything in New York burned brighter, tasted better, was more extreme, and more full of life. I felt like bursting every day with obsessed energy to do something, to plan something, to achieve something. **DE**

During both manic and depressive episodes, people with bipolar can do things they regret. They blow their family savings on cars and gifts for strangers, make mistakes at work and get fired, have affairs and damage family relationships.

People living with bipolar tell us that they frequently blame themselves for their behaviour. Self-stigma, guilt and shame are common feelings for people living with the condition. People also often tell us they experience intense anger and frustration at losing years of their lives and not being able to fulfil their potential.

These traumatic experiences, negative feelings and low self-worth further aggravate their condition making a balanced mood even harder to maintain. Without effective treatment, support and self-management many people get trapped in a vicious cycle and often end up being 'revolving-door patients' with frequent hospital admissions.

¹ Plans, L., et al. "Association between completed suicide and bipolar disorder: a systematic review of the literature." Journal of affective disorders 242 (2019): 111-122.

² A well-established approach to answering a research question through the identification of a consensus view across subject experts.

³ Vreeker, A., Boks, M., Abramovic, L., Verkooijen, S., Van Bergen, A., Hillegers, M., ... Ophoff, R. (2016). High educational performance is a distinctive feature of bipolar disorder. A study on cognition in bipolar disorder, schizophrenia patients, relatives and controls. Psychological Medicine, 46(4), 807-818. doi:10.1017/S0033291715002299

Jackie describes her thirties as a "lost decade". She was ill every year with a brief manic episode, followed by a period of balance, before falling into a deep depression, with the whole cycle starting again. Gradually during her 40s, when she was no longer stopping and starting her medication, living with bipolar became easier to self-manage.

The experience of bipolar is complicated by the presence of hypomania, which is the stage between a balanced happy mood and mania. It is akin to a permanent adrenaline rush. When someone with bipolar is in a hypomanic state, they can be incredibly productive and the hypomania can sometimes feel very pleasurable.

During the exam period in my third year at university, I'd been working really hard, I'd been sleeping less and I was feeling more sociable. The only way I can describe it is that my brain felt strange — as though it was fizzing. I was extremely successful and productive. JR

It is one of the reasons why people with bipolar can be high achievers and the condition is sometimes associated with genius and creativity³. It is impossible to give a definitive posthumous diagnosis, but it is believed that both the artist Vincent Van Gogh and the writer Virginia Woolf lived with bipolar.

The issue, though, is that if it's left untreated, hypomania can tip into full-blown mania, which people tell us feels incredibly scary. Spotting and managing a hypomanic state before it becomes mania is one of the main challenges for people living with bipolar.

Types of bipolar

People living with bipolar can experience the condition in different ways and to different extremes. At any one time most people with bipolar are living within a balanced mood range, which is known as 'euthymia'. The type of bipolar someone has will determine the severity and type of moods they will experience.

The most common types of bipolar are:

Type I	where people experience depression, hypomania and mania.
Type II	where people experience long periods of depression and hypomania.
Cyclothymia	which is considered a milder form of bipolar.

Despite the severity and dangers of the condition it is possible to live well with bipolar with effective treatment and support. Many people living with bipolar are able to manage the condition very effectively and hold positions across all sectors, from law and medicine to retail and banking.

After 21 years, bipolar is so much a part of who I am. I cannot imagine life without it. I can cope with the infrequent lows, and love and equally fear the hypomanic episodes when I feel creative, amusing and fun. I know how hard it can be to prevent it developing into a full-blown manic episode and potentially destroying everything. As I am more prone to high moods, my top strategy to stay well is that if my sleep is disturbed for more than two nights, I take a sleeping tablet (my GP has given me a small supply for this) and, if necessary, take a half-day off work and avoid alcohol. If I feel my mood rising (I am spending more than usual, talking lots on the phone or having lots of ideas). cutting back on social engagements and getting rest and alone time are vital. If I'm feeling low, things to look forward to in the diary (holidays or a spa day or catch-up lunch with friends) are essential to stay on an even keel. Medication and self-management are what keep me well. They're what allow me to do my job well and to keep my family together. They make me hope that whatever life throws at me in the future I will be able to deal with it. GW

How many people have bipolar?

Worldwide prevalence rates of bipolar disorder are estimated to be between 1.0% and 5.0%⁴.

The range is due to the different criteria used to give a diagnosis of bipolar and the different methods used to measure it in various research studies.

In the UK the most comprehensive bipolar prevalence data is from the Adult Psychiatric Morbidity Study (APMS) in 2014 which found that 2% of the UK population aged 16 and above were living with bipolar⁵.

That's over a million people, making it one of the most prevalent long-term mental health conditions. That's roughly 30% more than the number of people who have dementia⁶ and twice the number of people who have schizophrenia⁷.

Prevalence of bipolar was spread evenly across all ethnicities and backgrounds, male and female. Like many mental health conditions, bipolar usually first becomes evident in teenagers and young adults 8 . Young people were significantly more likely to screen positive than older people: 3.4% of 16-24-year-olds screened positive compared with 0.4% of those aged 65-74.

The reason for this significant variation is unknown, although limitations in the screening tool, lower life expectancy and increased prevalence amongst young people are all potential factors. Further research needs to be conducted. In the meantime, the updated Adult Psychiatric Morbidity Study due to be released in 2022 will provide some important clues.

Even a small increase in prevalence could have a devastating impact on tens of thousands of lives.

⁴ Bebbington and Ramana: The epidemiology of bipolar affective disorder, Soc Psychiatry Epidemiology 1995 Nov;30(6):279-92.

⁵ It conducted a survey of 7,076 people using the Mood Disorder Questionnaire (MDQ) – see appendix 1 (Demographic information). The questionnaire describes 13 manic symptoms. If respondent had experienced 7 or more symptoms at the same time and that cause them problems then they were considered to have bipolar.

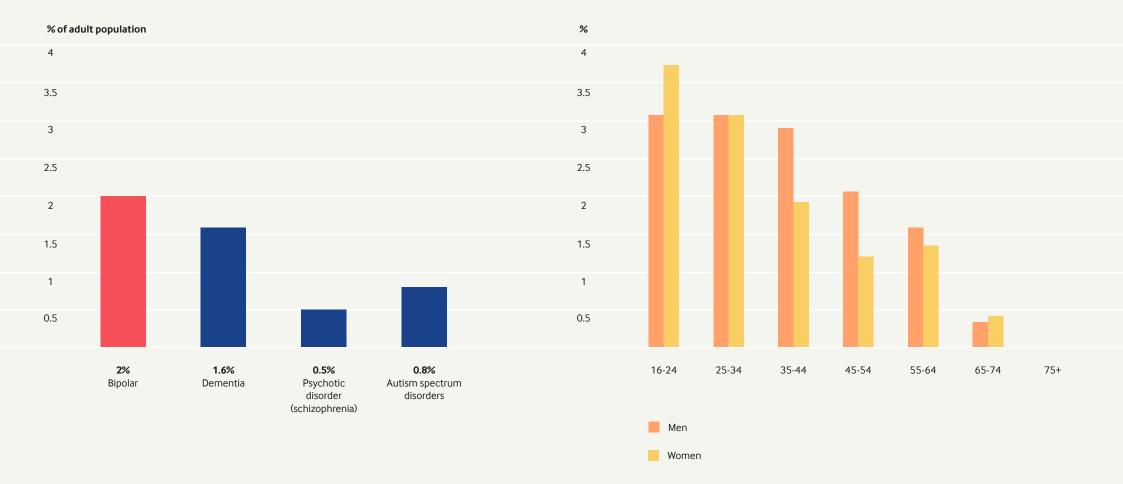
⁶ In 2019, there were 850,000 people with dementia in the UK, https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report.

