



Bipolar Minds Matter

Quicker diagnosis and
specialist support for
everyone with bipolar

November 2022



Bipolar Minds Matter - Executive Summary



Quicker diagnosis and specialist support for everyone with bipolar

Bipolar is a severe mental illness characterised by significant and sometimes extreme changes in mood and energy, which go far beyond most people's experiences of feeling a bit down or happy.

There are over one million people with bipolar in the UK¹ – 30% more than those with dementia² and twice as many as those with schizophrenia³. Millions more are impacted through close friends and family.

Launched in March 2021, the goal of the Bipolar Commission is to achieve parity of healthcare services for people with bipolar.

“ I'd been sleeping less, I was extremely productive and I felt really sociable. The only way I can explain it is that my brain felt strange – as though it was fizzing. **CR** ”

The delay in diagnosis is dangerous

It takes an average of 9.5 years to get a diagnosis of bipolar⁴. 36% of survey respondents said they had attempted suicide because of the delay. This is backed up by research which shows that 'time to treatment' is significantly associated with hospitalisations and lifetime suicide attempts⁵.

It is estimated that 56% of people with bipolar don't have a diagnosis and 60% of people with bipolar don't get any bipolar-specific treatment or support⁶. Yet even once someone has a diagnosis, the current 'episodic care' model – where they have access to a GP but are only referred to a psychiatrist if they become unwell - isn't working.

The burden of disease for bipolar

The Commission heard from many inspiring individuals who manage the condition well. We know it is possible for even the most unwell patient who's had multiple hospital admissions to make a recovery and live a full and successful life. And yet this is far from the norm.

According to a landmark study by the London School of Economics⁷, bipolar costs the UK economy about £20 billion a year - 17% of the total burden of mental illness – and has an enormous impact on individuals, the NHS and society generally.

- **Having bipolar increases the risk of suicide by 20 times⁸ and at least 5% of all suicides are by people living with bipolar⁹**
- **Relapse rates are high - 98% of survey respondents told us they had relapsed at least once and 52% had been hospitalised**
- **44% of survey respondents are clinically obese (over 50% more than the national average¹⁰)**
- **People with bipolar live an estimated 10-15 years less than the average population, partly due to the higher rates of cardiovascular disease¹¹**
- **15% of survey respondents had lost their home because of their bipolar**

The case for specialist services

People with bipolar are asking for something very simple. A clinician who knows them, who is an expert in bipolar and who will work with them for years to manage the condition well.

This report puts forward the case for developing a dedicated care pathway so that people with bipolar can have access to specialist treatment and continuity of support over a lifetime. It is what both patients and doctors want and is proven to reduce relapse rates. It is cost neutral and makes sense on all levels – for the NHS, the individual, society and the economy.

The million people with bipolar in the UK deserve specialist treatment to reduce immeasurable suffering and lead to substantial savings in the long-term.



The Bipolar Commission is calling for:

- ✓ **Better understanding of bipolar in society**
- ✓ **Quicker diagnosis of bipolar**
- ✓ **All suicide prevention policies to include bipolar**
- ✓ **Access to specialist bipolar treatment and support**
- ✓ **Optimum bipolar medication management**
- ✓ **Investment to improve inpatient care significantly**
- ✓ **Fair funding for bipolar research and treatment (17%)**
- ✓ **Bipolar-appropriate NHS services**

Foreword

by Professor Guy Goodwin, Emeritus Professor of Psychiatry, University of Oxford and co-chair of The Bipolar Commission



“ The findings of the Bipolar Commission have shocked me.

Professor Guy Goodwin

I have been treating people with bipolar for more than 40 years. Over that time, I have frequently been astonished by the stories of patients who have been poorly served by services ostensibly designed to help them live better lives. I guess I accepted that things were that way because those patients were often referred to me when they were unhappy with their care. For too long, I assumed that for most patients things were different and better.

The findings of the Bipolar Commission have shocked me out of my complacency. People with bipolar should be very angry about the policy failures of the past two decades. As we say in the report, bad ideas can have innumerable unintended consequences.

Two facts stand out above all others: bipolar accounts for 17% of the total burden of disease attributable to mental illness and yet there is no priority given to its specialist treatment in policy documents produced by the Department of Health. Instead, since the 1999 National Service Framework, bipolar has been lumped into policy documents as the invisible twin of schizophrenia. Worse still, bipolar gets a mere 1.5% of research resources allocated to mental health.

