

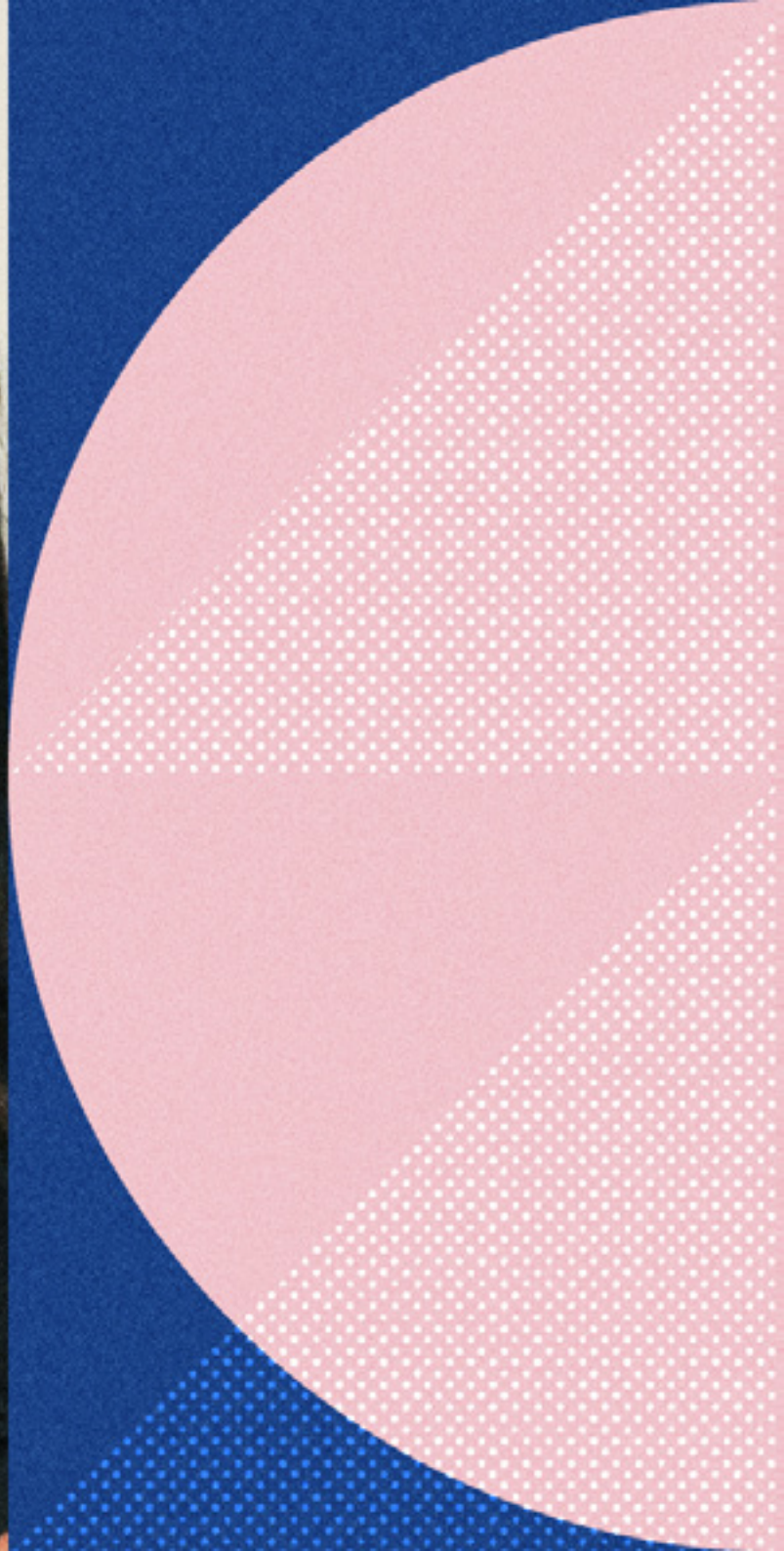


# Hidden in plain sight

A lived experience report  
by Bipolar UK

Published  
March 2022

Let's talk at [bipolaruk.org](https://bipolaruk.org)



# Introduction

The Bipolar Commission was launched on 30 March 2021 (World Bipolar Day) with a dual aim of reducing suicide rates and improving health services for people with bipolar in the UK.

The Commission brought together 22 commissioners who represent a broad cross-section of the bipolar professional and lived-experience community with a balance of ages, ethnicities, sexualities, gender identities and geographic locations. Professional experts include healthcare economists, leading academics, therapists and frontline clinicians, including psychiatrists and GPs. Nearly all the Commissioners either live with bipolar or have a close family member with it.

The Commission is co-chaired by Professor Guy Goodwin, Emeritus Professor at Oxford University, 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's research methodology has included a look at the current literature, stakeholder and patient interviews and a series of comprehensive online surveys of the community.

The Bipolar Commission acknowledges that bipolar impacts upon and is impacted by a range of social factors such as housing, welfare and work, but its initial focus is the health service itself. It fully embraces both the social and medical model of bipolar and appreciates that neither can work effectively without the other.

The first interim report, published in October 2021, focuses on what bipolar is, and what causes and triggers it, and provides vital insights into patient experiences of getting a diagnosis. This 'Bipolar Diagnosis Matters' report includes our 'What needs to change' recommendations.

This second interim report focuses on the lived experience of the bipolar community to paint a comprehensive picture of what it's like living with bipolar in the UK today. What are the treatments? What impact does the condition have on physical health? Which services are working well – and which aren't? What's the link between bipolar and suicide?

The foundation of the research is three surveys we distributed via our eNewsletters, eCommunity and social media channels. The surveys have been completed by people with a diagnosis of bipolar:

Triggers and Diagnosis	2458 respondents
Treatment and Services	1036 respondents
Hospital Care and Physical Care	1092 respondents

Respondents were self-selected and more likely to be white British, female and graduates than the population as a whole.

The results from the surveys have been collated with over 50 qualitative interviews with academics, clinicians and people with lived experience. Literally thousands of people living with bipolar have shared their experiences with us, allowing us to compile a dataset to improve our understanding of the needs of the bipolar community.

The full Bipolar Commission report collating all our evidence will be published in June 2022 and will include sections on how bipolar affects females, and the economic impact of bipolar both to the individual and to the state. In April and May 2022, we will also be hosting six informal evidence gathering sessions with the world's leading bipolar experts on: Diagnosis, Medication, Post-Diagnostic Support, Suicide Prevention, Hospital Care and Physical Health.

The Commission has benefited from a network of engaged and committed academics and clinicians and a strong peer support community centred on Bipolar UK. It also has a sympathetic ear with hundreds of policy makers, health commissioners and professionals in a range of sectors who have first-hand experience of bipolar. Many people want to act but don't know how and are fearful of acting alone.

The Commission is about mobilisation: to provide a common goal and a route forward towards achieving it.

To fulfil the mission of the Bipolar Commission, we all have a part to play. Like our Bipolar UK Ambassador Andrew. He is living with bipolar type 2, diagnosed at the age of 50. He currently works as an app developer for an international travel operator. On hearing that his shocking delay to get a diagnosis was far from unusual, he worked pro bono with Bipolar UK to develop a mood tracker app to speed up the diagnosis journey. Thousands have downloaded it already and are using it to help them stay well.

Many of the statistics and stories uncovered by the Commission are both enlightening and harrowing. The more we investigated the more it became apparent that bipolar is having a huge unacknowledged impact, not just on individuals and families like our own but on society as a whole. From suicides rates to obesity, debt to detentions, the failure to support people living with bipolar to manage their condition is having a huge influence. Bipolar is hidden in plain sight in the world of policy as well as in our workplaces, our learning institutions and in our society generally.

While some elements might make difficult reading, the fundamental message is one of hope. Once people with bipolar have a diagnosis they can start their journey towards managing the condition. Through effective talking therapy, they can start to come to terms with the diagnosis and what they've already been through. Through effective psychoeducation, they can learn about lifestyle changes that can reduce triggers and relapses. With patience they can work with their psychiatrist to find the right combination of medication. It might take months or it might take years, but it is possible to live well with bipolar.

Hundreds of thousands of people with bipolar are self-managing well every day and making important contributions, like Andrew, to a range of sectors and professions. By empowering people with bipolar to live well, we will see benefits way beyond the individual and the family.

The Commission at this stage is uncovering more questions than answers and opening up several cans of worms, but it's the start of a national conversation. We are determined to get the voices of our community heard, to bring the issues of living with bipolar into plain sight.

# Foreword

by Simon Kitchen, Bipolar UK's CEO

We all have a relationship with bipolar whether we know it or not. Roughly one in 50 people is living with the condition. Millions more are affected through friends and family. Research suggests we each have a personal network of over 600 people, so if we do the maths we all know at least 12<sup>1</sup> people with bipolar.

Before I became CEO of Bipolar UK, the only experience of bipolar I was aware of was through a close school friend. He had cycled in and out of hospital while we were doing GCSEs and A-Levels. No one told us, his group of friends, that it was bipolar (or manic depression as it was called then) but we became very familiar with the symptoms of mania and depression.

Some months he would put on huge amounts of weight, others he would exercise for several days straight. We did our best to support him and enjoy life together, though as we grew older the friendship group drifted apart. We all headed to university and he was left at home, trapped by his condition and medication. It's a tragic story that will be familiar to hundreds of thousands of people.

Despite the prevalence of the condition, I was an exception in knowing I knew someone with bipolar. Research by our charity has found that 72% of people with bipolar didn't know anyone else with the condition before they were diagnosed<sup>2</sup>. This is often for the simple reason that it takes most people around 10 years to get a diagnosis, if they get one at all. Bipolar also still carries a lot of fear and stigma so people with a diagnosis can understandably be private about it. They often only tell people on a 'need to know' basis, for fear of losing their job or missing out on promotion or being treated differently.

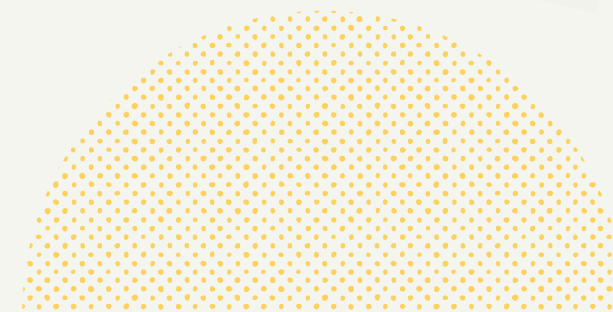
Since taking the role of CEO I have been struck by the number of people who have come forward to tell me they were either living with bipolar, had a family member with it or suspected they had it and were seeking a diagnosis. I actually knew quite a lot of people and they had all been struggling in ignorance and silence. They were ordinary people who had had extraordinary and difficult experiences.

The most tragic was my own brother-in-law Kevin. After a promising career as a chef on Jamie Oliver's TV show Fifteen, he took his own life having struggled for years with bipolar. As you will discover, his experience is all too familiar. I never met him, but his death has left a huge hole in my family. Tragically, few people in the family even knew he had bipolar and he got little help and support.

The Bipolar Commission has been established to help people like my brother-in-law and the thousands of others affected by bipolar who are struggling every day.



Simon Kitchen



# What is bipolar?



Bipolar 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.

Previously named 'manic depression' by German psychiatrist Emil Kraepelin in 1896 to describe a combination of 'mania' and 'melancholia', the name was changed to 'bipolar disorder' in 1980 to try to eliminate some of the stigma surrounding the condition. These days it's more widely known as 'bipolar'.

To explain the condition to people who have never met someone with bipolar, Bipolar UK uses a mood scale (see Figure 1 on page 6) which ranks mood from 0 – 10, with 0 being low and 10 being high. 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 identify the specific support and treatments that enable people with bipolar to maintain a balanced mood and prevent relapses. We also aim to find out whether 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 however 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.

Comorbidities for people with bipolar are extremely common. In fact, nearly one in three (32.6%) people have told us they also have a diagnosis of anxiety, 13.8% have post-traumatic stress disorder and 11% have a panic disorder as well as bipolar. And if the comorbidities aren't properly managed, it is very difficult to manage the bipolar itself. It is an understatement to say that it is a complex picture.

## What's it like living with bipolar?

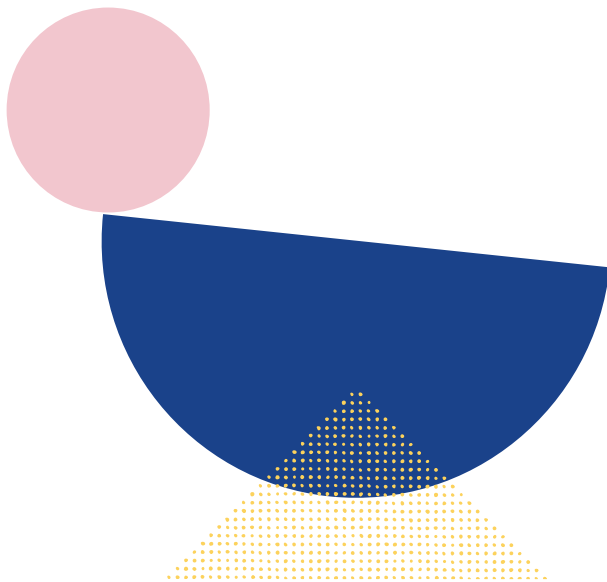
Some people with bipolar can live a 'normal' life with a relatively stable mood for weeks, months or even years at a time. This balanced mood range is known as 'euthymia'. But both a manic high and depressive low mood can be incredibly destructive.

Mania can result in reckless spending and impulsive decision making, hyper sexualisation and rapid uncontrollable thought patterns. In some cases it can 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 (see page 24).

“ During one of my worst periods of depression which lasted four months, I wanted to go to bed all day, I had a constant lump in my throat and felt like crying most of the time. To try to get the pain to go away, I was smoking and drinking a lot. At the lowest point I wanted to give up on life. **JD** ”

During both manic and depressive episodes, people with bipolar can do things they regret. They get into debt buying things they don't need and gifts for strangers, make mistakes at work and lose their jobs, 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.



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. The issue, though, is that if it's left untreated, hypomania can tip into full-blown mania, which people tell us feels incredibly scary.

“ When I'm hypomanic I feel very elevated, very energised, very happy. I excessively shop. I drive too fast in my car and have had speeding fines. I don't sleep a lot. It is dangerous for me. **CS**

“ My highs are much more enjoyable in the first few days, but then become out of control where I spend too much money, have rapid thoughts, don't sleep for days on end and become extremely sensitive to light and sound. **JD**

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. The type of bipolar someone has will determine the severity, duration and type of moods they will experience. The most common types of bipolar are:

<b>Type I</b>	where people experience depression, hypomania and mania.
<b>Type II</b>	where people experience long periods of depression and hypomania.
<b>Cyclothymia</b>	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.

## How many people have bipolar?

Worldwide prevalence rates of bipolar are estimated to be between 1% and 5%<sup>3</sup>. 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 estimated that 2% of the UK population aged 16 and above were living with bipolar<sup>4</sup>. That's over a million people, making it one of the most prevalent long-term mental health conditions – roughly 30% more than the number of people who have dementia<sup>5</sup> and twice the number of people who have schizophrenia<sup>6</sup>.

Prevalence of bipolar is 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<sup>7</sup>. Young people are 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.

## 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 predominantly genetic condition. If a twin has bipolar, their identical sibling has a 70% chance of developing the condition<sup>8</sup>. 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 depression.

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 condition<sup>9</sup>.

“ My maternal grandfather, mum, uncle and cousin all had/have bipolar. It wasn't the biggest shock when I was diagnosed last year. **AS**

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.

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%<sup>10</sup>, 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.