⁷ McManus, Sally, et al. Mental health and wellbeing in england: The adult psychiatric morbidity survey 2014. NHS digital, 2016.

⁸ Bolton, Sorcha, et al. "Bipolar disorder: Trimodal age-at-onset distribution." Bipolar disorders 23.4 (2021): 341-356.

Figure 2: Bipolar prevalence compared to other conditions

Figure 3: Positive bipolar disorder screen by age and sex



How does bipolar relate to other mental health conditions?

Bipolar disorder is considered a severe mental illness. This is an umbrella term without a clear definition that's often used to reflect the long-term nature of a condition and its severity. Schizophrenia, bipolar disorder, psychosis, obsessive compulsive disorder, eating disorders and borderline personality disorder are commonly grouped under this term⁹.

Understanding the connection between bipolar and other mental health conditions provides valuable insights into both the diagnosis journey and the provision of appropriate post-diagnostic support. To explore this, the Bipolar Commission survey on diagnosis asked people with bipolar about the different mental health conditions they have been diagnosed with — both previously and at the same time as their diagnosis of bipolar.

Despite often being grouped under the same umbrella term of "severe mental illness", the survey found only a small overlap between bipolar and other severe mental illnesses. 2.8% and 12.8% of respondents had previously been diagnosed with schizophrenia and psychotic disorder respectively. This dropped to 0.4% and 9.9% of current (multiple) diagnosis. Current diagnostic overlap with borderline personality disorder and eating disorders were 8.9% and 6% respectively.

Bipolar shared a much closer alignment with depression and anxiety. In fact, initial misdiagnosis with depression was extremely high with 60.9% of respondents having received a previous diagnosis of depression at some point. This fell to 21.6% when they were asked about their current diagnosis.

This chimes with an academic study reviewed by the Commission that found around 10% of UK primary care patients prescribed antidepressants for depression or anxiety have undiagnosed bipolar disorder¹⁰.

Out of 17 mental health conditions listed in the survey, only four showed 10% or more respondents having a dual / multiple diagnosis with bipolar. These were anxiety (32.6%), depression (21.6%), post-traumatic stress disorder (13.8%) and a panic disorder (11.0%).

The number of people reporting problems with alcohol and substance misuse almost halved following a formal diagnosis of bipolar. We can hypothesize that there was either some degree of self-medication before diagnosis and / or they were able to access more support to deal with the addiction once they were diagnosed.

The number of people diagnosed with panic disorders, attention deficit hyperactivity disorder, obsessive compulsive disorder and post-traumatic stress disorder increased once people had a diagnosis of bipolar. This may reflect the ongoing challenge of living with bipolar and / or the more frequent contact with specialist mental health services which inevitably leads to higher rates of diagnosis.

If they are given an incorrect diagnosis, people with bipolar are most likely to be misdiagnosed with depression¹¹. This has implications on how to target resources to boost diagnosis rates. People living with bipolar also experience a range of secondary diagnoses including anxiety¹², post-traumatic stress disorder¹³, panic disorder, obsessive compulsive disorder and social anxiety disorder¹⁴ which usually require additional support.

⁹ Zumstein et al. Frontiers in Psychiatry. Defining Severe and Persistent Mental Illness – A Pragmatic Utility Concept Analysis. 2020.

¹⁰ Hughes, Tom, et al. "Unrecognised bipolar disorder among UK primary care patients prescribed antidepressants: an observational study." British Journal of General Practice 66.643 (2016): e71-e77.

¹¹ Smith, Daniel J., and Nassir Ghaemi. "Is underdiagnosis the main pitfall when diagnosing bipolar disorder? Yes." Bmj 340 (2010).

¹² Spoorthy et al. World Journal of Psychiatry. Comorbidity of bipolar and anxiety disorders: An overview of trends in research. 2019.

¹³ Cerimele et al. Journal of Clinical Psychiatry. Patients With Co-Occurring Bipolar Disorder and Posttraumatic Stress Disorder: A Rapid Review of the Literature 2017

¹⁴ Eser et al. Frontiers in Psychiatry. Prevalence and Associated Features of Anxiety Disorder Comorbidity in Bipolar Disorder: A Meta-Analysis and Meta-Regression Study. 2018.

Figure 4: Have you ever been diagnosed with these conditions?



What causes bipolar?

Bipolar symptoms result from a system imbalance, which makes it difficult for the brain to regulate mood. In consequence, mood can become unstable or stuck in extreme states of depression or mania.

Twin studies suggest that bipolar is a predominately genetic condition. If a twin has bipolar, their identical sibling has a 70% chance of developing the condition¹⁵. There is no single gene that is responsible for bipolar but a collection of over 100,000 genes that are also associated with schizophrenia, anxiety and depression¹⁶.

Some families have high levels of heritability while some have very low levels. The difference is thought to be partly accounted for by early exposure to adversity, sometimes due to a parent experiencing unmanaged bipolar symptoms themselves. This gives an added imperative to diagnosis, treatment and support for the condition¹⁷.

Passing bipolar down to their children is a big concern for people living with the condition and some tell us they are reluctant to have children.



Over 20 years I have had 17 hospital admissions and a long-term battle with cannabis addiction. I've always longed for a child but knew that I wouldn't be able to be a good mum. Bipolar and my addiction have stolen that opportunity from me. RO

Yet the truth is that, with effective treatment and support, the risk of passing on bipolar is lower than many people think. Despite being a genetic condition, reports on heritability are variable and average out at 10%18, meaning that if a parent has bipolar their child has a one in ten chance of developing the condition. Bipolar can also skip a generation.



I used to think that I'd never live a normal life or be able to have a family. But I gradually rebuilt my life and, with support, was able to stop medication to become pregnant. GW

There is on-going research into better support for parents with bipolar so they can stay well and minimise the impact the condition has on their children

¹⁵ Barnet, I. H. and Smoller I. W. 2009. The Genetics of Bipolar Disorder. Neuroscience. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3637882/.