Ignorance of the price paid for this policy neglect is no longer a defence. The failure to diagnose, treat and research the condition is disgraceful. People with bipolar deserve better – and must demand better. The time to make changes is now.

It will take a village to manage a condition, as they say. Bipolar UK will lead the way on behalf of the bipolar community. I implore you to read this document, pledge your support and join us as a change maker.

Introduction



Bipolar is a severe mental illness characterised by significant and sometimes extreme changes in mood and energy, which go far beyond most people's experiences of feeling a bit down or happy. There are over one million people with bipolar in the UK and research shows young people are twice as likely to screen positive for it¹².

Launched in March 2021, The Bipolar Commission mobilised 26 Commissioners with academic, clinical and lived experience and conducted UK-wide research. Most, if not all, of the findings are relevant to both England and the Devolved Health Administrations in Wales, Scotland and Northern Ireland.

The ambitious goal of the Bipolar Commission is to establish a pathway to achieve parity of healthcare services for people with bipolar. The first step: to think big about what it would take to drastically improve care and start a conversation. What would an ideal service model to support everyone with bipolar look like?

Most of our recommendations aren't 'pie-in-the-sky'. Many elements of an ideal service model already exist in pockets of excellence across the UK. This report shines a light on these individual elements of specialist care and evidences a robust business case for fair funding to roll out these services nationwide. Investment in specialist care for everyone with bipolar is a necessity from all angles: moral, economic, social and clinical.

A lack of data

The initial significant finding of the Bipolar Commission was the lack of data on bipolar. The NHS has no idea how many people have a bipolar diagnosis. Instead, the Commission has had to rely on prevalence studies like the Adult Psychiatric Morbidity Study (2014)¹³ to provide any kind of insight.

Another key omission is linked to the number of people being detained under the Mental Health Act (MHA). Annual statistics on detentions record gender, deprivation, Trust and ethnicity but not condition. Understanding the extent to which different conditions are driving changes in detention rates is key.

A lack of attention

Alongside this lack of data, bipolar is rarely mentioned in policy documents. Expert witnesses have explained to the Commission that the marginalisation of bipolar has its historic origins in the National Service Framework for Mental Health (1999)¹⁴ in which bipolar received a total of seven references in the whole strategy while schizophrenia and depression received 62 and 74 references respectively. The Commission has also found this inexplicable omission (and relatively frequent focus on schizophrenia and depression) in many current strategies.

Bipolar costs the UK economy £20 billion a year



Ignoring bipolar doesn't mean it has gone away

To begin to fill this data gap, the Bipolar Commission conducted 1-1 interviews with over 100 expert witnesses, conducted extensive desk-based research and sent out seven surveys to patients, psychiatrists and friends and family, collating over 7,000 responses.

We heard from many inspiring individuals who manage the condition well. We know it is possible for even the most unwell patient who's had multiple hospital admissions to make a recovery and live a full and successful life. And yet this is far from the norm.

Who cannot be shocked by the recent findings that bipolar costs the UK economy an enormous £20 billion a year – nearly a fifth (17%) of the total burden of mental illness¹⁵?

People with bipolar tell us they have frequent contact with NHS services (an average of 34 appointments with GPs, psychiatrists and Community Mental Health Teams over three years) – but are still becoming unwell (98% told us that they have had at least one relapse and over 50% told us they had relapsed in the previous year). Why aren't all these appointments helping people with bipolar to live well?

Endless taxpayers' money is being wasted on reacting to crises instead of preventing and managing relapses in the first place.

What people with bipolar want and need

What we need is a true understanding of the complex nature of the condition across the NHS and society generally, and the development of a dedicated care pathway to provide specialist treatment and continuity of support over a lifetime – from first telling a GP about symptoms, going through the diagnostic process and getting ongoing specialist support from clinicians who focus on personal recovery and managing triggers and relapse to first-class inpatient care if needed.

Stepping back from the whirling complexity of the NHS, people with bipolar are asking for something very simple. A single clinician who knows them, who understands the condition and who will work with them for years, even decades, to manage their medication and be available at the point of need to support them to live well.

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You can read the previous reports from the Bipolar Commission:
www.bipolaruk.org/bipolarcommission

With thanks to the commissioners - you can see a list here:
www.bipolaruk.org/who-is-involved

What is bipolar?