**Figure 1:  
Bipolar UK Mood Scale**

**Mood Scale**

**Numbers**

<b>MANIA</b>	Total loss of judgement, exorbitant spending, religious delusions and hallucinations	10
	Lost touch with reality, incoherent, no sleep, paranoid and vindictive, reckless behaviour	9
<b>HYPOMANIA</b>	Inflated self-esteem, rapid thoughts and speech, counter-productive simultaneous tasks	8
	Very productive, everything to excess (phone calls, writing, smoking, tea), charming and talkative	7
<b>BALANCED MOOD</b>	Self-esteem good, optimistic, sociable, and articulate, good decisions, need less sleep and get work done	6
	Mood in balance, no symptoms of depression or mania	5
	Slight withdrawal from social situations, concentration less than usual, slight agitation	4
<b>MILD TO MODERATE DEPRESSION</b>	Feelings of panic and anxiety, concentration difficult and memory poor, some comfort in routine	3
	Slow thinking, no appetite, need to be alone, sleep excessive or difficult, everything a struggle	2
<b>SEVERE DEPRESSION</b>	Feelings of hopelessness and guilt, thoughts of suicide, little movement, impossible to do anything	1
	Recurring suicidal thoughts, no way out, no movement, everything is bleak and it will always be like this	0

# Triggers



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. The findings are in Figure 2 on page 8.

The biggest trigger for bipolar both for a first episode and a relapse, is 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. 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.

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 frustratingly, 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. The picture is particularly complex given that there are many, many triggers (we haven't listed them all). Also, some people have multiple triggers, and triggers often work in combination.

## Avoiding triggers

People with bipolar can lower their risk of relapse 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 planning ahead to cope with stressful times.

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. Nearly 1 in 5 (19%) of respondents reported that it played a major role in their first manic or mixed-state episode, meaning they might have avoided becoming so unwell had they not been prescribed it.

This reflects what our bipolar community tells 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

\* 'Unipolar' depression is about 10 times as common as bipolar : they can be very difficult to tell apart<sup>12</sup>.

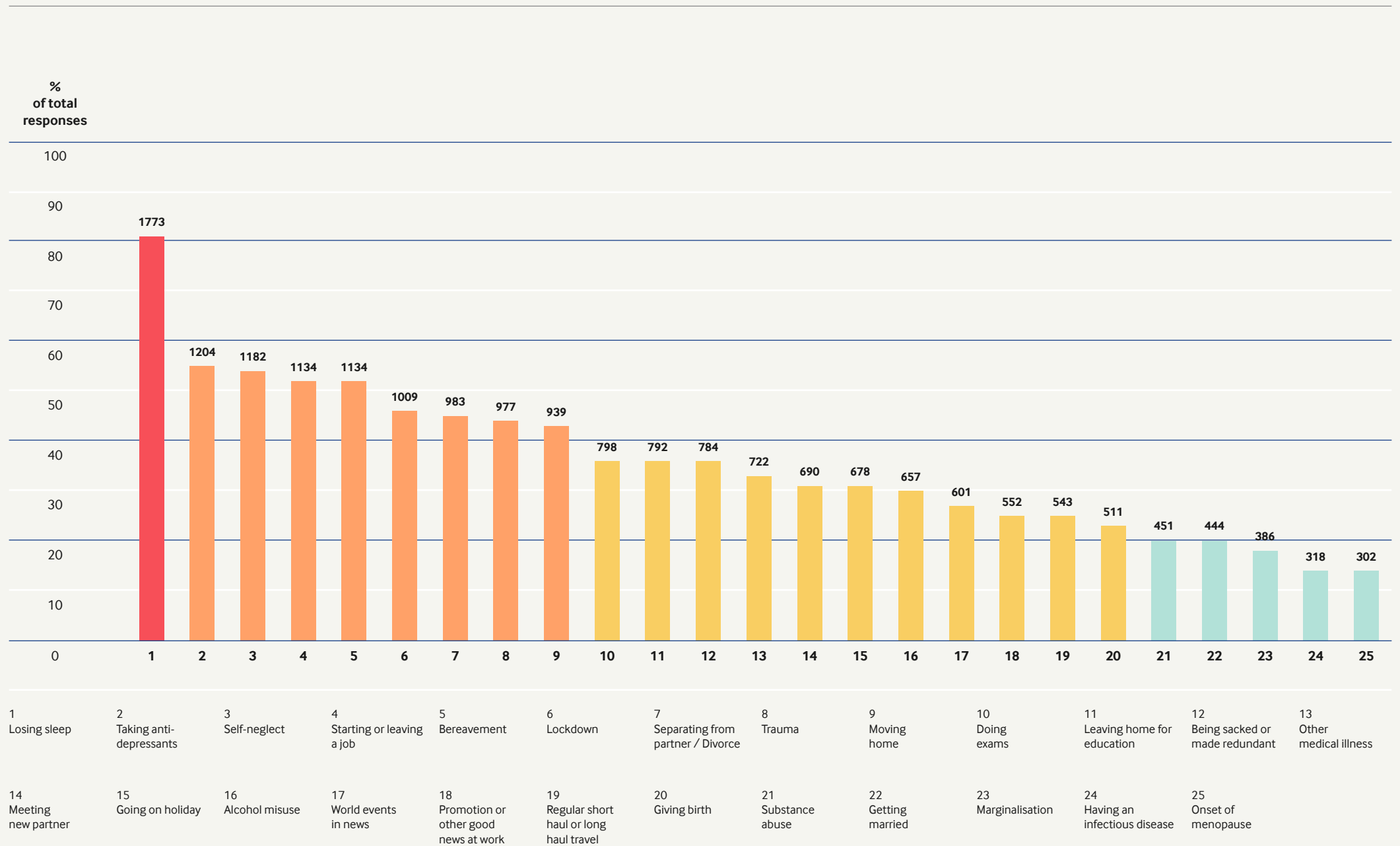
It also chimes with an academic study reviewed by the Commission that found around 10% of UK primary care patients prescribed antidepressants for depression or anxiety have undiagnosed bipolar disorder<sup>13</sup>.

## Conclusion

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.

**Figure 2:**  
**What life events have triggered a bipolar episode?**





# Diagnosis



Getting a diagnosis of bipolar isn't straightforward because there are no physical tests for bipolar unlike other conditions, such as diabetes (diagnosed by a blood test) or a stroke (diagnosed by a 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<sup>14</sup>, which found only 44% of people with bipolar have a diagnosis, albeit calculated using a small sample size. *In other words, 56% of people with bipolar in the UK don't have a diagnosis.*

To investigate the length of time it takes to get a diagnosis, the Bipolar Commission 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.

The survey used the respondents' 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 experiences 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 behaviour<sup>15</sup>. 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, the available screening tools (PHQ9 and GAD7) are far from perfect. Plus the Commission recognises that this is not always straightforward for GPs, not least because of how overstretched they are. One GP told us:

“ What we're being asked to do doesn't fit into a 10-minute model. I need to look at someone's medical history, medication list and perhaps a 10-page letter from a consultant. Then I have to speak to them. If they're presenting with mental health symptoms, I need to establish three things: 1. Are they a risk to themselves or others? 2. Can I deal with the symptoms they're having? 3. Do they need a referral to secondary care? Once they leave, I have to document everything. I don't have time to use a screening tool or think about their diagnosis. **Dr PA**

Another barrier to diagnosis is that there is also a resistance among some people to acknowledge they may have or have had bipolar symptoms as they are fearful of the negative effects of stigma, particularly on their job 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. This 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 bipolar<sup>16</sup>. 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 longterm. 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 people 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.

## 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 (40%) and by patients (40%) was also listed as a significant barrier. Only a third of respondents (32%) 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, eNewsletter, 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.

## Why diagnosis matters

NICE provides specific 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 services and bipolar-specific medication. It is also necessary for developing a comprehensive self-management plan.

People living with bipolar told us though that the primary benefit of diagnosis (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 others who have had similar experiences – particularly through peer support groups and online communities.



When I got my diagnosis it was like a weight was lifted off my shoulders because it kind of helps me and others understand why I do certain things. It was a relief. Also the diagnosis means my doctors take me more seriously. Whereas before if I told my GP I felt a bit depressed, she might tell me to go and do some exercise. But now, because bipolar is a serious mental illness, she listens. **CS**

## 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 unhelpful. A staggering 84% said a diagnosis was either helpful or very helpful. Less than 5% said it was unhelpful or very unhelpful.

## 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 successful<sup>17</sup>.

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 suicide<sup>18</sup>.

As well as lowering suicide risk, a diagnosis means someone can access group psychoeducation to learn self-management strategies to help them manage the condition better and lower the risk of relapse over the longterm. Research shows that the younger someone is when they are given psychoeducation, the significantly more effective it is<sup>19</sup>. Again, this highlights the need for earlier diagnosis.

## Conclusion

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 helpful circle with fewer relapses in both the short and longterm.

# Medication



As soon as someone is diagnosed with bipolar they are almost always prescribed medication to help manage the symptoms. For most people with bipolar, this medication is a key part of their self-management regime for the rest of their life.



Broadly speaking, there are three types of medication to treat bipolar: mood stabilisers, antipsychotics, and antidepressants. Some people also take additional medication to help manage symptoms and side-effects such as sleeping tablets. Getting someone on the right medication at the right dosage as quickly as possible is vital to their longterm outcome.

Within each medication type there are multiple different options that someone with bipolar might take to manage their condition. In fact, the Commission identified at least 25 different medications for bipolar, many of which are available in different formulations. Add to the equation the wide range of dosages and this means there's an almost infinite number of possible combinations.

## Why medication matters

Oral evidence received by the Commission from people with lived experience often highlights the 'eureka' moment many people have when they find the right medication combination – often only after years of adjusting medication options and doses. Finding the right combination has a profoundly positive effect on their life, completely transforming their and their family's prospects.

“ My psychiatrist has had the patience to keep tweaking my prescription and now it's working for me I feel like my old self again. I wouldn't have believed that was possible when I was at my lowest three years ago. **JK** ”

After recovery from an acute episode of illness, people with bipolar are, on average, symptomatic half of the time<sup>20</sup>. Without medication, these symptoms are likely to become more severe, eventually leading to relapse. So the great majority of people who do not take medication are likely to have more relapses, and these relapses may be increasingly difficult to treat<sup>21</sup>.

## Are people with bipolar on the right medication?

The most worrying evidence comes from the Adult Psychiatric Morbidity Study (APMS) from 2014. Based on a random sample of 7,076 individuals it found that of those who screened positive for bipolar disorder, 6 out of 10 were not getting any current medication or

treatment (60%). Combined with prevalence data this suggests that at least 600,000 people in the UK are not getting any medication to help manage their bipolar.

Anecdotal evidence from academics suggests these will predominantly be people with bipolar type 2 who are either invisible to the NHS or considered to have 'treatment resistant' depression. This is backed up by evidence from Professor Daniel Smith at Edinburgh University that found that 30-40% of people with treatment resistant depression actually have bipolar<sup>22</sup>. And another study found that over 3 in 20 patients with depression in primary care have unrecognised bipolar which can lead to harmful patient outcomes<sup>23</sup>.

There is also overlap with borderline personality disorder (which some clinicians refer to as emotionally unstable personality disorder or EUPD), or increasingly as complex post-traumatic stress disorder or CPTSD<sup>24</sup>.

As highlighted and detailed in the Diagnosis section (page 9), this lack of early diagnosis can have a devastating longterm impact.

“ For years I took antidepressants and had counselling for depression, but I didn't find it very helpful – mainly because I'd feel really depressed when I saw the GP who referred me, but by the time I saw the counsellor six weeks later I would feel okay again. So, I never received the counselling when I needed the help. I struggled with low moods for weeks and months and years on end. At times I was happy and at others I was irritable and angry. I was spending too much money facilitating the multiple hobbies and activities that I was constantly pursuing; never achieving the gratification I was seeking. At the age of 50 I was diagnosed with bipolar. As soon as I started taking mood stabilisers I noticed a difference and so did my family. **AT** ”

The delay in diagnosis can also often result in the prescribing of antidepressants without mood stabilisers which can be a common trigger for mania.

“ I went to the GP with depression in the September and she prescribed antidepressants. By the November I had stopped sleeping, I thought my husband was trying to poison me and I tried to kiss the postman. I was sectioned and diagnosed with bipolar. I really believe I might have avoided hospital if I hadn't been prescribed those antidepressants. **EB** ”

A lack of diagnosis is one barrier to getting the right medication, but even with a diagnosis it can be a lengthy process to find the right combination of formulations and doses. Even then, someone's physiology and lifestyle are constantly changing so regular medication reviews are essential.

## Medication reviews

For those taking medication, the Bipolar Commission asked people living with bipolar what medications they took, how often they got them reviewed and the impact on their lives. The NICE guidelines recommend that when working with people with bipolar in primary care, a GP needs to 'review their treatment and care, including medication, at least annually and more often if the person, carer or healthcare professional has any concerns'. Considering the enormous strain primary care is currently under, this is a big ask. Many of our expert witnesses highlight the chasm between primary and secondary care for people with bipolar and ongoing medication reviews are falling into that gap.

“ There should be more regular checks on the effects of medication. They're supposed to be regular but my GP often forgets or has to be prompted by me. If I don't go to see my doctor, I'm forgotten about... **JK**

“ I wish my GP would pay more attention to my written requests for changes to my medication. He just prescribes the same medication each time, without taking needed changes into account or bothering to ask any questions. **PS**

Two-thirds of respondents told us they'd had a medication review at least once a year. However, this might have been with a GP or healthcare assistant, not necessarily a psychiatrist.

## Lithium

The mood stabiliser lithium is the 'gold standard' and recommended as the frontline treatment for longterm treatment for bipolar by NICE. It is a naturally occurring salt and, first used in the 1950s, is one of the oldest treatments for bipolar. It is proven to lower the risk of suicide<sup>25</sup> and with regular bloods tests (every 3-6 months) the risk of salt toxicity can be dramatically reduced.

Clinicians told the Commission that for a third of people with bipolar lithium relieves almost all symptoms. Another third respond well to it and only a third need an alternative<sup>26</sup>. Evidence submitted by colleagues in Sweden, found a strong correlation between lower relapse rates and higher rates of lithium prescribing<sup>27</sup>. Their lowest regional prescribing rates were 37.7% and highest were 84.9% (giving a mean of 52.4%).

Direct comparisons of prescribing levels are difficult given uncertainties in prevalence data and limited UK datasets, especially around diagnosis. Still the range of data submitted to the Bipolar Commission indicates that lithium remains woefully under-prescribed.

The Bipolar Commission survey found that only 35% were taking Priadel and Camcolit (the two brands of lithium). This in itself would put the UK below the lowest prescribing region in Sweden. These figures are also considered an overestimate because it may be hypothesised that people who took our survey are more likely to be well (and therefore more likely to be taking effective medication) than people who didn't take our survey (as they don't engage with the charity and/or they're less likely to be well and not taking effective medication). Research by Professor Daniel Smith based on a rigorous case note review study found only 1 in 20 people with a bipolar diagnosis in Scotland were taking lithium, and that prescribing levels were falling<sup>28</sup>.

This is reinforced by data on Open Prescribing<sup>29</sup>, which monitors England's prescribing trends. In the year leading up to 30 November 2021, there was a monthly average of 68,630 prescriptions written for one of the formulations of lithium commonly prescribed in the UK, lithium carbonate. This compares to 72,577 in the year running up to 30 November 2017 – a drop of 5%. This suggests that lithium prescribing in the UK is at best stagnating, although we need more data to confirm whether this is a longterm decline.

Bear in mind that lithium is recommended by NICE to augment antidepressant medication in people with treatment refractory unipolar depression – and around a third to a half of lithium use is for conditions other than bipolar<sup>30</sup>. This means lithium use for people with bipolar is even lower than raw figures might suggest.

## Challenges of taking medication

A large minority (34%) aren't getting annual reviews, 5% haven't had one for at least five years, and 2% haven't ever had their medication reviewed. 77% of respondents also said improving the medication review process should be a priority, especially after someone has been recently discharged from hospital. Both clinical and lived experience witnesses said that lack of consistent close supervision and knowledge of bipolar medication in primary care (where most people with bipolar are supported), meant reviews often happened infrequently over long periods of time. People were sometimes left on high doses or too many medicines which they were prescribed in hospital after sectioning, making it difficult, if not impossible, to get back to everyday life.