¹⁶ Mullins, N.et al. 2021. Dissecting the shared genetic architecture of suicide attempt, psychiatric disorders and known risk factors. Biological Psychiatry.

¹⁷ Duffy, Anne, et al. "Candidate risks indicators for bipolar disorder; early intervention opportunities in high-risk youth." International Journal of Neuropsychopharmacology 19.1 (2016).

¹⁸ Craddock, Nick, and Ian Jones. "Genetics of bipolar disorder." Journal of medical genetics 36.8 (1999): 585-594.

What triggers bipolar?

If someone has an underlying genetic risk of bipolar a number of environmental factors can trigger the first episode or, post-diagnosis, a relapse.

The Bipolar Commission surveyed people living with bipolar to find out their top triggers for both manic and depressive episodes. Over 2,200 people responded to the question. The findings are in figure 5 below.

All types of bipolar have been grouped together to provide a macro picture. Further analysis needs to be conducted to understand how different diagnosis types and demographics are affected by different triggers. For instance, it is likely that a higher proportion of people with type I bipolar are affected by triggers for mania and only women who have had children can be triggered by childbirth.

Looking across the board, the biggest trigger for bipolar both for a first episode and a relapse is a lack of sleep. This is reported by 80% of respondents. Getting seven to eight hours sleep a night is one of the top protective factors in managing bipolar. Good sleep hygiene measures include avoiding substances and activities that both delay someone getting to sleep and inhibit sleep quality, such as alcohol and caffeine, and using electronic devices before bed.

Sleep and self-neglect (the third most common trigger) can be considered both a driver and a symptom of the relapse itself. For those with a close family member or friend with bipolar, these are often the first signs that someone needs extra support.

Extremely challenging life experiences like bereavement, trauma, lockdown and divorce also featured highly in both manic and depressive episodes. This underlines the complicated relationship between mood, environment and the brain's fight, flight or freeze response.

In the list of top ten triggers were also many of the stresses and strains that inevitably come from modern life, such as doing exams, moving home and starting and leaving a job. One in five people told us positive things like getting a promotion at work, getting married, starting a new relationship or going on holiday, had been major triggers.

The worries around triggers also puts an added emotional burden on people with bipolar and their families. Imagine if every time you accepted a new job or were asked to take an exam, you were at risk of being hospitalised under section? These are all considerations for people living with bipolar and for those without a diagnosis who are flying blind entirely. The picture is even more complicated than the one painted here because:

- We haven't listed all the possible triggers
- Some people have multiple triggers
- Triggers often work in combination

Being aware of the common triggers and trying to avoid more than one at the same time whenever possible is a crucial part of self-management for people with bipolar. This requires constant planning and management. Yet the frustrating thing is that even when someone with bipolar follows best-practice self-management to the letter, a relapse is still sometimes unavoidable. Given the range and prevalence of triggers in everyday life, it is impossible to avoid them all.

What people with bipolar can do to lower the risk of relapse is by making sure they have as many protective factors in place as possible. This gives them a buffer against any potential triggers. Protective factors include good sleep patterns, good lifestyle choices with diet and exercise and not trying to cope with too much change at once. It's also helpful to pre-empt stressful times, such as moving house or exams, by increasing protective factors in advance. This might mean getting extra support from a healthcare professional or booking in a medication review.

One avoidable trigger is taking antidepressants. These should only ever be prescribed to people with bipolar alongside a mood stabiliser. 55% of people we surveyed reported being triggered by an antidepressant, making it the second biggest cause of relapse. 19% of respondents reported that it played a major role in their first manic / mixed-state episode, meaning they might have avoided developing full blown bipolar had they not been prescribed it.

This reflects what our bipolar community tell us is a common pathway to diagnosis:

- Saw doctor with symptoms of depression
- Sometimes prescribed 'talking therapies', and/or diet and exercise changes
- Diagnosed with 'unipolar' depression and prescribed an antidepressant*
- Experienced manic episode
- Sectioned and hospitalised
- Received diagnosis of bipolar

It also chimes with an academic study reviewed by the Commission that found around 10% of UK primary care patients prescribed antidepressants for depression or anxiety have undiagnosed bipolar disorder²¹.

66

Diagnosed with depression and prescribed antidepressants in May 2000 following a suicide attempt, I was then diagnosed with bipolar type I in September 2000 and my life changed forever. That four-month climb to the heights of mania, when I was sectioned, irreparably damaged relationships and left me broke. **GW**

Jackie was in her late 20s when she received her diagnosis, a few weeks after being prescribed antidepressants for a period of depression. She very quickly became hypomanic which "felt so good after a long time of feeling all over the place", but it quickly developed into mania.

Life events are key triggers for people living with bipolar both in developing the condition and for subsequent relapses. People with bipolar are more affected by change than the general population so helping them to recognise the risks is crucial to their self-management and prognosis.

Triggers also introduce an important public health element of bipolar. Any public policy (social or economic) that improves healthy living, such as good quality sleep, would have a beneficial impact on people living with bipolar and reduce the risk and rates of relapse. It could even prevent some people developing the condition in the first place.

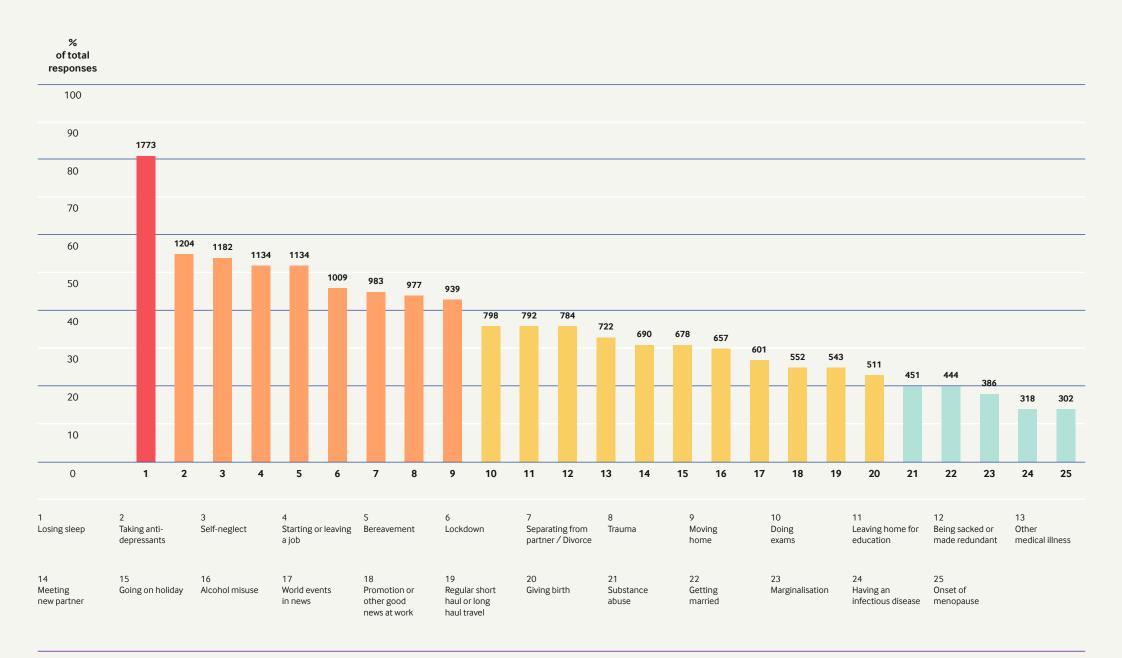
^{* &#}x27;Unipolar' depression is about ten times as common as bipolar¹⁹: they can be very difficult to tell apart²⁰.

¹⁹ Hirschfield, R. M. (2014). Differential diagnosis of bipolar disorder and major depressive disorder. Journal of affective disorders. 169, S12-S16.

²⁰ De Almeida, J. R. C. & Phillips, M. L. (2013). Distinguishing between unipolar depression and bipolar depression: current and future clinical and neuroimaging perspectives. Biological psychiatry, 73(2). 111-118.

²¹ Hughes, Tom, et al. "Unrecognised bipolar disorder among UK primary care patients prescribed antidepressants: an observational study." British Journal of General Practice 66.643 (2016): e71-e77.

Figure 5: What life events have triggered a bipolar episode?



Getting a diagnosis of bipolar

Getting a diagnosis of bipolar isn't straightforward because there are no physical tests for bipolar unlike other conditions, such as diabetes (diagnosed by blood test) or a stroke (diagnosed by brain scan). It does not show up on a brain scan.

Instead, the diagnosis of bipolar depends on specific and sudden changes in mood and behaviour, not otherwise explained by something else (for example, drug or alcohol misuse or a thyroid problem). These changes may be puzzling at the time and their significance may only be evident in retrospect.

A diagnosis of bipolar can only be made by a trained clinician, usually a psychiatrist, following a full psychiatric assessment to investigate a patient's case history for incidents of hypomanic, manic and depressive episodes.

The UK doesn't maintain a register of people living with bipolar. The best indicator is again the APMS, which found 44% of people with bipolar having a diagnosis, albeit calculated using a small sample size.

To investigate the length of time it took to get a diagnosis, the Bipolar Commission asked respondents when they first experienced depression symptoms and when they first experienced manic or hypomanic symptoms. On average it took 13.8 years from their first symptoms of depression and 9.8 years from their first symptoms of mania or hypomania to get a diagnosis.

The Bipolar Commission also asked respondents when they first told a clinician about symptoms of depression, hypomania or mania. Respondents reported that it took an average of 9.5 years for a diagnosis to be made after first telling a clinician about any symptoms.

To allow us to track changes over time, the Bipolar Commission also asked respondents for their date of birth and when they were diagnosed. The average age for receiving a diagnosis was 33.7 years, with ages of diagnosis ranging from 13 to 72 years old.

The survey used the respondent age and year of diagnosis to break the figures down into age cohorts and observed change over time. Despite the fact that mental health services were listed as a priority for the NHS over that period, the study found no evidence that there's been a reduction in the time it takes to get a bipolar diagnosis.

There are huge variations in people's experience of diagnosis. Delays ranged from less than a year to 50 years. The younger someone was, the less time it took for them to get a diagnosis.

Where do people get a diagnosis?

According to NICE guidelines, when adults present in primary care with depression, they should be asked about previous periods of overactivity or disinhibited behaviour²². This is to identify key signs of mania and hypomania. If the overactivity or disinhibited behaviour lasted for four days or more, a GP should consider referral to a specialist mental health assessment, usually an outpatient psychiatrist. In practice, we recognise that this is not always straightforward for GPs. The screening tools so far developed are not perfect and asking such questions can be a lengthy and complex process which is difficult to shoehorn into a short consultation, especially considering how overstretched GPs currently are.

There is also a resistance among some people to acknowledge they may have/may have had bipolar symptoms as they are fearful of the negative effects of stigma, particularly on their jobs or insurance status.

The Bipolar Commission survey on diagnosis found that 54% of respondents had received a diagnosis through the recommended NICE route. 4% got a diagnosis after a second opinion referral.

32% of people reported that they had received a diagnosis from a psychiatrist after a hospital admission. Voluntary admissions are rare, particularly for a first admission, which means that almost a third of people with bipolar struggled without a diagnosis until it got so unmanageable that they became a danger to themselves or others. This is particularly common for people living with type I bipolar²³.

Receiving a diagnosis via this pathway also means that early intervention wasn't possible which can have a huge impact on the level of havoc the condition may have caused in someone's life, as well as worsening their prognosis in both the short and long-term. On the other hand, it may mean someone gets a diagnosis more quickly than someone who only ever sees a clinician with symptoms of depression.

Is the length of time it takes to get a diagnosis an issue?

To assess the impact of the gap between reporting symptoms of bipolar and getting a diagnosis, the survey asked if the delay had had any impact on their lives. 9% said they felt there hadn't been a delay and 4% said that any delay had no impact on their lives. A staggering 60% said the delay had a significant impact on their lives.



I was 19 and in the army when I had a couple of outbursts and attempted to take my own life. I was referred to a psychiatrist who diagnosed depression. For years I took antidepressants but still struggled with low moods. And at times I was spending too much, irritable and angry. Then three years ago, when I was 50, my daughter who's studying medicine, suggested I see a psychiatrist because she thought I might have bipolar. The psychiatrist diagnosed bipolar type II, put me on a mood stabiliser and adjusted the dose of the antidepressant. Everybody around me noticed the difference straight away. Getting a diagnosis has had quite a dramatic effect on me to be honest. AT

22 National Institute for Care and Excellence (NICE) Guidelines. Recognising And Managing Bipolar Disorder In Adults In Primary Care. Last updated September 2021. https://cks.nice.org.uk/topics/bipolar-disorder/diagnosis/ suspecting-bipolar-disorder/.

Figure 6: How long did it take to get a diagnosis?

Years since first diagnosed	Under 5	5-9	10-14	15-20	20-29	30+	Average
Number of participants in this category	593	422	284	190	221	130	1840
Average (mean) age of diagnosis	34.2	35.5	34.3	34	31.1	26.5	33.7
Average (mean) years between first low mood and diagnosed	14.2	15.9	14.8	13.2	10.6	7.7	13.8
Average (mean) years between first high mood and diagnosed	9.9	11.1	11.3	10.3	7.4	5.2	9.8
Average (mean) years between contact with mental health services and diagnosed	10.2	10.9	9.1	8.8	7.6	5.1	9.5

²³ DelBello, Melissa P., et al. "Twelve-month outcome of adolescents with bipolar disorder following first hospitalization for a manic or mixed episode." American Journal of Psychiatry 164.4 (2007): 582-590.