“ After I'd been sectioned and hospitalised due to a manic high I was prescribed a really high dose of the antipsychotic Olanzapine. When I came out of hospital three months later, I was still on the high dose even though I was now in a depression phase. I could only get an appointment with my psychiatrist eight weeks after discharge and for all that time I could barely get out of bed. If the dose had been lowered earlier, my recovery would have been quicker. The other issue is that I put on nearly two stone in weight during that time. **HA**

People living with bipolar understandably have a conflicted relationship with medication. Only 14% report no challenges in taking medication and a small minority (11%) believe that medication isn't the answer. One in ten people who responded distrust the pharmaceutical industry (10%). Overwhelmingly, however, the biggest challenges are around side-effects (60%).

## Coping with side-effects

The most significant side-effects are often physical, including weight gain (79%), feeling sluggish and tired (78%), dry mouth (51%), increased thirst (40%), frequent urination (36%), face and hand twitching (37%) and dizziness/nausea (36%). There are also additional cognitive symptoms such as loss of concentration (62%), anxiety (44%) and depression (34%). 18% also highlight increased suicidal thoughts from taking the medication.

"It is unreasonable to expect patients to tolerate side-effects in the longterm," says Professor Guy Goodwin, Emeritus Professor at Oxford University. "The objective is always to find the highest well-tolerated dose for the individual patient to balance efficacy (which requires as high a dose as possible) with tolerability."

Yet it is apparent that many of these side-effects cause individuals a lot of concern and distress, especially if they're not discussed before the medication is first prescribed.

“ When I was first prescribed medication for bipolar 26 years ago I was slim. My weight has increased year on year and now I am so overweight I can hardly walk. My first psychiatrist told me not to worry about gaining weight, that it was more important for me to be well mentally. But now I've got high cholesterol, diabetes and a blood clot lodged in my groin. They won't operate because of my weight. I wish I'd been told right from the beginning how important it was for me to stay slim and fit. **CR**

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“ When I was prescribed antipsychotics, no-one told me about the side-effects on the metabolism even though I've got a family history of diabetes. I wasn't given any blood tests or physical check-ups or anything. **JY**

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“ Before taking medication to treat my bipolar I would have liked more specific information about the side-effects and how the meds affect the body. It took me a long time to work out that quetiapine lengthens a racing heart (takes a lot longer to slow down) in the case of panic attacks, and it was pretty scary noticing that my body had changed when I switched from lithium to quetiapine. **SL**

In terms of the balance of risk, several lived experience witnesses note that the emphasis is on mood management rather than quality of life, referring to a systemic lack of care or concern about the longterm health impacts of prolonged medication use and its impact on quality of life. The aim is to keep someone stable enough to stay out of hospital rather than helping them to fulfil their potential. The implications on physical health are discussed later in this report (page 20).

“ I'm overmedicated to keep me out of the way. Society would like me to be slightly depressed because I'm easier to handle. I would like to be slightly manic because then I could work and enjoy my life. **CT**

Having to take medication every day is also a major challenge for some people. This lies both around remembering (25%) and not wanting (25%) to take medication every day. In fact, acceptance of having to take medication every day for the rest of their lives, even if they feel well, is a big psychological hurdle for many people. For some people it is the most obvious manifestation and reminder of the condition. They often need therapy for many years to help them come to terms with it.

“ I came off lithium in February and in April began to notice subtle changes – talking more, sleeping less, feeling happy. When I saw my GP in May, he wanted me to go back on lithium but I refused. I moved house in May and practically stopped sleeping. Since realising that my diagnosis of bipolar type 2 is correct and that I need to take meds for the rest of my life, my moods still fluctuate but not so severely. **JD**

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“ Realising that you need to take daily medication to literally 'keep you sane' takes a lot of getting used to, especially when – thanks to those very pills – you're feeling well and 'normal' again. This is where peer support and therapy help a lot, otherwise you're in danger of thinking you can do without the meds and ending up in hospital again. **CD**

Even when on the right medication, this is far from the end of the journey. Surety of supply can be an issue with trusted brands of medication being threatened with withdrawal due to decisions by regulators or manufacturers. For example, the bipolar community was faced with an anxious wait to find out whether Priadel (a brand of lithium commonly prescribed in the UK) was going to be withdrawn as part of price negotiations in 2020<sup>31</sup>. While this only directly affected 3% of respondents, 48% said withdrawal of a medication was very unhelpful, even if an alternative was provided. Some clinicians also told the Bipolar Commission that they were nervous about switching their patients' brands.

The issue is further complicated by the fact that switching between different formulations of lithium (eg. from lithium carbonate to lithium citrate) is not recommended. The NICE guidelines state<sup>27</sup>: 'All lithium preparations vary widely in bioavailability and lack of clarity over which preparation is intended can lead to the person receiving a subtherapeutic or toxic dose.'

Research published in February 2022<sup>33</sup> found that the most common brands of lithium carbonate appear to produce similar plasma lithium levels if taken at the same dose. This suggests that switching brands (eg. from Priadel to Camcolit) is unlikely to increase the risk of relapse. With hindsight the anxiety caused by the potential withdrawal of Priadel could have been avoided. As it was, the potential changes triggered unnecessary confusion and anxiety in the bipolar community.

### New medication

Conversations with academic psychiatrists and pharmaceutical companies reveal there is only a limited pipeline of new treatments for bipolar. This development has been hindered by the failure of past clinical trials. However, the repurposing of medication approved for other conditions does hold out hope. The limited bipolar research infrastructure for this makes it harder to recruit to clinical trials and to test repurposed medication. The community will therefore have to make do with the treatments that are already available for the foreseeable future.

## Conclusion

Medication remains a vital part of self-management for the vast majority of people living with bipolar. 60% of people with bipolar are still not getting access to even basic medication. For those who are, 63% of survey respondents told us they have an annual medication review, although the quality of this review is under question. Some people are experiencing serious, extremely unpleasant side-effects many of which have lasting health implications. The gold standard treatment, lithium, is under-prescribed.

## What needs to change

Medication management where clinician and patient collaborate and make decisions together needs to be at the heart of bipolar care. There are a number of simple changes that could dramatically improve the lives of hundreds of thousands of people with bipolar without any new treatments being brought to market.

### Focus on diagnosis

There must be a clear focus on diagnosis. Without a diagnosis it is impossible for someone to access bipolar-specific medication. There is enormous unmet need, especially for those with bipolar type 2 who expert witnesses tell us are often diagnosed with 'treatment-resistant' depression and who can spend years trying various antidepressants yet still experience symptoms. Another common scenario is that many people only receive a diagnosis of bipolar after a manic episode triggered by the prescribing of antidepressants without a mood stabiliser. Reducing the current average 9.5-year delay in diagnosis needs to be a top priority for clinicians and policy makers.

**Sign our 'speed up bipolar diagnosis' petition [here](#).**

### Regular and effective medication reviews

Regular reviews with a trained psychiatrist who has detailed knowledge of bipolar are essential. People with bipolar tell us that this is best done with the same clinician over a number of years. Patients value being able to build up a relationship with their doctor that enables them to spot the early warning signs and symptoms of an impending episode and take steps to nip a potential relapse in the bud. Medication is also intimately connected with self-management and lifestyle, so knowing the patient and their medical history is vital. This ongoing support can be done in person or, given the burden on the health services following the pandemic, remote options can also make up part of the care package to ensure continuity of care, such as FaceTime appointments and phone calls, particularly in conjunction with primary care support.

Positive treatment models have also been identified in Newcastle<sup>34</sup> where patients are hosted in voluntary inpatient units under close supervision. This speeds up the review process and allows more radical changes to be made to someone's medication. If these units are linked to specialist units they are also more likely to be prescribed gold standard treatment like lithium.

### Dealing with side-effects as well as bipolar

Medication reviews need to consistently consider not just the mood stability of the patient but the side-effects as well. These have longterm health implications for the individual and incur additional costs on the NHS and wider society. Additional support to manage weight gain and lower the risk of cardiovascular disease in particular is vital – not just to improve adherence to medication routines, but also to extend life expectancy. Encouraging and supporting healthy lifestyle choices right from the point of diagnosis (for example, funding gym memberships) could have a cost-effective, longterm impact.

### Putting patients in the driving seat

The most effective medication-management is done by people with bipolar who have a strong and trusting relationship with their psychiatrist (or knowledgeable GP). They have found tried-and-tested medication and are able to increase and reduce their dosages within certain parameters depending on their mood. They are also sometimes given 'PRN' (from the Latin 'pro re nata') medication to keep at home which they can take as and when they need it (such as a sleeping tablet or extra dose of antipsychotic). This can help to ward off a potential relapse as soon as they notice any warning signs. This approach often requires years of trial and error, but in the longterm reduces the burden on the clinician, the financial burden on the state and, more importantly, puts the patient in the driving seat.

# Post diagnostic support



Bipolar is a longterm condition that requires ongoing treatment and support. Post diagnostic support can include a range of services and should enable someone to self-manage effectively and live well with the condition.



At the most basic level, this means someone is offered support from a clinician to help manage their medication. It can also include psychoeducation about the ways to manage bipolar well, psychological therapies, peer support, a crisis service, a telephone helpline, advocacy services and supported living.

The current model of post diagnostic support in the UK is known as episodic care. This is set out in NICE guidelines. Day-to-day bipolar care is supposed to sit within primary care or more specifically with the GP. When someone with bipolar becomes unwell they are then referred to secondary care, usually a psychiatrist, for additional treatment.

## What the evidence tells us

To improve our understanding of post diagnostic support the Bipolar Commission surveyed 1032 people in the summer of 2021 to investigate the level of support they received and health outcomes such as relapse rates. As with all the surveys done by Commission, respondents self-referred. For this survey 68% were women, 77% were heterosexual, 86% were white British and 40% were employed. All the respondents had a bipolar diagnosis and the Adult Psychiatric Morbidity Study (APMS) suggests 60% of people with bipolar don't get any treatment or support. The findings therefore reflect those who are currently supported by the system as it stands.

## The system is delivering episodic care

The most common form of support was via GPs and primary care (reported by 55%) followed by psychiatrist outpatient support (40%). Unexpectedly 29% said they have previously used a GP but weren't now, 2% had been offered the support of a GP but didn't want it and 13% had never been offered the support of a GP. This suggests GPs only play an ongoing role for about half of the respondents. Almost a third of respondents (32%) were either using or had used a private psychiatrist.

The level of cross referrals between primary care and secondary care is positive. Respondents were asked if their GP referred them onto and sought advice from secondary care if their situation deteriorated. In all six of the criteria set out in NICE guidelines for a referral, respondents said that this happened 95-99% of the time.

## Specialist knowledge is crucial

The most common form of secondary care was seeing an outpatient psychiatrist, used by 90% of respondents. This was followed by community mental health teams (77% of respondents), psychological therapies (76%), inpatient care (59%), early intervention services (34%) and specialist bipolar services (14%).

The bipolar community valued this support with 70% saying their support from the psychiatrist was either helpful or very helpful. The secondary care service respondents said the most helpful support was the specialist bipolar services – 42% of users say they are very helpful. This compares with 19% for community mental health teams and 25% for inpatient services. Early intervention and crisis services were only very helpful for 23% and 22% of respondents. This is similar to primary care, with 23% finding community pharmacists and GPs very helpful.

This result generally mirrors respondents' perception of knowledge with 48% saying their psychiatrist was very knowledgeable about bipolar compared with 19.5% for the community mental health team (CMHT), 28% for psychiatric nurses, 21% for care coordinators and 9% for GPs.

## Despite support, relapse rates are high and increasing

A relapse is when someone's mood becomes unbalanced and they become unwell and experience either a depressive or manic episode. During a relapse an individual undergoes tremendous mental anguish and is at high risk of both sectioning and suicide. It's the equivalent of a diabetic's blood sugars becoming out of balance and going into diabetic shock. Lived experience witnesses compare a relapse to a runaway train – once it builds up momentum it's very difficult to stop.

“ I can be hypomanic for a while when I'm sleeping less, doing more, being more productive. But if I don't stop it in its tracks, there's a point of no return where I suddenly tip into mania. At that point I always end up in hospital because it's now out of my control and only high doses of medication will bring me back to earth. **SH** ”

# 70%

of people say support from a psychiatrist is helpful or very helpful

Relapse rates were high among respondents. In the past six months alone, a staggering 37% had relapsed and 5% had attempted suicide. That's 52 people out of the 896 who responded to that question who had attempted to take their own life in the past six months.

This compared with 15% who most recently relapsed and 4% who had attempted suicide in the six months prior to it. That was the year covered by the pandemic and suggests either rising or repeat relapses by a large cohort.

This could be reflective of the accumulative challenges caused by the pandemic (see our report on the impact of Covid-19). It may also reflect life pre-pandemic for many people living with bipolar. It is worth noting that the overall suicide rate in the UK isn't thought to have gone up during the pandemic<sup>35</sup>. However in the bipolar community it is shockingly high, equating to an estimated 2 people with bipolar a day taking their own life<sup>36</sup> (the link between suicide and bipolar is explored later in this report – see page 24).

Tragically a tiny minority (2%) of respondents had only had one episode of being unwell in their lifetime, suggesting the NHS fails to prevent relapse rates in the vast majority of people with bipolar. 90% of respondents had experienced suicidal thoughts and 59% had attempted suicide at some point in their lives. And although a 98% relapse rate may be overinflated due to our self-selected respondents who are, by definition, engaged with the charity, it does suggest that much more can be done post diagnosis to help prevent relapse.

### **Episodic care puts pressure on both primary and secondary care**

As would be expected within a model of episodic care, support is directed towards people who become unwell. When relapse rates are cross referenced with clinician contact it's clear that those who have relapsed most recently have received the most care.

The current model of episodic care places significant burdens on both primary and secondary care. This is particularly true of community psychiatric nurses and care coordinators whose time appears to be directed to a small group of individuals who relapse frequently. This suggests there is a core cohort of people who relapse and need ongoing intensive support and that the ramping up of care when people become unwell isn't preventing relapse rates overall.

This chimes with evidence submitted by lived experience witnesses who state that the interventions tend to be focused on crisis management rather than early intervention, relapse reduction and episode prevention.

Sadly, specialist bipolar services are not part of the usual design of secondary psychiatric service for adults. They may be provided by academic departments (such as the excellent examples at King's College London and Cardiff University) usually because there is a local interest in bipolar research. While this is welcome, it means the services are subject to changes in policy – or the failure to secure research funding may curtail them altogether.

### **Clinicians aren't focusing on prevention and planning**

Despite the intensity of support provided by the NHS to people with bipolar, a surprisingly small proportion is directed towards prevention and planning. This is particularly remarkable because lifestyle and self-management play an enormous role in reducing the risk of relapse.

Only 54% had received support with producing a care plan, 47% a safety or crisis plan and 40% received support to improve their knowledge and understanding of bipolar. The latter is probably the most surprising as absolutely everyone with bipolar could benefit from improved knowledge and understanding.

### **Most self-management is self-directed and solitary**

When asked where they got their self-management advice from, only 23% of respondents said psychoeducation from a health professional or recovery college. A massive 72% found it unguided online through websites and apps, or books (54%). Only 22% received it through peer support. Only 48% of respondents received any advice about lifestyle changes that would reduce this risk of relapse. This is the equivalent of someone who has a high risk of lung disease not being told to give up smoking.

When asked about the key components of their self-management strategies, 'family' was the most commonly chosen response (67%), followed by sleep (63%), exercise (57%) and friends (56%). Middle tier self-management techniques included 'diet and nutrition' and 'music/art/creative hobbies' (both 42%), followed by work (40%), mood

monitoring (33%), and mindfulness (31%) and journaling/writing (30%). All of these may require some basic education (eg. good sleep hygiene tips and mindfulness training) but need no ongoing support.

### **Bipolar-specific peer support was not widely used**

Peer support was only used by 20% of respondents. Of those that did use it, most found it useful. In fact, 36% found bipolar-specific support and 20% generic peer support very helpful. Stats that are comparable to the helpfulness of psychiatrists and GPs. This peer support was delivered online, over the telephone and in person. Other forms of more generic support were less helpful, such as staff led groups (26% very helpful), day services (18%) and telephone helpline (17%).

Only 21% said that expanding peer support should be a top priority for funding though we wonder if this figure is so low because not many people have used the services.

### **Psychological therapies**

Many people with bipolar have been through difficult challenges and are living with trauma which can trigger relapses and make living well with the condition more difficult. Psychological therapy, also known as 'talking therapy', can help someone deal with these experiences and build effective self-management strategies.