I'm pretty certain I had a manic episode three years ago that lasted about three months and I was never diagnosed with bipolar disorder. I had far too much energy that was very difficult to deal with and was threatened with being sectioned if I didn't take an antipsychotic but I was never diagnosed with mania. I felt incredibly high in mood and had delusional and spiritual thoughts but the psychiatrist I saw didn't seem to know what was going on. I also have had a hypomanic episode quite recently and everyone seemed to think I was just in a really good mood but I was only sleeping a couple of hours a night for two to three weeks, felt very high and had to be on the go all the time, which is very out of character for me. I also had a number of other typical symptoms of hypomania. I then crashed into a severe depression after this. My CPN mentioned bipolar disorder, but nothing was done after that. I've been seeing a psychiatrist for about five or so years now and they've never asked me about having a high mood. RM

What is causing the delay in diagnosis?

When asked about the delay clinicians provided a number of explanations, including:

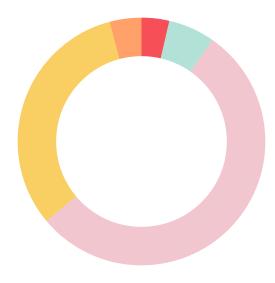
- a lack of psychiatrists
- diagnostic complexity
- overlap with other mental health conditions
- people not presenting severe symptoms to primary care
- people not recognising the significance of previous periods of hypomania
- a reluctance to get a bipolar diagnosis which still carries stigma

In the survey, people living with bipolar said misdiagnosis (50%) and failure to pick up high moods (48%) were the biggest reasons for the delay. Lack of understanding of bipolar by health professionals (39.6%) and by patients (39.4%) was also listed as a significant barrier.

A third of respondents (31.8%) said that the lack of access to mental health services was the reason, suggesting increases in provision alone will not be enough to fix the problem.

A tiny proportion of people (2.6%) said they didn't want to get a diagnosis. This may be explained by the fact that respondents answered the survey via our ecommunity, newsletter, website or social media platforms which indicates they're engaged with our services and may not be representative of people with bipolar in the wider population.

Figure 7: Who gave you your diagnosis?



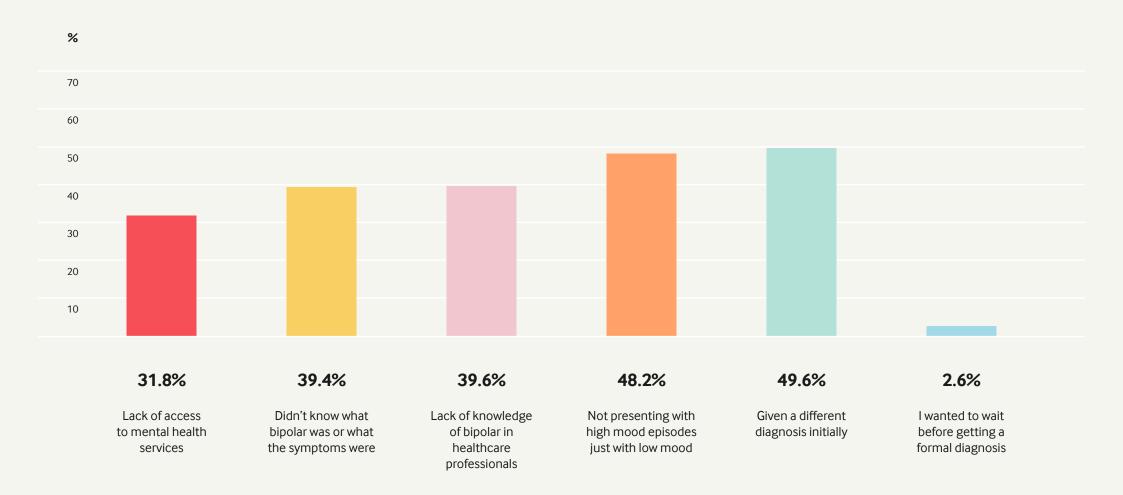
- 3.7% GP
- 6.1% Other
- 54.2% Outpatient psychiatrist
- 31.9% Psychiatrist after hospital admission
- 4.1% Second opinion referral

Figure 8: Did a delay in receiving a diagnosis of bipolar have an impact on your life?

No delay	No impact	Small impact	Moderate impact	Large/significant impact
8.74%	3.68%	7.28%	20.22%	60.07%
204	86	170	472	1,402

TOTAL RESPONSES – 2,334

Figure 9: If there was a delay in getting a diagnosis, why do you think it was?



Why does diagnosis matter?

A diagnosis is required for someone to be able to access support, medication, psychological therapy and information about self-management. NICE provides tight guidelines on treatments for bipolar and they can only be accessed with a diagnosis. Without a diagnosis, someone living with bipolar will find it harder, if not impossible, to access the new service provision provided through the Community Mental Health Framework and specialist medication. It is also necessary for developing a comprehensive selfmanagement plan.

People living with bipolar told us though that the primary benefit (selected by 80.5% of respondents) was that it gave them an explanation for their past experiences. This is particularly important given the regrets and shame people often feel about their behaviour when they've been experiencing periods of mania or severe depression.

The lack of diagnosis also increases the risk of prescribing antidepressants without a mood stabiliser which is dangerous for people living with bipolar and the second biggest trigger for both an initial episode and relapse (a lack of sleep is the first biggest trigger). For 68% of respondents, getting a diagnosis enabled them to get better medication.

Nearly half (47%) of respondents said getting a diagnosis helped them be better understood, despite the stigma. Having a diagnosis enables people to connect with other people who have had similar experiences – particularly through peer support groups and online communities.

Are there any drawbacks to diagnosis?

A diagnosis can be a double-edged sword. To get a balanced perspective, the Bipolar Commission survey on diagnosis also asked about negative experiences linked to getting a diagnosis.

Almost half (44%) of respondents said they have experienced stigma due to getting a diagnosis and 22% said they had been prescribed medication they didn't find useful. 7% said getting a diagnosis didn't help to explain their past experiences.

Does diagnosis do more harm than good?

The Bipolar Commission survey on diagnosis asked respondents to take into account both the positive and negative impacts of a diagnosis and assess whether their diagnosis of bipolar was helpful or helpful.

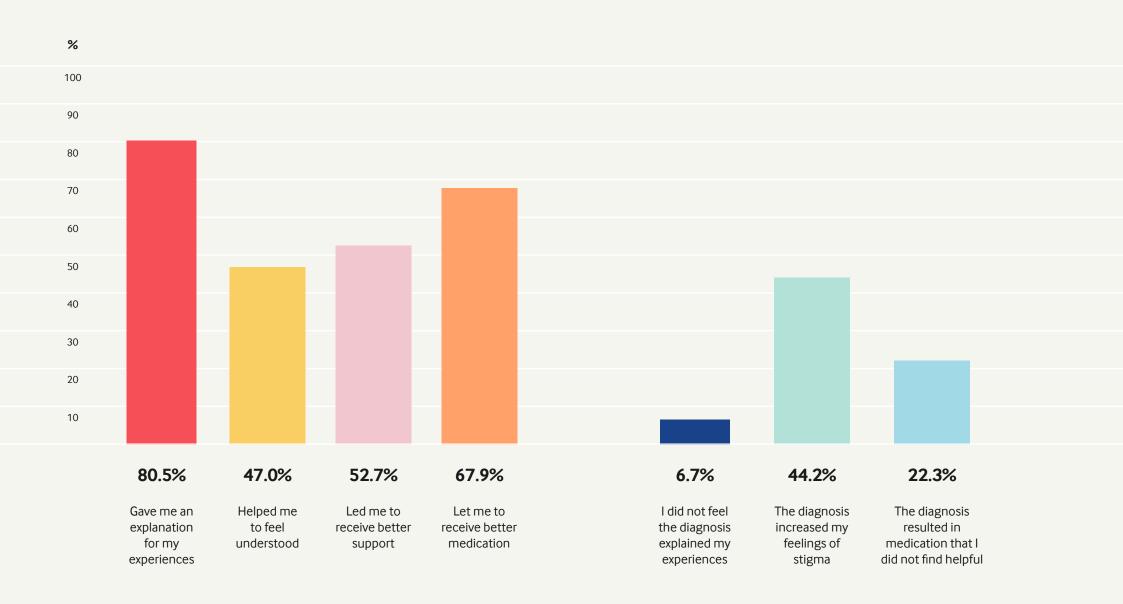
A staggering 83.9% said a diagnosis was either helpful or very helpful. Less than 5% said it was unhelpful or very unhelpful.

The majority view of people living with bipolar is that despite the stigma and risk of taking medication that doesn't work for them, getting a diagnosis was incredibly beneficial overall. This reinforces anecdotal evidence from our lived-experience commissioners who said that receiving a 'label' gave them a vital way of understanding themselves and what had happened before diagnosis.

Jackie said she was "absolutely horrified" when she first received her diagnosis. She knew about Spike Milligan, and this gave her an image of someone who spent a lot of time in psychiatric hospital. She was frightened by the diagnosis and didn't believe it at first. This resulted in her stopping the lithium, after which she became ill again. This happened several times until she came to accept the diagnosis. Early on she was assigned a CPN (community psychiatric nurse) who referred her to the local Bipolar UK support group, which she found helpful. She also read the book by Kay Redfield Jameson *An Unquiet Mind.* "And I thought, that's what I've got. And that's when I actually accepted the diagnosis. She explained it so well and I really related to it."

Figure 10: Did receiving a diagnosis help you in any of the following ways?

Figure 11: Did you find receiving a diagnosis unhelpful in any of the following ways?



Julie described the experience of getting a diagnosis of bipolar as "bittersweet", due to the hard choices she had to make about medication: "the red pill or the blue pill?... okay, so I've now got this label. I felt more ashamed than I ever did. I felt I was stigmatised." Nevertheless, there was a sense of relief about the diagnosis, and a sense of relief from being believed and understood by a helpful psychiatrist.

What is the impact of the delay in diagnosis?

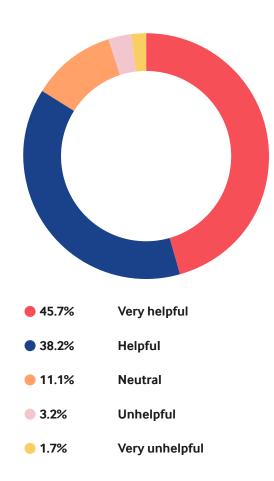
The Bipolar Commission survey on diagnosis found that 60% of respondents said the delay in diagnosis had a significant impact on their lives. Experiencing extreme bipolar symptoms without treatment or specialised support can have devastating consequences on someone's professional and personal lives.

Many respondents reported significant financial loss with 53% saying they lost their job or left their studies because of the delay, losing out on an average (median) of £30,000 in income from a loss of earnings. 54% said that through impulsive spending they took on unwanted debts totalling an average (median) of £10,000. There were also significant impacts on wider mental health, and on relationships with friends and family.

Most devastatingly, 75% said they had had more suicidal thoughts and 40% said they had attempted to take their own life because of the delay. It is unknown how many people will have lost their life to suicide because of a delay in diagnosis, though studies suggest for every 12 attempts one will be successful²⁴. It is a sobering thought that for the 839 people who told us they had attempted to take their own life because of the delay, there could be another 70 people who are no longer here to tell their story. This once again highlights the need for early intervention – research shows that the most commonly prescribed medication for bipolar (lithium) lowers the risk of suicide²⁵.

Multiplied across the whole bipolar population of over one million, this equates to a significant loss of economic output and a devasting loss of life.

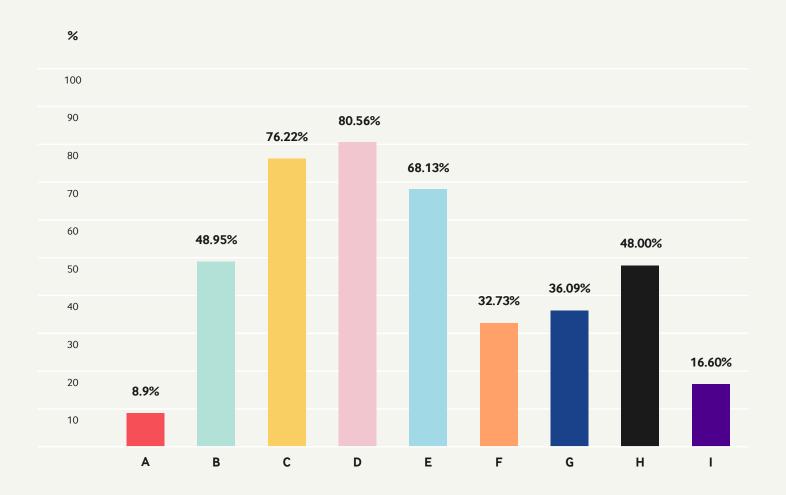
Figure 12: On the whole, has receiving a bipolar diagnosis been helpful?

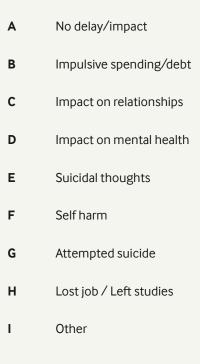


²⁴ Tondo, L., et al. "Suicide attempts in bipolar disorders: comprehensive review of 101 reports." Acta Psychiatrica Scandinavica 133.3 (2016): 174-186.