In terms of psychological therapies, 58% of people who responded to the survey had used psychological therapies in the past, 13.5% were currently using them and 5% had been offered them but not used them. Overall, 76% of respondents had been offered or received therapy at some point in their lives, 69% said they had been referred for psychological therapy (defined as counselling, psychotherapy, CBT, a mindfulness group, a psychoeducation/therapy group or family therapy for bipolar disorder) on the NHS at some point.

However, 20% reported that they had never been offered psychological therapy, and 29% had never been offered it on the NHS. Overall, 26% had reported that they had been told that they could not get therapy on the NHS and would have to pay for it themselves. Nearly half of respondents (49.4%) reported they had had to pay privately for therapy or counselling at some point.

A separate survey about hospital admissions asked about being offered therapy following discharge. 37% of respondents were offered therapy and accepted, 32% said they were offered therapy but would have been too unwell to use it, 12% were not offered it and felt they would have been too unwell to use it, 2.6% were offered but declined and 16% were not sure.



Of those who had used in the past or were currently using psychological therapies, 68.5% found them very helpful or helpful, 16% said the experience was neutral and 15% said they were unhelpful or very unhelpful.

“ Longterm therapy (60-70 weekly sessions) with a psychologist is very helpful and I am starting to see small changes in myself. I found counselling extremely unhelpful and damaging because all we did was talk about thoughts, feelings and experiences but then we didn't talk about a plan or any coping mechanisms. **SB**

In terms of specific therapies recommended in the NICE guidelines, 66% of people had been offered or received Cognitive Behavioural Therapy (CBT), and of these 52% found it helpful or very helpful, 30% found it unhelpful or very unhelpful and 18% reported feeling neutral.

And while a handful of people with bipolar who had CBT found it helpful for noticing the early signs of mania or hypomania and/or managing depression, most people who'd had CBT told us it was too general and not tailored enough to be useful for their bipolar diagnosis.

“ I have repeatedly been offered CBT, and when I say I have previously done lots of CBT and want to try something different because it doesn't help me, I'm told I can only have CBT. **JD**

“ CBT – I just don't get it, it really doesn't work for me. **SB**

“ I found CBT very helpful, but my Bipolar UK peer support group provided me with more information about how best to manage my bipolar. **KI**

Only 15% of survey respondents had been offered Improving Access to Psychological Therapies (IAPT) and 2.2% had been offered but declined. Of those who received IAPT, 52% found it helpful or very helpful, 21% were neutral, and 27% found it unhelpful or very unhelpful. *This suggests that only 7% of people with a bipolar diagnosis have found the NHS's flagship talking therapy programme helpful for managing their bipolar.*

For many years IAPT services excluded people with a bipolar diagnosis because the service was set up for people with depression and anxiety disorders, not conditions like bipolar that fall in the 'severe mental illness' bracket<sup>37</sup>. Many people with bipolar will have used the IAPT service before getting a diagnosis, and one researcher, Dr Rebecca Strawbridge who's a post-doctoral research associate at King's College London, told us: "We did a study of almost 400 people at a London-based IAPT service which included lots of research assessments and interviews. We found that almost 30% of the participants were indicated to have possible undetected bipolar which was higher than we expected."

As well as accessing IAPT services before getting a diagnosis, a tiny minority of trusts have now extended IAPT services to include people with a severe mental illness<sup>38</sup>, so some people with bipolar may have access through that route. However, our research didn't determine whether these people had used these services pre or post diagnosis.

A diagnosis should not exclude anyone from accessing essential services. Experts tell us that IAPT typically has many more therapists and much shorter waiting times than secondary care, suggesting that if trusts invested in training for IAPT services to work with people who have bipolar then this may help improve timely access to therapy. Preferably, trusts need to provide integrated specialist services for people with bipolar so they can get the life-changing therapy they need.

The most shocking statistic of all is that only one in five people had been offered or received group-based psychoeducation/therapy, yet when they did have it 78% found it helpful or very helpful compared to only 17% who felt neutral and 5% who found it unhelpful.

“ I am grateful I had access to a specialised bipolar service and was given 10 sessions of group therapy with others with bipolar and 4 one-to-one sessions to create an individual care plan. I found this so, so helpful. **CU**

“ I have never been offered psychological therapies despite numerous episodes of severe symptoms leading to inpatient admissions. It seems my episodes are only ever managed at crisis point with no follow-up until a further episode. **PP**



Only 1 in 5 people were offered or received any group-based psychoeducation

## Conclusion

60% of people with bipolar get no dedicated treatment and support. For those who do, the NHS is delivering a model of episodic care. Despite NICE guidelines, only half of respondents had an ongoing relationship with their GP and about a third have gone private.

The support provided in primary and secondary care is only directed towards a core group of individuals who are at highest risk of relapse. Opportunities to prevent serious episodes of illness, and the expensive care they entail, are being missed.

The system is failing to prevent high levels of relapse and suicide attempts within the bipolar community. It is also placing a large burden on both primary and secondary care. Those that provide the most intensive support in the secondary sector to this core cohort (care coordinators and community psychiatric nurses, or CPNs) also appear to have the lowest levels of knowledge of bipolar. Early intervention and crisis services are also underperforming in terms of effectiveness.

There is a lack of focus on prevention with only a minority receiving support on improving their knowledge of bipolar, and barely half receiving care plans and safety plans. The most helpful services are the bipolar specialist ones which are being used by only 14% of respondents.

Our research found that most self-management is self-taught and solitary, focusing on lifestyle changes such as sleep, diet and exercise rather than group activities. Peer support is not widely used but when it's bipolar specific, it is highly valued.

“ My local support group has been my lifeline for the past six years. I attend all the meetings and social events and have made a wonderful bunch of friends. I can't imagine that I'd be coping with my condition so well if I didn't have such amazing support just round the corner. **SW** ”

“ The peer support group began to share one by one, and I started to realise that this may be the right place for me after all. I shared my experience of a time that I was feeling invincible and on top of the world. I was on a long drive on busy main roads and I believed I was controlling the traffic. I looked around and was met with a circle of nodding faces and some knowing but warm and validating smiles. I felt a huge weight lift from me, along with a lifting of shame, embarrassment, and fear of being judged. I realised I didn't need to hold these thoughts and beliefs about myself, I wasn't a bad person, I wasn't a freak! Everything was ok, I was ok, I wasn't alone! **EB** ”

“ The Bipolar UK Support Line got me through my most difficult time. Without those calls – where I could share anything and everything without judgement – I honestly don't know if I would still be here. **HH** ”

## What needs to change?

Bipolar is a specialist condition that requires specialist support. The model of episodic care isn't working for the bipolar community or the NHS. It is soaking up huge resources and failing to prevent relapses and suicide attempts. To understand preferred models of care the Commission asked people with bipolar what they wanted.

When asked who should be responsible for supporting them with their bipolar, 41% said their psychiatrist, and 21% said their community psychiatric nurse. Only 16% said their GP, which is the current model. This is reflected in the respondents' funding priorities. When asked what they would invest any additional funding in, they said their top priority would be improving access to psychiatrists and specialist bipolar services, and research into better treatment.

Alongside seeing a psychiatrist, respondents overwhelmingly wanted to see the same clinician each time. When asked to choose, 73% preferred continuity of care over frequency of contact (9%) and choice of clinician (18%). Respondents also valued specialist knowledge of bipolar and empathy over the clinician sharing the same identity as them or having a high level of proficiency in English.

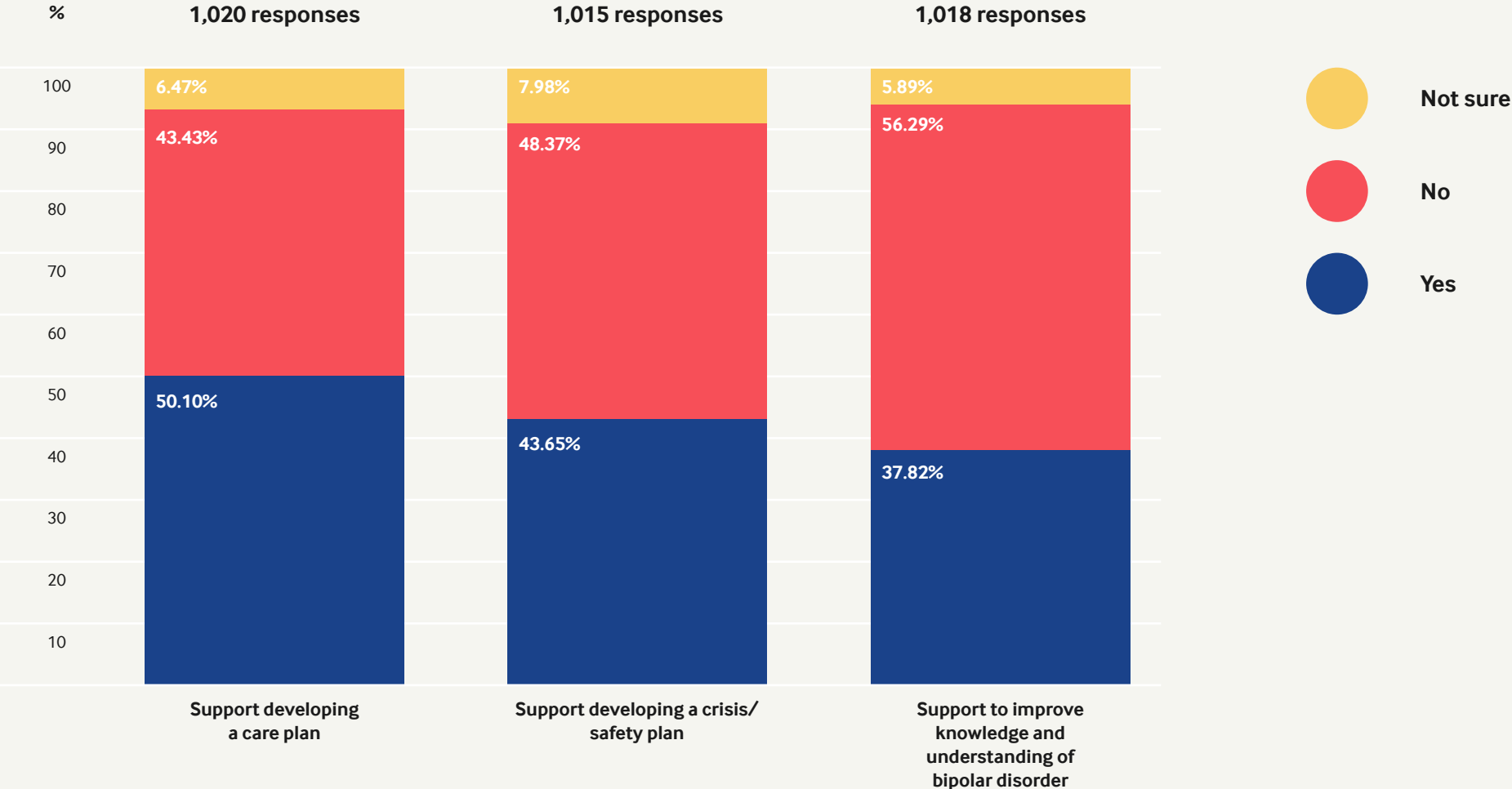
People with bipolar want something very simple: a trained professional who has specialist knowledge of bipolar, who knows them as a person and who will be with them in the longterm, supporting them to learn to self-manage the condition. The most obvious professional to fulfil this need is a psychiatrist, but it doesn't necessarily have to be. Several experts have told us that this was the model two or three decades ago.

The NHS needs to move from a model of episodic care that focuses on crisis management to a model that focuses on building longterm relationships between patients and clinicians. These relationships are fundamental for a patient and clinician to be able to collaborate so they can find the unique combination of medication, treatments and support that will enable the individual to live well with bipolar and achieve their potential.

The focus needs to be on early intervention and self-management, and preventing, or at worst, minimising the impact of, relapses. Everyone with bipolar should have access to psychological therapies on the NHS in line with NICE guidelines, particularly psychoeducation groups.

Peer support and other services have an important role to play but they cannot be seen as a substitute for clinician support. Where possible these should be bipolar specific.

**Figure 3:**  
**Have you had support from mental health services with the following?**



# Physical health



Bipolar is first and foremost a mental illness, though it also has very real physical symptoms. During manic episodes someone might have enormous amounts of energy and not sleep for days or even weeks at a time.



During a depressive episode someone is likely to experience the opposite of a manic episode: low energy levels, struggling to get out of bed and needing long periods of sleep. There are also secondary symptoms from living with the condition. For example, mania will increase someone's exposure to danger through increased risk taking.

There are also significant side-effects from medication and the physical health challenges associated with living on a lower income. Having bipolar puts enormous strain on the body as well as the mind. It is possible to live well with bipolar and have a long life, but only if both mental and physical health are considered priorities.

## What the evidence tells us

### People with bipolar die younger

The best data on the physical health of people with bipolar comes from Scandinavia where a patient record-linking system allows them to conduct large-scale longitudinal studies. One Swedish study investigating the deaths of people with bipolar from 1975 to 1995 provided a detailed breakdown of causes of deaths by comparing observed deaths of people with bipolar to expected deaths based on standardised mortality rates<sup>39</sup>.

The leading cause of death for both men and women with bipolar was cardiovascular disease which was almost twice the national average. More recent research has also found that young people (aged 18-34) with a serious mental illness have an increased risk of heart disease<sup>40</sup>.

Other leading causes of 'natural' death were respiratory disease and cancer. Just as worryingly people with bipolar were also ten times more likely to die from 'unnatural' causes including not just suicide but accidents and homicide.

Research in the UK on comorbidities of people with severe mental illness in general suggests the gap has continued to widen. Currently people with severe mental illnesses tend to live on average 15 to 20 years less than those in the general population<sup>41</sup>. Expert witnesses claim that this premature death rate is one of the contributing factors behind why the Adult Psychiatric Morbidity study found 16 to 24 year-olds were almost eight times more likely to screen positive for bipolar than those over 65.

### People with bipolar in the UK report poorer health

These study findings are backed up by the Bipolar Commission's own physical health survey findings. 44% of respondents report that their physical health is 'good' or 'very good'. This is almost half the proportion of the people in England and Wales (81%) who reported good or very good health in the 2011 census.

### Comorbidities

Only 27% of respondents state that they have no additional physical health conditions. The most common conditions diagnosed alongside bipolar are high cholesterol (17%), thyroid issues (17%), asthma (16%), arthritis (16%), irritable bowel syndrome (12%) and diabetes (10%).

These conditions come with their own physical symptoms and risks, and most likely need to be treated with medication, further complicating the self-management of bipolar. For example, 64% of respondents say it is harder to exercise because of the side-effects of their medication, trapping them in a vicious cycle of weight gain and a sedentary lifestyle.