²⁵ Cipriani, Andrea, et al. "Lithium in the prevention of suicide in mood disorders: updated systematic review and meta-analysis." Bmj 346 (2013).

Figure 13: Did a delay in receiving a diagnosis of bipolar cause the following impacts?





What happens after diagnosis?

A diagnosis makes it possible for someone to get effective treatment and support, and to live well with bipolar. The shorter the delay in diagnosis, the sooner someone can empower themselves with effective self-management and foster a virtuous circle with fewer relapses in both the short and long-term.

Good self-management includes access and good adherence to a range of medication, a healthy lifestyle, (good sleep, routine, diet, exercise); good support from both a healthcare team and family/friends; avoidance of triggers where possible; and access to specialised psychological therapies

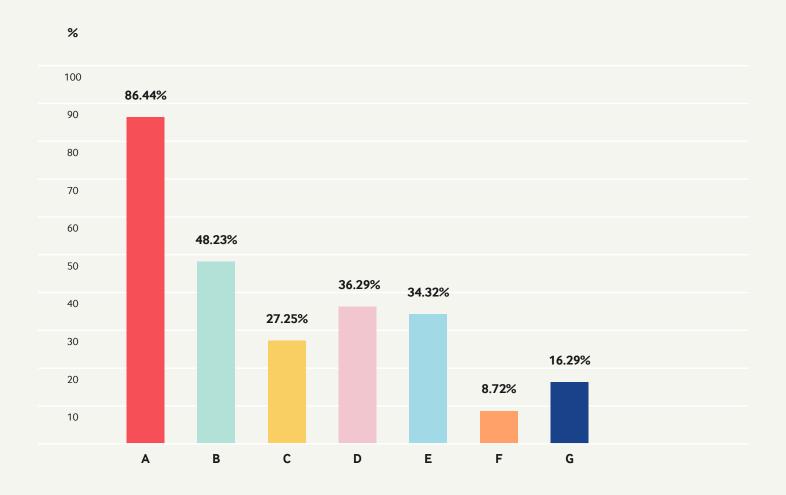
Self-management includes access and good adherence to a range of medication including mood stabilisers (including lithium), antipsychotics and antidepressants. Different combinations work for different people at different times. Regular reviews and dosage changes are required to manage changing moods, ever-changing external environmental factors and any intolerable side effects.

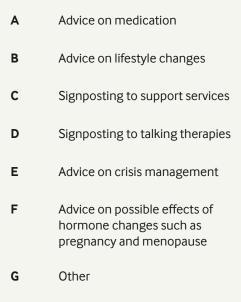
Alongside medication, psychological therapies, lifestyle and support networks play an important role. Getting enough sleep, avoiding triggers where possible, maintaining a routine with regular exercise, getting a balanced diet and daily mood monitoring all contribute to effective self-management. People with bipolar also report the huge role that family, friends and peer support can play in monitoring mood and helping them access professional support.

Despite the crucial role these factors play, the Bipolar Commission survey found that when they'd received their diagnosis, only 36% were signposted to psychological therapies. And only 48% of respondents received any advice about straightforward lifestyle changes that would reduce risk of relapse. This is the equivalent of someone who has a high risk of lung disease not being told to give up smoking.

They are also missing out on a range of support services, such as free online peer support and in-person peer group support provided by Bipolar UK.

Figure 14: What advice did you get on receiving a diagnosis?





Conclusions

There are over a million people living with bipolar in the UK. It is a severe mental illness that increases the risk of suicide by 20 fold and does untold damage to people's lives.

At least 5% of all suicides in the UK are by people with a bipolar diagnosis. The true figure is likely to be much higher as almost half the people with the condition don't have a diagnosis and there is an on-going issue with misdiagnosis.

Bipolar is a genetic condition but is triggered by many different environmental factors, such as lack of sleep and both traumatic and everyday life events. The mundane nature of so many triggers is one of the most insidious aspects of the condition. It is extremely difficult for someone to avoid all their triggers even if they have a diagnosis, let alone if they don't.

It is possible to live well with bipolar but it usually requires a combination of the right medication, specialised therapy and careful self-management, such as quality sleep, good routines and avoidance of triggers whenever possible. Again, all of these protective factors are only possible if someone has a diagnosis of bipolar.

Getting a diagnosis matters a great deal to people with bipolar. The vast majority told us they found a diagnosis either helpful or very helpful. While gaining access to services and medication was important, the overriding benefit for many was that it gave them an explanation for the traumatic and difficult experiences unmanaged symptoms had previously caused. In other words, a diagnosis helped them to make sense of their previous behaviour and let go of the shame they felt over decisions they'd made.

Research by the Commission suggests it takes on average 9.5 years from the point when someone living with bipolar goes to a clinician with their symptoms to finally getting a diagnosis. Without access to specialist treatment and no knowledge of the triggers it would be helpful to avoid, it is little wonder people often describe these as "lost years". People frequently lose jobs, rack up debt, put their families under huge strain and tragically sometimes try to take or take their own lives.

Survey evidence suggests one of the key drivers for the delay in diagnosis is the overlap between unipolar and bipolar depression. They can be very difficult to tell apart²⁶, and GPs see people with unipolar depression approximately ten times more frequently than they see someone with bipolar depression²⁷. In an ideal world, a GP would be able to refer a patient who they suspect may have bipolar to a psychiatrist. However, with the chronic shortage of secondary provision services, this isn't always possible.

60% of respondents told us they had been previously diagnosed with depression. This may have been because they hadn't previously experienced hypomania. Or it may have been that they didn't tell their GP about previous hypomania (either because they didn't recognise they'd previously had a period of hypomania or because they were too afraid of a diagnosis of bipolar).

55% of respondents told us they had had manic and depressive episodes triggered by taking antidepressants. An explanation for this is that often people don't go to see a doctor when they're in a high mood because they feel so good. Or, again, it may have been that they didn't tell their GP about a previous episode of hypomania.

²⁶ De Almeida, J. R. C. & Phillips, M. L. (2013). Distinguishing between unipolar depression and bipolar depression: current and future clinical and neuroimaging perspectives. Biological psychiatry, 73(2). 111-118.

²⁷ Hirschfield, R. M. (2014). Differential diagnosis of bipolar disorder and major depressive disorder. Journal of affective disorders. 169, S12-S16.

Emerging reflections on how bipolar diagnosis rates could be improved in the UK

Learning from other campaigns to boost diagnosis rates

The Prime Minister's Dementia Challenge successfully increased diagnosis rates for people with dementia through combing local registers with prevalence data to set national targets and incentives. We will be seeking evidence from this and other initiatives to see what can be emulated. 78% of survey respondents told us they think that GPs should routinely screen people with depression for bipolar and, though we recognise there are shortcomings with the screening tools and secondary care provision that's currently available, more research needs to be done in this area.