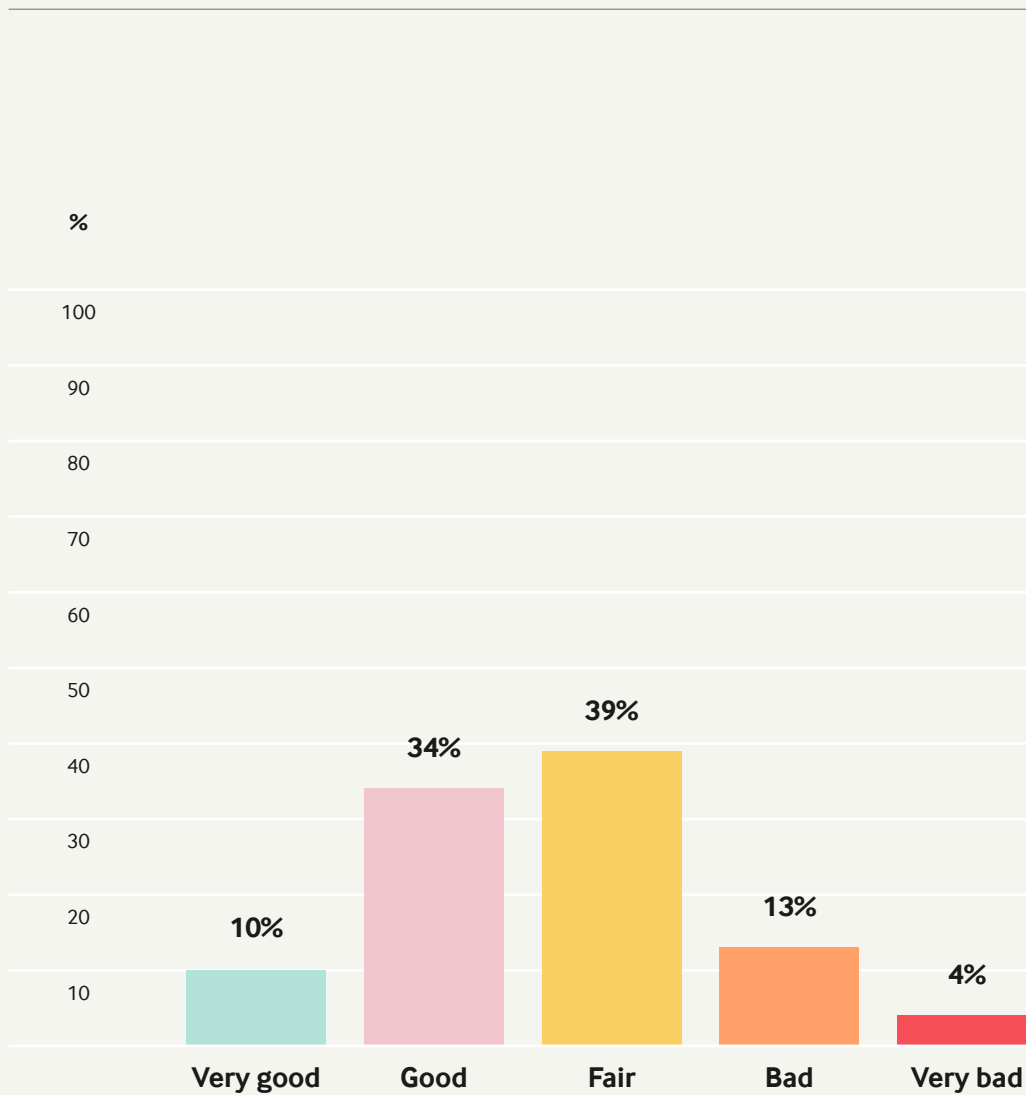
### GPs are getting mixed reviews

GPs are the main point of contact for people living with bipolar. Only 42% say their GP looks after both their mental and physical health well. A further 21% say GPs are good at supporting their physical health, but only a further 10% say they are good at supporting their mental health.

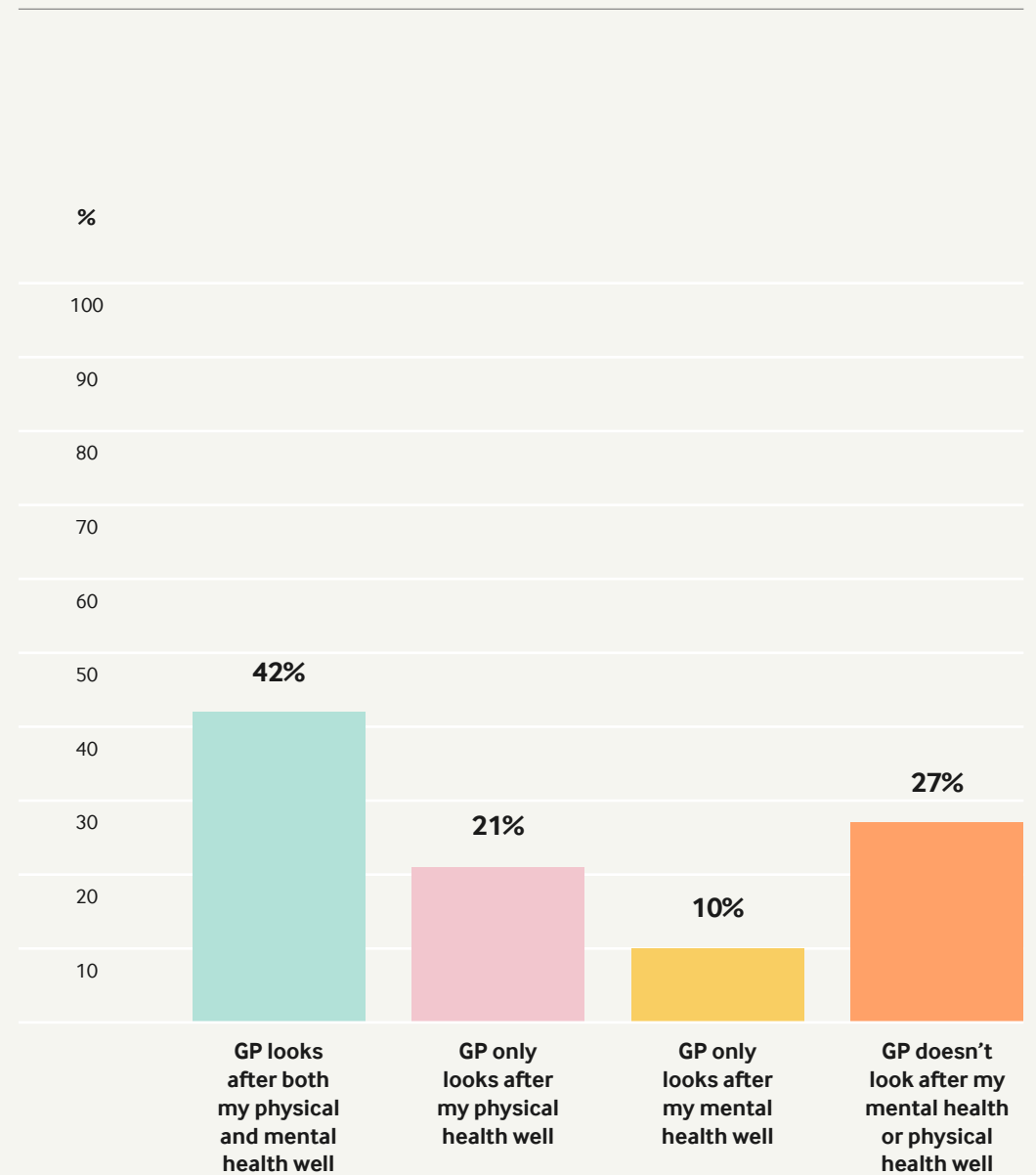
“ My GP isn't interested in my health. I could go in with an ingrown toenail and she'd say it was a job for the CMHT [Community Mental Health Team]. SA

Although diagnostic overshadowing (when a clinician makes the assumption that a person with learning disabilities behaviour is a part of their disability without exploring other factors such as biological determinants) is low, with only 9% reporting that their GP missed symptoms of a physical condition because of their bipolar and 12% because of side-effects from their medication, it was conspicuous that many participants did not feel they were taken seriously by healthcare professionals when trying to address their physical health needs. It's worth noting that the survey hasn't picked up undiagnosed conditions.

**Figure 5**  
How is your health in general?



**Figure 6**  
Do you think your GP is looking after your physical and/or mental health?



“ I would like to be believed and trusted to know what is normal for my body and what is a new development. I would like staff to see beyond my bipolar diagnosis and being overweight, and to consider the same possibilities as they would for anyone else. **JK** ”

### There are areas for improvement

Several participants highlighted difficulties obtaining initial appointments, follow-ups, and required physical health tests, often leading to feelings of frustration and anxiety. 27% say their GP could help them more with either their physical or mental health. Shockingly, only 1 in 5 respondents have been told about their increased risk of cardiovascular disease and of those who have been told, 70% haven't been offered support to try to reduce that risk.

Physical health care assessments, which all people with severe mental illnesses are eligible for, are inconsistent. Even taking into account the impact of Covid-19, the findings are disappointing: 29% of respondents either haven't had a physical health care assessment for at least five years or not at all and 50% have never been offered an electrocardiogram test (ECG), both of which are recommended by NICE which states that GPs need to: "Monitor the physical health of people with bipolar disorder at least annually. The health check should be comprehensive, focusing on weight or BMI, cardiovascular status, metabolic status, liver function, renal and thyroid function and calcium levels for people taking longterm lithium."

“ I can only recall being given an ECG by the mental health team when I've been sectioned. **DO** ”

“ I had been on lithium and other medications for 10 years before ever having an ECG and that was only because of my new care co-ordinator... It would be nice to have a mental health nurse who you could check in with a couple times a year to manage things like med side effects, med tweaks, sorting things like ECG and tests. **GH** ”

Evidence from lived experience witnesses tells us that those reviews that do go ahead often miss opportunities, with no helpful discussions about how bipolar self-management can be integrated into positive lifestyle choices. Another commonly reported barrier to optimum physical health is appointments being too short, thus not covering everything needing to be discussed, as well as long waiting times to be seen.

### There's not a holistic approach to healthcare

Over half of the participants outlined that healthcare professionals did not incorporate a holistic approach when discussing their mental and physical health, often needing to have separate appointments to discuss each issue.

“ No one takes a holistic or well-ness-based view. I've never had my bipolar mentioned in the context of physical health problems.” **JJ** ”

### Support for people who are taking lithium

Most people who are taking lithium have regular blood tests every 3 – 6 months. Positively only 3% report kidney disease, which is a classic symptom of lithium toxicity. This low report of lithium-induced kidney disease chimes with the latest research which describes lithium posing a lower risk of kidney damage than previously thought<sup>42</sup>.

### People with bipolar are more prone to thyroid problems

The number of thyroid issues is high, reported by 17% of respondents. This is unsurprising as research has found that people with bipolar are 2.55 times more likely to experience thyroid dysfunction than the general population<sup>43</sup>. Thankfully, the problem is usually corrected by taking thyroid pills, although careful monitoring is crucial because two common medications for bipolar (lithium<sup>44</sup> and quetiapine<sup>45</sup>) have also both been linked to thyroid dysfunction.





Expert witnesses tell us that regular blood tests could potentially provide increased opportunities for positive contact time between clinician and patient, but in reality these tests are often done by a phlebotomist and the results are given by a receptionist on the phone, neither of whom provide any mental health or self-management support.

### Ageing with bipolar

Research by King's College London suggests that another contributing factor to poor physical health is that bipolar pre-programmes people to age faster. The study provided evidence that familial risk for bipolar is associated with shorter telomeres, which may explain why people with bipolar also have a greater risk of age-related diseases<sup>46</sup>, such as dementia. Recent research has identified a link between lithium and a decreased risk of developing dementia<sup>47</sup> – yet another reason for increasing prescribing rates.

### Risk factors for heart disease

People with bipolar have a significantly increased risk of cardiovascular disease – and it's clear what underlying causes are driving it. Research published in March 2022<sup>48</sup> found that people with a severe mental illness (SMI) are more likely to be obese, to smoke, to have diabetes and to have high blood pressure than people without an SMI:

Risk Factor	SMI	No SMI
 <b>meet criteria for obesity</b>	<b>50%</b>	<b>36%</b>
 <b>currently smoke</b>	<b>36%</b>	<b>12%</b>
 <b>have diagnosed diabetes</b>	<b>14%</b>	<b>7%</b>
 <b>have diagnosed high blood pressure</b>	<b>15%</b>	<b>13%</b>



## More than 2 in 3 people with bipolar are overweight or obese

These findings are backed up by our survey – 19% of respondents smoke tobacco and 10% vape. One in ten have diabetes. And more than two in three are either overweight (27%) or obese (44%).

“ My weight is a consequence of my mood. I've been extremely thin and then obese and again almost anorexic. Now I'm very depressed and overeating. **FF**

“ My eating pattern is cyclical. As soon as the clocks go back in October I start craving carbs and eating more. Over the ten years I've been taking bipolar meds I've put on four stone. My belly is huge, which I know is really unhealthy. **HA**

Yet, many people also tell us that the generic health advice isn't always enough:

“ I was told I was overweight and should eat a balanced diet. As if I didn't know that already. But then no questions were asked about what I was eating. And I felt too embarrassed to say that when I'm depressed I can't face cooking so all I eat is junk and sugar. **CR**

“ I put on weight very easily. And then it's quite difficult to lose it. I've been going to the gym and I've been eating the same, but I'm still putting on weight. And I find it so depressing. It is genuinely the medication. **JK**

“ My mental health nurse created an exercise routine for me. I do understand how important exercise is for people with bipolar. But what my nurse doesn't understand is that it's impossible to do exercise when I feel suicidal. **GJ**

“ I wish I had been warned and helped with weight gain when I was first diagnosed with bipolar. Now I'm so overweight it feels too late. **GH**

### The need for lifestyle medicine

A specialty in medicine in its own right, there are now national lifestyle medicine institutions in most countries, including the UK British Society of Lifestyle Medicine. This 'lifestyle' medicine focuses on healthy eating, mental wellbeing, healthy relationships, physical activity, minimising harmful substances and good sleep, yet is about much more than making positive lifestyle choices. Rather it is a comprehensive training package tailored to individual needs. That's what people with bipolar need as soon as they are diagnosed and especially if they're prescribed any medication – a support package to help address their individual healthcare needs around weight management, exercise, smoking and alcohol intake. Personalised, relevant, preventative advice.

For acute physical illnesses like asthma, diabetes or rheumatoid arthritis, the focus tends to be on keeping people well, and episodes are seen as a failure of preventative treatment. People with these physical conditions regularly automatically get access to relevant lifestyle advice and continuity of care from a specialist team as soon as they're diagnosed. They often have access to an advanced nurse practitioner in their GP practice who does their routine check-ups, who offers lifestyle advice and who can refer them to their consultant. These nurses are extremely knowledgeable in their area. It is a model that works extremely well. It would be life-changing for our community if a similar set-up was introduced for everyone with bipolar – not just those in crisis but everyone.

As one expert witness puts it: "There are so many benefits to giving somebody an understanding of their bipolar and how to manage it, and how to prevent episodes. Now, obviously, if you're dealing with a group of people who have been very frequently admitted then if you can prevent those admissions, you're going to save much more money in that group than you would be in the group who are admitted less frequently. But if we think about the human cost of suffering an episode of mania, if we think about the lost employment costs, there's still a strong case for people who are not being as frequently admitted. The other point I would make is the importance of maintenance, treatment and good preventative treatment being seen as a priority rather than just treating people when they're suffering. That needs to be the focus of our efforts. Not just managing when things go wrong, but actually trying to make sure that things go wrong less often."

### Examples of positive health

Despite the challenges it is possible to live well with bipolar. Tens of thousands of people with the condition live to old age. There are many positive examples of NHS Trusts supporting people to manage their weight by paying for gym memberships and personal trainers.

### Conclusion

The poor physical health of people living with bipolar is well documented and the tragic reason why so many people with bipolar die prematurely. While the physical health of people living with SMI's is a priority for the NHS, it hasn't yet implemented effective solutions to overcome the many health inequalities embedded in the system.

### What needs to change

People with bipolar have a number of risk factors that can make it harder for them to maintain good physical health. The biggest improvement in life expectancy for people living with bipolar comes from looking after the person's physical needs. This has a significant positive impact on their quality of life as well.

The physical health of someone with bipolar needs to have as much prominence as their mental health. Annual physical tests and ECGs should be standard for everyone living with the condition and should be universally rolled out. This requires a proactive focus on diagnosis.

Those physical health tests must also be made to 'work harder' by tailoring health advice to the self-management plan of each individual. As soon as possible after they're diagnosed, people with bipolar need to be made fully aware of their risk of developing cardiovascular disease and given proactive support to help manage that risk with physical activity and healthy eating.

Avoiding weight gain, smoking cessation and personalised lifestyle advice should be top priorities for these integrated health reviews.

Health trusts should explore interventions that help overcome the motivational challenges people with bipolar experience when taking medication. This could include covering the cost of personal trainers and gym memberships to help keep people active.

Most participants emphasised the need for free or subsidised weight management services. For example, access to gyms, personal trainers, fitness groups, swimming pools, slimming groups, or online work-out groups via Zoom. Likewise, ideas such as exercise on prescription or referral programmes via GPs were also well liked. It was common for participants to request access to proper nutritional advice to accompany their exercise regime.

# Suicide prevention



When things go wrong for people living with bipolar, they can go catastrophically wrong.



Suicidal thoughts and actions can occur across the mood spectrum, especially when someone is in a severely depressed mood or in a mixed state experiencing both severe depression and mania at the same time.

Importantly there is hope. With the right treatment and support, the risk of suicide can be significantly reduced to the national average.

## What the evidence tells us

One literature review found that up to 20% of (mostly untreated) people with bipolar end their life by suicide, and 20 to 60% of people with bipolar attempt suicide at least one in their lifetime<sup>49</sup>. In the general population, 24.9% of suicides are by women<sup>50</sup>, whereas in the bipolar community, 44% of suicides are by women<sup>51</sup>. The bottom line is that suicide risk for people with bipolar is greater than with most other psychiatric disorders. Heartbreakingly, suicide attempt rates are over 50 times higher among juveniles with bipolar than among those without bipolar<sup>52</sup>.

Of the million people living with bipolar in the UK at the moment, at least 50,000 will die by suicide unless significant action is taken.

Tragically these statistics are borne out in the findings of the Bipolar Commission. Our survey found that 90% of respondents had experienced suicidal thoughts and an astonishing 61% had attempted suicide at some point. 10% had made an attempt in the past year alone.

There are a number of physiological and social factors which are driving these shocking suicide figures.

Episodes of bipolar are associated with impaired rational thinking, which can sometimes manifest as recurrent suicidal thoughts. In the same way a diabetic might go into a diabetic shock due to low blood sugar levels, someone with bipolar can experience suicidal thoughts regardless of their social circumstances. These feelings can pass of their own accord, though for those periods when the feelings are present someone with bipolar is at heightened risk.

Social factors can add an extra layer of pressure for people living with bipolar, and many people are also dealing with secondary impacts that further increase their risk.

“ 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. I was recovering from my first manic episode that had thrown my academic life into disarray. During the depressive episode that followed the mania, I had no psychological tools to manage suicidal thoughts. I concentrated on salvaging my A-levels and in time was lucky that the extreme negative thought patterns subsided, despite a level of residual depression that lingered for several years. **JC** ”

Many people with bipolar have experienced trauma<sup>53,54</sup>. Childhood trauma can be an underlying trigger of bipolar and people also experience traumatic events related to their bipolar such as mania, sectioning and hospital admission. They are more likely to be overweight due to their medication and are often struggling financially due to low income and debts incurred from spending sprees when manic. They are more likely to live alone and be unemployed, so may also have fewer of the 'protective' factors, such as being close to family and having purpose and structure through work.

Additional risk factors for suicide in the community are alcohol dependence/misuse, borderline personality disorder, depressive illness and current/recent in-patient admission<sup>55</sup>. Research by the Commission found that delayed diagnosis could also be an additional risk factor (see our 'Bipolar Diagnosis Matters' report). Pre-diagnosis, someone experiences all the anguish of bipolar without any of the treatments, support and self-management strategies that can help them stay well.

Data held by the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness indicates the rate of suicide amongst people with bipolar has remained static over the past 25 years<sup>56</sup> while suicide rates across the country have been falling. This suggests bipolar suicides are a growing proportion of all suicides.

Estimating the scale of bipolar suicides in the UK is challenging because of the lack of reliable prevalence and diagnosis data. A Delphi exercise conducted by the Bipolar Commission with a number of suicide prevention experts and academics estimated that at least 5% of all suicides in the UK are carried out by people living with bipolar.



# 90%

of people with bipolar have experienced suicidal thoughts

This 5% estimate of all suicides in the UK being carried out by people with bipolar was heavily influenced by a recent Autism-focused psychological autopsy study<sup>57</sup> which reviewed 372 coroner records from 2014-17. It found 5.91% had a bipolar diagnosis. Given that the Adult Psychiatric Morbidity Study estimates that less than half the people with bipolar have a diagnosis, the true figure could be more than double that.

## Suicide prevention needs to be an urgent priority

Evidence from expert witnesses informed the Commission about interventions that would reduce the risk of suicide. The top recommendation is the correct prescribing of lithium which has proven suicide-reduction qualities. For a third of people with bipolar it can reduce the risk of suicide to the national average<sup>58</sup>. Safety or crisis plans have also been described as useful tools to keep people well during those periods when they're having suicidal thoughts.

There is also an important role more generally for psychoeducation on self-management and relapse prevention to reduce the number of episodes where someone's risk of suicide is at its highest. Health services can also provide more proactive support to anyone who is at particularly high risk, such as if they've just been discharged from hospital or if they have an alcohol or drug dependency.

Notable suicide risk factors in bipolar include: previous suicidal acts, depression, mixed-agitated-dysphoric moods, rapid mood-shifts, impulsivity and co-occurring substance abuse<sup>59</sup>.

The Bipolar Commission surveys also provide helpful insights. When asked about their own preferred methods of suicide prevention, 57% of those who had attempted suicide said quicker access to a psychiatrist would have helped, followed by quicker access to crisis care (39%) and therapy (35%). Listening helplines (like Samaritans) and suicide prevention training for friends, family and colleagues were both only referenced by 14% of respondents.

“ When I was grappling with bipolar in the early noughties, I found a psychotherapist who specialised in Neuro-Linguistic Programming (NLP), a branch of Cognitive Behavioural Therapy (CBT). A few sessions of NLP helped me establish a greater awareness of my inner voice and observe the way my mind gave me all sorts of unhelpful messages. Developing an ability to spot self-sabotaging thought patterns, and to consider alternative ways to appraise myself and the world around me, helped me significantly. **JC** ”

## A mixed policy response

The policy response to the bipolar suicide challenge has been mixed. The Cross-Government Suicide Prevention Workplan 2019 acknowledges the importance of a new framework for adult and older adult community mental health services that considers the needs of people with bipolar and commits to increase access to psychological therapies for people with the condition<sup>60</sup>. The extent to which this has translated into action on the ground is limited.

A review of 70 national and local suicide prevention plans and progress updates in England found that only 14% had made reference to bipolar in particular and 30% to severe mental illness more broadly. Only one (Gloucestershire) referenced lithium and only 7% made reference to increasing access to psychiatrists (though not exclusively for people with bipolar).

Positively 56% of plans did make reference to improving access to crisis care, 31% to improving access to psychological therapies and 27% to improving self-management of conditions. Again, these weren't specific commitments for people living with bipolar and the review could find no discernible coordinated plan to proactively reduce risk for this vulnerable community.

## Conclusion

The risk of suicide by someone living with bipolar is extremely high. It is underpinned by a combination of physiological symptoms and poor social circumstances. The prevalence of the condition means bipolar suicides make a significant 5 to 10% contribution to national suicide statistics.

It is possible to reduce the suicide risk through medication, such as lithium, safety plans, quicker access to a psychiatrist and crisis services and improved self-management in general. Regrettably, there is currently no plan to put these in place for everyone living with bipolar.

## What needs to change

The risk of suicide for people with bipolar is greater than for other psychiatric disorders and people living with the condition need to be considered a high-risk group. Bipolar should be included in all suicide prevention plans. At the heart of these plans should be psychoeducation to educate people diagnosed with bipolar about their increased risk of suicide. People with bipolar also need support to produce self-management plans to reduce relapses and safety plans to protect them when they relapse.

Another protective option is ongoing peer support to help people living with bipolar to live well and find common strategies to keep themselves safe.

Alongside psychoeducation there needs to be a national push to improve bipolar diagnosis rates and lithium prescribing. Getting everyone with bipolar who responds well to lithium onto lithium would be the quickest and most effective route to reducing suicides within the community. Clinicians should encourage their patients to try it before other medications.

For those who do become suicidal there needs to be a clear and effective medical response. Quicker access to psychiatrists and crisis care will help. It should also be standard procedure that when anyone with bipolar is discharged from hospital, they are risk profiled so anyone at high risk of suicide is identified and given the post-discharge support they need.

# Hospital care



Hospital is, at times, a life-saving treatment option for many people living with bipolar. Often perceived as a necessary evil and something to be avoided at all costs, it is the treatment option of 'last resort' that literally saves lives.



Admission to a psychiatric hospital, and the intensive treatments and supervision that accompanies it, is sometimes the only thing that can bring someone back from a manic or deep depressive episode, or a psychotic episode where they've completely lost touch with reality. Good quality hospital care is therefore a vital component of longterm bipolar treatment and support.

Hospital care for people with severe mental illnesses in general has received substantial interest in recent years, including annual reports by the Care Quality Commission<sup>61</sup> and the Independent Review of the Mental Health Act<sup>62</sup>, by Professor Simon Wessely, Regius Professor of Psychiatry at King's College London.

The reports focus primarily on detentions under the Mental Health Act, but also highlight common concerns that detentions are rising rapidly. For example, the CQC 2020/21 report says detentions under the Act rose by 4.5% over the year, while the number of hospital beds are in longterm decline generally – with the biggest drop in overnight mental health beds, which fell by 73% between 1987/88 and 2019/20<sup>63</sup>.

The reports came at the end of a longterm push towards deinstitutionalisation where severe mental illness was treated primarily in the community with detention and hospital care to be avoided at all costs.

Evidence presented to the Bipolar Commission suggests this is a deeply unhelpful approach. In fact, there is a clear link between declining numbers of hospital beds and increasing detentions and admissions.

Inpatient care for people with bipolar is a Cinderella service, for a Cinderella condition within a Cinderella sector. Expert witnesses tell us that while trusts focusing on physical health operate on a tariff model that allows them to run deficits and flex provision when demand increases, mental health trusts remain on a block contract which means funding remains static regardless of demand.

Starved of investment, inpatient services are usually under-staffed and suffer from some of the highest levels of job vacancies<sup>64</sup> in the NHS. This has been compounded by Covid-19 when clinicians and support staff were withdrawn to support the Covid-19 response or were off sick and/or isolating.

## Getting bipolar-specific data on hospital care is a challenge

The Bipolar Commission is yet to find reliable statistics on the number of psychiatric beds taken up by people living with bipolar. It is also impossible to extrapolate what proportion of detentions under the mental health care act are by people living with the condition. This is particularly difficult due to the low levels of diagnosis and the fact many people only receive a diagnosis after they have been admitted.

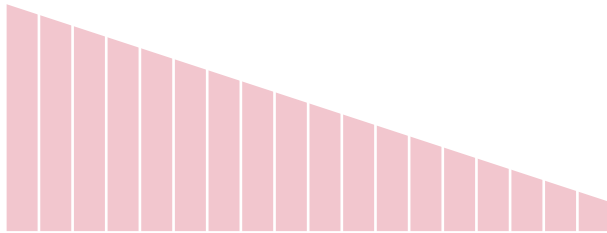
To build up a picture of admission and hospital care, the Bipolar Commission surveyed the bipolar community directly to establish their collective experience. Inpatient or hospital care is a relatively common experience for people living with bipolar. Out of our physical health and hospital survey respondents, 52% say they have been hospitalised for their bipolar.

## Voluntary admissions still happen despite a reduction in beds

There are two ways someone with bipolar might find themselves in hospital for their condition. The most common, reported by 54% of our community, is a voluntary admission. This is when a clinician and the patient, sometimes in consultation with their family, agree that a period in hospital is necessary. Of those, 58% were discharged without having been sectioned.

Expert witnesses highlight the importance of voluntary admissions in helping halt manic episodes before they escalate. This is thought to provide lasting benefits. We are told that bipolar defaults into different patterns of severity so the more severe the episode, the bigger the chance of an equally severe episode in the future. By reducing the severity of the episode, you therefore reduce the chance of a future episode. By treating and stopping an episode in its tracks, the sooner you also curtail excessive spending and potentially harmful behaviour that could lead to challenges for the person to deal with as they recover.

Despite the declining number of beds, only 6.7% of respondents tell us they have requested a voluntary admission but were turned away because they either weren't unwell enough (4.4%) or because there weren't enough hospital beds (2.3%). However, given the seriousness and prevalence of the condition, this still represents thousands of seriously unwell people not being given the support they need when they need it.



**The number of psychiatric beds fell by 73% between 1987/88 and 2019/20**

The second route into a psychiatric ward, reported by 54% of respondents, is involuntary admission, which is where someone is admitted without requesting it. This is often described as sectioning, when someone becomes so unwell they can't make an informed choice and are taken to hospital against their will. A voluntary admission can also become an involuntary admission (reported by 23%) when someone wishes to leave but clinicians believe they are better off in hospital, so section them to prevent them leaving.

Most people (79%) tell us they were able to be admitted to a hospital within 20 miles of where they live and 41% were admitted within 5 miles. However, 20% have had to travel further afield for treatment, with 4% being taken over 100 miles.

Both manic and severe depressive episodes are terrifying experiences. They can involve hallucinations and a total lack of control over thoughts and actions. People are commonly physically restrained by strangers and taken to an unknown location against their will. Being sectioned can be incredibly traumatic and many people tell us the memories stay with them for the rest of their lives.

### **Being sectioned is still a common experience for people with bipolar**

Overall, 54% of those who had been to hospital for their bipolar had been sectioned at some point. They had had an average of three sections in their life and, during their most recent stay, they had spent on average 58 days in hospital. Despite the trauma most people (72%) recognise it was necessary in hindsight, with 16% disagreeing it was necessary and 11% not sure.

### **Crisis team has limited effectiveness**

In terms of pre-admission support, only 22% had contacted their crisis team and found it helpful. Crisis teams (sometimes called crisis resolution teams or home treatment teams) support people who are having a mental health crisis in the community. Over half of respondents didn't use a crisis team with 28% saying they weren't called and 29% reporting they didn't have one (which they wouldn't have without a diagnosis and/or previous admission).

### **Many people are still being treated like criminals because of their illness**

The most common method of getting to hospital was by ambulance (41%). Just over one in five (21%) were taken by friends and family in their car. Shockingly, almost one in five people are still being taken to hospital in a police car (19%). Just over a quarter (26%) of respondents also said they had been taken to a police cell when they were unwell, and 1 in 3 of those people told us they had been handcuffed. This is totally unacceptable and desperately needs to change.

A sizable minority report horrific experiences. While at their most vulnerable, they have been taken to hospital by police car, forced to wear handcuffs and locked in a police cell before admission to hospital.

“ I had two circles of bright blue bruises around my wrists after the police had handcuffed me when I was sectioned last time. **RO**

“ ... the handcuffs hurt my wrists. I was not aggressive or violent, there was no reason to put me in handcuffs. **GG**

“ My grandma had manic depression (as it was then called) but when I experienced a manic high in 2020 I latched onto the wrong people who were drinking a lot and taking drugs. I was so unwell I can hardly remember what happened, but when the police tried to arrest me I lashed out and assaulted a police officer. I was put in handcuffs, stripped naked and put in a cell for 72 hours. It was horrific. Because I didn't have a diagnosis, the judge ignored the psychiatric report and I got a 9-week prison sentence suspended for two years. At least I've got the correct diagnosis of bipolar and I'm on the right medication now. I'm definitely not a criminal, I was just incredibly unwell. **RL**

### **The legal rights of people under section aren't always respected**

Removing someone's liberty when they haven't been charged with a crime is a serious action. On the positive side, the Mental Health Act puts a series of safeguards in place to protect someone's rights and ensure they are aware of them. This includes providing a leaflet informing someone of their rights, providing sectioning papers to explain why they have been sectioned, showing them the Mental Health Act Code of Practice and making sure they're aware they can appeal the decision.

Responses from the survey suggest these rights aren't universally applied. Aggregating the results together, roughly a third of respondents could remember these legal rights being respected, a third could remember them not being respected and a third couldn't remember or weren't sure.

### **Psychiatric hospitals can be harrowing places**

The Bipolar Commission heard several harrowing lived-experience testimonies that highlight the more challenging aspects of an admission to a psychiatric hospital. To try to quantify how common they were, the Commission survey invited respondents to share their difficult experiences. They were, however, given the option to skip questions if they felt they might be triggered by remembering challenging experiences.

Of those who said they had been sectioned due to their bipolar, 24% said they had received medication by injection (usually a sign of high-level intervention), 22% had experienced physical restraint and 15% some form of seclusion. 10% said they received bruises during their stay and two reported broken bones.