Embracing people power and online screening

63% of survey respondents said they would welcome an online screening tool. In response to that Bipolar UK has launched a **Mood Tracker app** to introduce the Mood Disorder Questionnaire (MDQ) to as wide an audience as possible and to encourage those completing it to use the app for daily follow-up mood monitoring. The MDQ can't diagnose but the app will raise awareness of bipolar and its symptoms and could be used to support people through the diagnosis journey. This means that even before someone receives a formal diagnosis, they will have a good idea about whether or not they have the condition and can start implementing some elements of effective self-management.

Advocating for more money into genetic research and its ethics

Expert witnesses tell us that it is currently not possible to conduct a DNA test to provide a definitive assessment of whether someone has the underlying genetics for bipolar, though it may one day be possible. 71% of respondents said they would welcome a genetic test. Further research in this area could open the door to much earlier and definitive diagnosis — and precision medicine that's specifically tailored to someone's genetic makeup. DNA testing for bipolar would also open up ethical dilemmas around prenatal screening and lifestyle choices. Further research into the ethical implications of this would also be welcome.

Improving awareness of self-management

Diagnosis is only the start of the self-management journey. Everyone who receives a diagnosis of bipolar needs to be signposted to wider support services and information, such as the Bipolar UK website www.bipolaruk.org. Those already with a diagnosis need to be given annual reminders of resources and the latest techniques and approaches to managing triggers and best-practice self-management. This would help to prevent relapses and improve long-term prognosis, thus saving people with bipolar more suffering and the NHS money by reducing the need for expensive hospital care.

The full Bipolar Commission report due to be released in March 2022 will put forward recommendations to:

- Make it easier and quicker for someone withbipolar to get a diagnosis
- Improve access to specialist treatment for people with bipolar
- Develop an evidence-based online screening tool for bipolarity to prompt someone to seek assessment from a healthcare professional
- Fund more research into bipolar, including genetics and its ethical implications
- 5. Improve awareness of proven self-management techniques
- Change the narrative around the public perception of bipolar to reduce stigma and encourage understanding

Bipolar UK would like to thank all the commissioners, expert witnesses and volunteers who gave their time and expertise to help compile this report.

The Bipolar Project project board:

- Professor Guy Goodwin co-chair Emeritus Professor of Psychiatry, University of Oxford
- Dr Clare Dolman co-chair Institute of Psychiatry, Psychology and Neuroscience at King's College London
- Professor Allan Young Chair of Mood Disorders and Director of the Centre for Affective Disorders Institute of Psychiatry, Psychology and Neuroscience at King's College London (Trustee)
- Professor Ian Jones Cardiff University/ Director/Clinical Professor, National Centre for Mental Health (Surveys)
- Simon Kitchen CEO Bipolar UK Project Sponsor

Annex 1: Demographic information

ANSWER CHOICES	RESPONSES	% OF TOTAL
Male	637	29.50%
Female	1,514	70.13%
Prefer not to say	5	0.23%
Other (please specify)	3	0.14%
TOTAL	2,159	

ANSWER CHOICES	RESPONSES	% OF TOTAL
White – English, Welsh, Scottish, Northern Irish or British	1,766	82.03%
White — Irish	58	2.69%
White – Gypsy or Irish Traveller	1	0.05%
White – Any other White background	133	6.18%
Mixed or Multiple ethnic groups — White and Black Caribbean	24	1.11%
Mixed or Multiple ethnic groups — White and Black African	11	0.51%
Mixed or Multiple ethnic groups – White and Asian	14	0.65%
Mixed or Multiple ethnic groups — Any other Mixed or Multiple ethnic background	20	0.93%
Asian or Asian British	11	0.51%
Asian or Asian British — Indian	15	0.70%
Asian or Asian British — Pakistani	4	0.19%
Asian or Asian British — Bangladeshi	2	0.09%
Asian or Asian British — Chinese	3	0.14%
Asian or Asian British — Any other Asian background	4	0.19%
Black or Black British – African	12	0.56%
Black or Black British – Caribbean	17	0.79%
Black or Black British – Any other Black, African or Caribbean background	6	0.28%
Arab	5	0.23%
Any other ethnic background	8	0.37%
Other	39	1.81%
TOTAL	2,154	

What is your highest level of qualification?

ANSWER CHOICES	RESPONSES	% OF TOTAL
No academic or professional qualifications	75	3.49%
Passed 1-4 GCSEs or equivalent; 1-4 O Levels/CSE/GCSEs (any grades), Entry Level Foundation Diploma, NVQ Level 1, Foundation GNVQ, Basic/Essential Skills	142	6.60%
Passed 5+ GCSEs or equivalent; 5+ O Levels (passes) CSEs (grade 1) GCSEs (grade A*-C), School Certificate, 1 A Level/2-3 AS Levels/VCEs, Intermediate/Higher Diploma, Welsh Baccalaureate Intermediate Diploma, NVQ Level 2, Intermediate GNVQ, City & Guilds Craft, BTEC First General Diploma, RSA Diploma	218	10.14%
Apprenticeship	16	0.74%
Passed 2+ A Levels or equivalent (level 3 qualifications); 2+ A Levels/VCEs, 4+ AS Levels, Higher School Certificate, Progression/Advanced Diploma, Welsh Baccalaureate Advanced Diploma, NVQ Level 3, Advanced GNVQ, City & Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma	261	12.14%
Degree level or above (level 4 qualifications and above); degree (e.g. BA, BsC), higher degree (e.g. MA, PhD, PGCE), NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level, Foundation Degree (NI), Professional Qualifications (e.g. teaching, nursing, accountancy)	1,368	63.63%
Other qualifications; Vocational/work-related qualifications, foreign qualifications, qualifications gained outside the UK, not stated/level unknown	70	3.26%
TOTAL	2,150	

What is your approximate gross income? (individual, without benefits)

ANSWER CHOICES	RESPONSES	% OF TOTAL
Only benefits	488	22.78%
Up to £10,000	229	10.69%
£10,000 — £20,000	344	16.06%
£20,000 - £30,000	345	16.11%
£30,000 - £40,000	213	9.94%
£40,000 — £50,000	131	6.12%
£50,000 — £60,000	59	2.75%
£60,000+	116	5.42%
Prefer not to say	217	10.13%
TOTAL	2,142	

Contact Bipolar UK

If you have been affected by anything included in this report please get in touch.

Bipolar UK

info@bipolaruk.org www.bipolaruk.org www.bipolaruk.org/faqs/mood-scale

Follow us at:
twitter.com/bipolaruk
facebook.com/bipolaruk
youtube.com/user/BipolarUKvideos
instagram.com/bipolar_uk