Also striking are the statistics around verbal abuse in hospital; 15% reported experiencing verbal abuse from other patients and 9.7% reported verbal abuse from staff. 5% reported physical abuse from patients and 1.1% (6 individuals) reported physical abuse by staff. 2% (11 individuals) reported sexual abuse from other patients and 1 individual reported sexual abuse by a staff member.

There is absolutely no justification for any form of abuse and it's deeply worrying that so many people have experienced abuse when they were at their most vulnerable.

When asked whether they had reported the abuse, only 42% said that they did, suggesting most of the abuse goes under the radar of health authorities. The reasons people gave for not reporting the abuse included feelings of shame, not trusting the judicial system, not wanting to waste police time or not knowing that they could report it.

When the abuse was reported, most respondents said that hospitals would deny the allegations made, often saying that the victim of this abuse was making it up or exaggerating. One member of our community told us she had to apologise to a staff member, while another had her complaints ignored so she called the police while she was staying on the ward.

“ I reported the assault by staff when they threw me in the air and pinned me to the ground to administer an injection, which caused bruising. They were dismissive. **HP** ”

On the other hand, several people told us that the abuse they'd had was acknowledged, investigated and actioned – in one case another patient was moved into a different ward, in another court action was taken. Two people told us they had received a written or a verbal apology from staff.

### Hypersexuality can be an issue

6% of patients are having sexual experiences in hospital which they later regret.

Hypersexuality can be one of the symptoms of a bipolar manic episode. People can engage in sexual activity which they later regret, and people can also take advantage of them and even coerce them into sex.

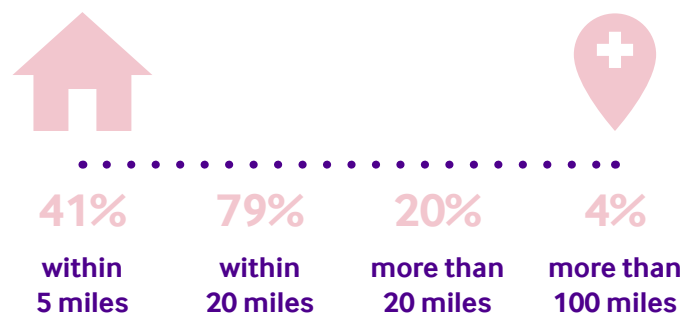
The Commission was interested to find out how hospitals had kept people safe during these episodes. 265 people were willing to share their experiences. 91.7% reported they didn't engage in any sexual relationships while in hospital. 4 (1.5%) reported having sexual relations with another inpatient that they didn't later regret. 13 (4.9%) reported having sexual relations with another inpatient that that did later regret, and one reported having sexual relations with a staff member that they later regretted.

While plans to deliver same-sex accommodation in psychiatric units were put forward in September 2019 by the NHS<sup>65</sup>, 57% of respondents report they had been on a mixed-sex ward and 54% tell us they had to share a bathroom. This significantly increases the risk to patients.

### Hospitals aren't always seen as places of safety

Only 52% of respondents tell us that their psychiatric hospital had been a place of safety. This reinforces academic literature that finds that patients often feel unsafe on psychiatric wards<sup>66</sup>. A key issue is the perception of threat from other patients, highlighting the need to consider patient safety as more than physical safety.

### How close to home were people before being admitted to hospital?



Many people have told us about a lack of empathy, understanding and support from healthcare professionals in the hospital. Another common complaint about hospital care is that people felt overmedicated.

Perhaps unsurprisingly, 30% of respondents believed they were experiencing post-traumatic stress symptoms due to their experiences in hospital.

41% said a hospital admission left a significant lasting negative effect compared to 35% who said it left a lasting positive effect.

It is little wonder many are left with post-traumatic stress and report a significant negative lasting effect. Some of these failings could be put down to well-meaning staff working in an overstretched system. There is, however, absolutely no justification for the abuse of patients by staff.

“ I was so traumatised when I left hospital (and I lied to leave by telling them what they wanted to hear), I never went near a doctor for any mental health care for 10 years. I left with a misdiagnosis of depression/anxiety and didn't get a correct diagnosis until many years later. **SF** ”

“ Decades later I still have recurring memories of an old Victorian wing where heavily medicated patients watched television through the night while chain-smoking. Fortunately it's closed now. **WF** ”

“ I am still troubled by flashbacks or intrusive thoughts of being physically restrained and injected with sedatives. **NE** ”

“ When sectioned, I was physically restrained and received medication by injection. This was nearly five years ago and I am still traumatised by the memory. **CR** ”

### People are missing out on treatment like ECT

Only 10.5% of respondents said they were offered electroconvulsive therapy (ECT) when they were last in hospital despite 65% of people who had had it saying that it was helpful.

“Prejudice against the use of ECT is often based on images from the distant past or the portrayal of its too liberal use in the 1950s. Clinical trials from the 1970s have consistently shown a benefit from ECT in patients with severe or treatment resistant depression, which echoes the experience of our patients in the survey,” says Professor Guy Goodwin, Emeritus Professor at Oxford University. “This has to be set against the disadvantage that some personal memories appear to be vulnerable to loss after ECT. This effect is quite subtle and may be partly due to depression itself. However, successful efforts have been made to reduce the more obvious and immediate effects of ECT, such as triggering confusion on the day of treatment and slowing new learning in the days afterwards. All the claimed adverse cognitive effects of ECT have to be weighed up against the fact that depression itself impairs memory and concentration very markedly.”

### The hospital experience isn't improving

Psychiatric hospitals have long been victims of under investment. We were interested to know whether the recent increase in mental health spending had found its way to the acute hospital ward. To investigate, the Commission asked those who had experienced multiple hospital admissions whether their experiences were getting better or worse. Of the 228 who responded, the majority (51%) said their experience either remained the same or some things were better and some things worse. Only 24% said it was getting better and 22% said it was getting worse

When looking at the different components of the experience, such as ward environment and treatment by staff, the number of people who tell us things are better and things are worse is similar. The one area where significant numbers of respondents said things had got worse was activities on the ward, which is a missed opportunity because many people have told us that activities make a huge difference to the recovery journey:

“ There were a lot of groups on the ward which really helped – cooking, art, exercise. **JK** ”

“ The first hospital I went to had fabulous activities – drumming, singing, art, a lovely garden. **TC** ”

“ Before the new ward was built, the first time I was sectioned in the old female ward it was far more therapeutic with more OT. My last section was poor for therapeutic interventions due to shortages of staff. There were also more lock-ins and little opportunities for decent outside walking. There was nowhere outside to sit, and the one arbour seat was used by smokers so smelt. **EN**

### Early discharge and mixed support

When asked whether in hindsight they had been discharged too early, 32% said yes. This compares to 46% who said they were discharged when they were ready and 10% when it was too late. Respondents were mostly positive about support post discharge with 15.5% saying the support was excellent and helped with recovery, 22% that it was good and 34% that it helped it bit. However, 11% said they got no support or contact and 18% that the support they did get didn't help.

Only 38% said they had recovery plans put in place and only 28% said their families were involved in that process (10% said they didn't want them involved). Just as worryingly, only 34% were offered a medication review within four weeks of discharge and 42% were not offered one at all. This is particularly unhelpful as patients are often prescribed high doses of medication in hospital which can be extremely debilitating and unsuitable for longterm self-management.

Despite the challenges, the Bipolar Commission did identify some areas of positive experiences. 40% rated their hospital as either 4 or 5 stars, although there was a clear preference if they were rating private care compared to if they were rating an NHS hospital:

“ I was placed into the Priory due to a lack of NHS beds. If I could have stayed there for my entire treatment then I would have. My days were filled with different therapy groups and the food was amazing. I can see now how those who can afford private care can go there and never need to go back as an inpatient. **JE**

“ My experiences of being in a Priory hospital have been so much better than any NHS. I am lucky to have been sent out of area. My local hospital has been rated poorly by the CQC and am concerned that I will be admitted there instead. **SI**

Many people described the staff as personal and 'human':

“ My assigned staff nurse was transformatively kind to me, giving me thoughtfulness and time despite the busy ward... all at a time when my self-esteem was rock bottom. I was up late one night, and rather than just sending me to bed, she spent time with me quietly on a jigsaw, which enabled me to talk about my biggest fears. Having done so, I was able to recover and go home. I cannot thank her enough. **FW**

“ Staff were kind and looked out for the interests of patients. A number talked about what I wanted, we played table tennis and discussed what changes could be made...” **JE**

“ Some members of staff are trying really hard in very difficult circumstances. Some less so, and verge on trying to trigger you. **SI**

Positively 73% of respondents reported having their own private room. There are also positive steps to introduce Advance Choice Document so patients can at least try to plan and reflect on their care (even if the choices aren't always implemented).

### Conclusion

Caution must be taken when drawing sweeping conclusions because bipolar-specific hospital data is difficult to come by and the survey sample analysed by the Commission is small and not necessarily representative. Nonetheless, with the data and lived experience accounts available it's easy to paint a damning picture of inpatient care for people with bipolar.

Once in hospital, their basic legal rights aren't routinely observed; they miss out on treatment like ECT, stay on mixed-sex wards, and are vulnerable to sexual predation and abuse from both other inpatients and staff. They are often discharged too early and only a minority are offered a medication review when they would like one or supported to produce a care or crisis plan aimed at reducing relapse and readmission.

Inpatient care is, however, a vital element of care on the bipolar care pathway. The research by the Bipolar Commission did unearth positive examples of excellent good practice, particularly when it comes to individual healthcare professionals. Most patients are able to get voluntary admissions, often near to where they live. Many people do get excellent care, are discharged at the right time and are properly supported with their recovery.

To provide some balance we asked respondents whether their last hospital was more a place of healing or hurt. They said on average it was 60% healing and 40% hurt. While it could be worse, that's still two in five people who didn't have a good experience, which shows there are huge areas for improvement. Despite the high incidence of trauma, the majority of people who have been sectioned said they thought it was a right decision in hindsight, indicating by proxy that when they were acutely unwell they felt they were better off in hospital.

### What needs to change

There is nothing inevitable about poor inpatient care or any reason why inpatients with bipolar should have such negative experiences. In an ideal world, no one with bipolar would ever be taken to hospital in a police car, experience abuse or be discharged without proper support. Not one of these are mandated in policy and there are a range of initiatives and procedures in place to try to prevent them. Nonetheless they are happening.

Negativity breeds negativity and perhaps the most important change that is needed is to take a positive attitude to our psychiatric hospitals. The choice between hospital care and community care for people with bipolar is a deeply unhelpful approach. One reinforces the other.

Going into hospital is no more a failure for the individual, their family or the local health service as someone with cancer having chemotherapy or someone with a broken hip getting a hip replacement. Someone experiencing an acute bipolar episode needs intensive inpatient treatment in a place of safety where they can't harm themselves or others. Trusts should not view reducing the number of hospital beds as a laudable aim: hospitals have a duty to provide a vital sanctuary for the acutely unwell. A quality service is desperately needed.

Investment in psychiatric hospitals, both by expanding the number of beds and increasing the quality of the inpatient services, should be the centre piece of any mental health strategy. It would improve patient experience and counterintuitively also reduce the number of patients needing them. Improving the hospital environment would also improve staff recruitment and retention and reduce the risk of abusive staff being drafted into the system.

Expanding provision would also reduce the threshold for admission and allow more voluntary admissions. This would allow more people with bipolar to get access to treatment sooner, reduce severe manic and depressive episodes and prevent the trauma and stigma of sectioning.

# Conclusion



It's likely that bipolar symptoms have been around since the dawn of time. The ancient Greeks referred to 'melancholy' and 'hypomania' and we can hypothesise that other cultures had their own terms.



In 1896 the symptoms were formally described as a condition by a German doctor, Emile Kraepelin, and the term 'manic depression' was first used. In the 1980s, the American Psychiatric Association renamed it 'bipolar disorder' to reflect what it called the 'bi-polarity' of the illness (the characteristic highs and lows). Today it's more widely known as 'bipolar'.

Whatever you call it, bipolar is a complex condition that requires specialist treatment and support. Living well with the condition is possible – the Commission has interviewed doctors, lawyers, film producers, policy makers, psychologists, app developers and presenters as part of our evidence-gathering process and they're all thriving. But unless the right support and treatment is in place, living well can be a challenge, if not impossible.

Sadly, the Commission has also met several members of the bipolar community who are far from thriving. They have poor physical and mental health and, statistically speaking, are significantly more likely to die of cardiovascular disease and suicide. In fact, the Commission estimates that at least 5% of all suicides in the UK are carried out by people who have the condition. And our research is uncovering many of the reasons why.

Diagnosis is taking far too long – there's an average of 9.5 years between someone first seeing a healthcare professional with symptoms of bipolar and eventually getting a diagnosis. This also excludes the thousands of people who live with, and die from, bipolar without ever knowing they had the condition. Yet the vast majority of our community (84%) tell us that a diagnosis is helpful.

Even when they finally get a diagnosis, little advice or no advice is given on how to manage the condition. This is astonishing as lifestyle changes, such as good sleep habits and avoiding triggers, can dramatically reduce the risk of relapse. It's the equivalent of someone diagnosed with lung cancer not being told to give up smoking.

Medication is a vital part of self-management, yet nearly two in three (60%) people with bipolar are not getting access to even basic medication. For those who are, some people are experiencing serious, extremely unpleasant side effects, many of which have lasting health implications. The gold standard treatment, lithium, is under-prescribed.

The NHS is delivering a model of episodic care and support provided by both primary and secondary care, yet most of this support is only directed towards a core group of individuals who are at highest risk of relapse. In spite of this, the system is failing to prevent high levels of relapse, physical health issues and suicide.

This model of episodic care isn't working either for people living with bipolar or for the NHS. NICE guidelines expect GPs to provide specialist support for people with bipolar, but the primary sector is under immense pressure with limited time and resources. It's not surprising, then, that only half of respondents have an ongoing relationship with their GP and about a third have gone private. Support in the secondary sector is provided by those who appear to have the lowest levels of knowledge of bipolar (care coordinators and CPNs).

There is very little focus on prevention with only a minority receiving support on improving their knowledge of bipolar, and barely half receiving care plans and safety plans. The most helpful services are the bipolar specialist ones which are being used by only 14% of respondents.

Inpatient care is a vital element of care on the bipolar care pathway, yet two in five people describe the hospital they were in as a place of hurt rather than of healing. Basic legal rights aren't routinely observed, people are missing out on treatment like ECG, they stay on mixed-sex wards and are vulnerable to sexual predation and abuse from other patients and staff. People are often discharged too early and only a minority are offered a medication review when they need one or are supported to produce a care or crisis plan aimed at reducing relapse and readmission.

This is against a backdrop of fewer inpatient beds and rising detentions under the Mental Health Act. The hospital system is under pressure and people with bipolar are bearing the brunt of it.

## The urgent need for specialist services

There are specialist healthcare services for people with cancer, arthritis, asthma, diabetes – the list goes on. However mental health conditions are often lumped together under one umbrella service for 'severe mental illness'. Decision makers talk about moving towards a parity of esteem but imagine the outcry if there was an umbrella service for 'severe physical health'.

In the same way that someone with cancer has different needs to someone with heart disease or asthma, someone with bipolar has different needs to someone with schizophrenia or an eating disorder. The high level of comorbidities complicates the picture (see page 8 of our 'Bipolar Diagnosis Matters' report) and some needs overlap just as they do with physical conditions, but the overwhelming consensus of clinicians, academics and people with bipolar themselves is that bipolar-specific services are significantly more effective.

The NHS is providing services for people with bipolar. The frequency of contact with healthcare professionals is fairly high. While this may tick boxes and look like it's working on paper, it is not working. Relapse rates are shocking. What's needed, then, isn't just frequency of contact but efficacy of contact. People with bipolar need to be supported by specialist clinicians who understand their very specific needs – medication, comorbidities, psychological therapy, self-management, physical health.

Whether counting the cost to the individual (in terms of lost income, jobs, relationships, opportunities) or the cost to the state (the high level of intervention that's needed to support someone when they relapse alongside the lost productivity over a lifetime), it's a no-brainer.

The system urgently needs to look at ways to significantly lower the average 9.5-year delay in diagnosis. It needs to introduce integrated specialist bipolar services that focus on relapse prevention and long-term strategies that lower the risk of someone with bipolar dying 15-20 years earlier from heart disease. Stakeholders told us that early intervention services for psychosis provided a useful model.

There remains an ongoing debate about the relative merits of the medical and social model for mental health – should people receive medical treatment or social support for their mental health issues? The Commission has found that people with bipolar need both.

We don't believe we've found all the answers. As we've already said, our aim is to start a conversation, to get bipolar on the agenda. We welcome research, studies or viewpoints that support or challenge any of our findings. This is just the beginning, and we'd love you to get involved. Email us at [commission@bipolaruk.org](mailto:commission@bipolaruk.org)

## The bipolar community is asking for:

- 01 Significantly easier and quicker bipolar diagnosis
- 02 Improved understanding of bipolar triggers and symptoms so people can recognise the condition in themselves and those close to them
- 03 Universal access to specialist treatment for people with bipolar, including psychological therapies and peer support
- 04 Improved access to a named psychiatrist who provides ongoing (not episodic) care
- 05 Holistic medication and lifestyle reviews that take into account the physical side effects of medication, such as weight gain
- 06 Increased prescribing of lithium
- 07 More beds and higher quality care in psychiatric wards
- 08 An evidence-based online screening tool for bipolarity to prompt someone to seek assessment from a healthcare professional
- 09 Improved access to psychoeducation to help prevent relapse and lower suicide rates
- 10 Fund more research into genetics and treatments for bipolar

These asks will be refined into recommendations for the final report due in summer 2022.

# References

- 1 611 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3666355/>
- 2 Self Management Survey Results, April 2020, <https://www.bipolaruk.org/reports>
- 3 Bebbington and Ramana: The epidemiology of bipolar affective disorder, *Soc Psychiatry Epidemiology* 1995 Nov;30(6):279-92.
- 4 The Adult Psychiatric Morbidity Study (APMS) conducted a survey of 7,076 people using the Mood Disorder Questionnaire (MDQ). 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.
- 5 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>.
- 6 McManus, Sally, et al. Mental health and wellbeing in England: A survey carried out for NHS Digital by NatCen Social Research and the Department of Health Sciences, University of Leicester, 2016.
- 7 Bolton, Sorcha, et al. "Bipolar disorder: Trimodal age-at-onset distribution." *Bipolar disorders* 23.4 (2021): 341-356.
- 8 Barnett, J. H. and Smoller J. W. 2009. The Genetics of Bipolar Disorder. *Neuroscience*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3637882/>.
- 9 Duffy, Anne, et al. Candidate risks indicators for bipolar disorder: early intervention opportunities in high-risk youth. *International Journal of Neuropsychopharmacology* 19.1 (2016).
- 10 Duffy, Anne, et al. Candidate risks indicators for bipolar disorder: early intervention opportunities in high-risk youth. *International Journal of Neuropsychopharmacology* 19.1 (2016).
- 11 Hirschfield, R. M. (2014). Differential diagnosis of bipolar disorder and major depressive disorder. *Journal of affective disorders*. 169, S12-S16.
- 12 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.
- 13 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.
- 14 The Adult Psychiatric Morbidity Study (APMS) conducted a survey of 7,076 people using the Mood Disorder Questionnaire (MDQ). 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
- 15 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/>.
- 16 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.
- 17 Tondo, L., et al. Suicide attempts in bipolar disorders: comprehensive review of 101 reports. *Acta Psychiatrica Scandinavica* 133.3 (2016): 174-186.
- 18 Cipriani, Andrea, et al. Lithium in the prevention of suicide in mood disorders: updated systematic review and meta-analysis. *BMJ* 346 (2013).
- 19 Daveney, J., Panagioti, M., Waheed, W., Esmaila, A., Bipolar disorder in patients with depression managed in primary care: A systematic review and meta-analysis. *General Hospital Psychiatry* Volume 58, May–June 2019, Pages 71-76. [doi.org/10.1016/j.genhosppsych.2019.03.006](https://doi.org/10.1016/j.genhosppsych.2019.03.006)
- 20 Grande I et al. Bipolar Disorder. *The Lancet* 2016, 387;1561-72 [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)00241-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)00241-X/fulltext)
- 21 Goodwin GM et al. Evidence-based guidelines for treating bipolar disorder: Revised third edition recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology* 2016;30:495-553. [https://www.bap.org.uk/pdfs/BAP\\_Guidelines-Bipolar.pdf](https://www.bap.org.uk/pdfs/BAP_Guidelines-Bipolar.pdf)
- 22 Al-Harbi, K., S., Treatment-resistant depression: therapeutic trends, challenges, and future directions. Published online 2012 May 1. doi: 10.2147/PPA.S29716
- 23 Reinares, M., et al. A prospective longitudinal study searching for predictors of response to group psychoeducation in bipolar disorder. *Journal of Affective Disorders*, Vol 274, Sept 2020, pages 1113-1121. [doi.org/10.1016/j.jad.2020.02.047](https://doi.org/10.1016/j.jad.2020.02.047)
- 24 Cerimele et al. *Journal of Clinical Psychiatry*. Patients With Co-Occurring Bipolar Disorder and Posttraumatic Stress Disorder: A Rapid Review of the Literature. 2017.
- 25 Severus, E., Bauer, M., & Geddes, J. (2018). Efficacy and effectiveness of lithium in the long-term treatment of bipolar disorders: an update 2018. *Pharmacopsychiatry*, 51(05), 173-176.
- 26 Cousins, D.A., Squarcina, L., Boumezbear, F., Young, A. H., Bellivier, F., Lithium: past, present, and future. *Lancet Psychiatry*, 2020 Mar;7(3):222-224. doi: 10.1016/S2215-0366(19)30365-7. Epub 2019 Sep 26.
- 27 Sköld et al., Regional lithium prescription rates and recurrence in bipolar disorder, *International Journal of Bipolar Disorder* (2021) 9:18 <https://doi.org/10.1186/s40345-021-00223-7>
- 28 Lyall, L., M., Penades, N., Smith, D. J., Changes in prescribing for bipolar disorder between 2009 and 2016: national-level data linkage study in Scotland, *British Journal of Psychiatry* (2019), doi 10.1192/bjp.2019.16.
- 29 Opening Prescribing – Lithium Carbonate & Lithium Citrate, <https://openprescribing.net/chemical/0402030K0/>
- 30 National Institute for Health and Care Excellence (NICE), Lithium Carbonate, Indications and Dose, <https://bnf.nice.org.uk/drug/lithium-carbonate.html>
- 31 Collins, L., Patient Representative (Royal College of Psychiatrists). Withdrawing Priadel - very expensive for the NHS and extremely worrying for patients, *The BMJ Opinion*.
- 32 Bipolar Disorder: Lithium: How should I prescribe lithium? <https://cks.nice.org.uk/topics/bipolar-disorder/prescribing-information/lithium/>.
- 33 Cousins, D.A., Barnes, T.R.E., Young, A.H., Delgado, O., Paton, C., Plus ca change? Switching lithium preparations, *BJPsych Bull.* 2022 Feb 18;1-6. Doi: 10.1192/bjb.2021.126.
- 34 <https://www.cntw.nhs.uk/services/regional-affective-disorders-outpatient-service-rads-specialist-service-newcastle/>
- 35 Appleby, L., What has been the effect of covid-19 on suicide rates? *British Medical Journal* 2021, doi: 372:n834
- 36 Tondo, L., et al. "Suicide attempts in bipolar disorders: comprehensive review of 101 reports." *Acta Psychiatrica Scandinavica* 133.3 (2016): 174-186.
- 37 NHS England. Adult Improving Access to Psychological Therapies programme, <https://www.england.nhs.uk/mental-health/adults/iapt/#:~:text=The%20Improving%20Access%20to%20Psychological,disorders%20and%20depression%20in%20England>
- 38 NHS England. Adult Improving Access to Psychological Therapies programme, <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/better-care-for-major-health-conditions/adult-mental-health-services/>
- 39 Osby U, Brandt L, Correia N, Ekblom A, Sparén P. Excess mortality in bipolar and unipolar disorder in Sweden. *Arch Gen Psychiatry*. 2001 Sep;58(9):844-50. doi: 10.1001/archpsyc.58.9.844. PMID: 11545667.
- 40 Rebecca C. Rossom, Stephanie A. Hooker, Patrick J. O'Connor, A. Lauren Crain, JoAnn M. Sperl-Hillen. Cardiovascular risk for patients with and without schizophrenia, schizoaffective disorder, or bipolar disorder. *Journal of the American Heart Association*, 2022; DOI: 10.1161/JAHA.121.021444
- 41 Chesney, E., Goodwin, G. M., Fazel, S., Risks of all-cause and suicide mortality in mental disorders: a meta-review, *World Psychiatry*, 2014, doi.org/10.1002/wps.20128.



# References

- 42 Van Alphen, A. M., Bosch, T. M., Kupka, R. W., & Hoekstra, R. (2021). Chronic kidney disease in lithium-treated patients, incidence and rate of decline. *International Journal of Bipolar Disorders*, 9(1), 1-5.
- 43 Krishna VN, Thunga R, Unnikrishnan B, et al. Association between bipolar affective disorder and thyroid dysfunction. *Asian Journal of Psychiatry*, 2013;6(1):42–45. doi:10.1016/j.ajp.2012.08.003
- 44 Kraszewska A, Abramowicz M, Chłopocka-Woźniak M, Sowiński J, Rybakowski J. Wpływ stosowania litu na czynność gruczołu tarczowego u pacjentów z chorobą afektywna dwubiegunowa [The effect of lithium on thyroid function in patients with bipolar disorder]. *Psychiatr Pol*. 2014 May-Jun;48(3):417-28. Polish. PMID: 25204089.
- 45 Li C, Lai J, Huang T, Han Y, Du Y, Xu Y, Hu S. Thyroid functions in patients with bipolar disorder and the impact of quetiapine monotherapy: a retrospective, naturalistic study. *Neuropsychiatr Dis Treat*. 2019;15:2285-2290 <https://doi.org/10.2147/NDT.S196661>.
- 46 Timothy R Powell, Danai Dima, Sophia Frangou, Gerome Breen. Telomere Length and Bipolar Disorder. *Neuropsychopharmacology*, 2017; DOI: 10.1038/npp.2017.125.
- 47 Shanquan Chen, Benjamin R. Underwood, Peter B. Jones, Jonathan R. Lewis, Rudolf N. Cardinal. Association between lithium use and the incidence of dementia and its subtypes: A retrospective cohort study. *PLOS Medicine*, 2022; 19 (3): e1003941 DOI: 10.1371/journal.pmed.1003941.
- 48 Rebecca C. Rossom, Stephanie A. Hooker, Patrick J. O'Connor, A. Lauren Crain, JoAnn M. Sperl-Hillen. Cardiovascular risk for patients with and without schizophrenia, schizoaffective disorder, or bipolar disorder. *Journal of the American Heart Association*, 2022; DOI: 10.1161/JAHA.121.021444.
- 49 Dome, P., Rihmer, Z., & Gonda, X. (2019). Suicide Risk in Bipolar Disorder: A Brief Review. *Medicina (Kaunas, Lithuania)*, 55(8), 403. <https://doi.org/10.3390/medicina55080403>
- 50 Office for National Statistics, Suicides in England and Wales: 2020 registrations, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesintheunitedkingdom/2020registrations>
- 51 Clements C, Morriss R, Jones S, Peters S, Roberts C, Kapur N. Suicide in bipolar disorder in a national English sample, 1996-2009: frequency, trends and characteristics. *Psychol Med*. 2013 Dec;43(12):2593-602. doi: 10.1017/S0033291713000329. Epub 2013 Mar 19. PMID: 23510515.
- 52 Tondo, L., Vazquez, G., H., Baldessarini, R., J., Prevention of suicidal behaviour in bipolar disorder, 2021 Feb; *National Library of Medicine*, 23(1):14-23. doi: 10.1111/bdi.13017. Epub 2020 Oct 27.
- 53 Wrobel, A. L., Russell, S. E., Jayasinghe, A., Lotfaliani, M., Turner, A., Dean, O. M., ... & McClinnis, M. G. Attachment insecurity partially mediates the relationship between childhood trauma and depression severity in bipolar disorder. *Acta Psychiatrica Scandinavica*.
- 54 Watson, S., Gallagher, P., Dougall, D., Porter, R., Moncrieff, J., Ferrier, I., N., Young, A., H., Childhood trauma in bipolar disorder, *Aus N Z J Psychiatry*. 2014 Jun; 48(6):564-70. doi: 10.1177/0004867413516681. Epub 2013 Dec 16.
- 55 Clements C, Morriss R, Jones S, Peters S, Roberts C, Kapur N. Suicide in bipolar disorder in a national English sample, 1996-2009: frequency, trends and characteristics. *Psychol Med*. 2013 Dec;43(12):2593-602. doi: 10.1017/S0033291713000329. Epub 2013 Mar 19. PMID: 23510515.
- 56 Clements C, Morriss R, Jones S, Peters S, Roberts C, Kapur N. Suicide in bipolar disorder in a national English sample, 1996-2009: frequency, trends and characteristics. *Psychol Med*. 2013 Dec;43(12):2593-602. doi: 10.1017/S0033291713000329. Epub 2013 Mar 19. PMID: 23510515.
- 57 Cassidy, S, Au-Yeung, S, Robertson, A, Cogger-Ward, H, Richards, G, Allison, C, Bradley, L, Kenny, R, O'Connor, R, Mosse, D, Rodgers, J & Baron-Cohen, S 2022, Autism and autistic traits in those who died by suicide in England, *British Journal of Psychiatry*, vol. (In Press), pp. (In Press). <https://doi.org/10.1192/bjp.2022.21>
- 58 Tondo, L., Vazquez, G., H., Baldessarini, R., J., Prevention of suicidal behaviour in bipolar disorder, 2021 Feb; *National Library of Medicine*, 23(1):14-23. doi: 10.1111/bdi.13017. Epub 2020 Oct 27.
- 59 Tondo, L., Vazquez, G., H., Baldessarini, R., J., Prevention of suicidal behaviour in bipolar disorder, 2021 Feb; *National Library of Medicine*, 23(1):14-23. doi: 10.1111/bdi.13017. Epub 2020 Oct 27.
- 60 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/772210/national-suicide-prevention-strategy-workplan.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/772210/national-suicide-prevention-strategy-workplan.pdf)
- 61 Monitoring the Mental Health Act in 2019/20: The Mental Health Act in the COVID-19 pandemic, [https://www.mentalhealthlaw.co.uk/CQC\\_%27Monitoring\\_the\\_Mental\\_Health\\_Act\\_in\\_2019/20:\\_The\\_Mental\\_Health\\_Act\\_in\\_the\\_COVID-19\\_pandemic%27\\_\(26/11/20\)](https://www.mentalhealthlaw.co.uk/CQC_%27Monitoring_the_Mental_Health_Act_in_2019/20:_The_Mental_Health_Act_in_the_COVID-19_pandemic%27_(26/11/20))
- 62 Independent review of the Mental Health Act 1983, [www.gov.uk/government/publications/mental-health-act-independent-review](http://www.gov.uk/government/publications/mental-health-act-independent-review)
- 63 The King's Fund, September 2021, updated by Deborah Ward, NHS hospital bed numbers: past, present, future, <https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers>
- 64 The King's Fund, October 2019, Securing money to improve mental health care... but no staff to spend it on <https://www.kingsfund.org.uk/blog/2019/10/mental-health-staff-shortage>
- 65 Delivering same-sex accommodation, NHS England, September 2019, [https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/05/NEW-Delivering\\_same\\_sex\\_accommodation\\_sep2019.pdf](https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/05/NEW-Delivering_same_sex_accommodation_sep2019.pdf)
- 66 Stenhouse RC. 'Safe enough in here?': patients' expectations and experiences of feeling safe in an acute psychiatric inpatient ward. *Journal Clinical Nursing*. 2013 Nov;22(21-22):3109-19. doi: 10.1111/jocn.12111. Epub 2013 Jul 22. PMID: 23876128.

# Contact Bipolar UK

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

Read the 'Bipolar Diagnosis Matters' report at [bipolaruk.org/bipolarcommission](http://bipolaruk.org/bipolarcommission)

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