Bipolar is a severe mental illness characterised by significant and sometimes extreme changes in mood and energy, which go far beyond most people's experiences of feeling a bit down or happy.

To explain the condition, Bipolar UK uses a mood scale which ranks mood from 0 – 10, with 0 being low and 10 being high. For most people without bipolar, on their worst day they will 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 where they might experience paranoia and/or 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.

People can go into a 'mixed state', too, where symptoms of depression and hypomania or mania occur at the same time.

“ The highs of hypomania felt like I had all the energy in the world. Depression felt like I had no energy at all. **SS** ”

The Bipolar UK Mood Scale

Mood Scale		Numbers
MANIA	Total loss of judgement, exorbitant spending, religious delusions and hallucinations	10
	Lost touch with reality, incoherent, no sleep, paranoid and vindictive, reckless behaviour	9
HYPOMANIA	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
BALANCED MOOD	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
MILD TO MODERATE DEPRESSION	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
SEVERE DEPRESSION	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

Why bipolar is unique



Understanding what bipolar is – and isn't – is vital to be able to identify the appropriate solutions for people living with the condition.

While people with bipolar may experience secondary symptoms which overlap with other conditions, the unique combination of depression and hypomania and mania is specific to bipolar. People with bipolar need and deserve specialist care and treatment.



Bipolar is ancient and universal

Hippocrates, the father of modern medicine described the symptoms of contrasting moods of depression (or melancholia) and mania. Bipolar affects everyone across all ages, cultures and backgrounds. Implementing cost-effective, high-quality models of care in the UK could be emulated elsewhere – and deliver benefits across the world.

Bipolar is genetic although more research is needed

Twin and other studies have demonstrated that there is a substantial genetic component to the risk of developing bipolar, but studies also show that environmental factors can be important too. The condition is linked to over 100,000 genes many of which overlap with conditions like anxiety, ADHD and depression¹⁶. The latest scientific research suggests it is related to the way brain cells communicate through chemical connections (or synapses). This is expressed most obviously in how the brain regulates the emotions, the sleep/wake cycle and stress hormones¹⁷. Early abuse and neglect can make expression of bipolar symptoms more severe and difficult to treat¹⁸.

Bipolar symptoms are distinct

Symptoms of bipolar, particularly mania, are distinct. The more specialised a clinician is in bipolar, the quicker they can identify them. A clinician, usually a psychiatrist, investigates a patient's family history and case history for episodes of both depression and hypomania or mania. Mania is experienced as high energy, often elated, moods that can result in changes in self-care, increased risk-taking behaviour and, in some cases, psychosis. Hypomania is a milder form of mania.

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

Bipolar is commonly initially diagnosed as 'unipolar' depression

Before getting a diagnosis of bipolar 61% of survey respondents said they had first been diagnosed with depression, 21% had first been diagnosed with anxiety. Less than 9% of respondents said they had got a prior diagnosis of another severe mental illness (borderline personality disorder or eating disorder), and less than 3% said they had got a prior diagnosis of schizoaffective disorder or schizophrenia.

Lifestyle and social experiences can trigger symptoms

When asked about triggers for relapse, our community responded that lifestyle factors, like lack of sleep and stress, were the biggest trigger (68% said they are a significant factor), followed closely by difficult social experiences like bereavement (64%). This underlines the importance of both psychoeducation to improve understanding of lifestyle triggers and psychological therapies to deal with underlying trauma. Lower down the list of triggers were an inability to access medical support (42%), money worries (39%) and housing issues (19%).

Many of these triggers are caused by and compound bipolar. For example, the traumatic memory of being sectioned or the stress of unwanted debt accumulated during a manic episode may make another episode more likely.

The Commission's Bipolar Diagnosis Matters report published October 2021 also highlighted that lifestyle triggers might not be obvious without expert knowledge of the condition and could often be counterintuitive. Getting a promotion at work was reported as a bigger trigger than substance misuse, for example.

Relapses are frequent (but often preventable or reduced in severity)

If someone with bipolar has a severe episode of depression or mania (or both simultaneously, known as a 'mixed episode'), this is a relapse. 98% of survey respondents had relapsed at least once and 54% had relapsed in the previous year, confirming that it is a regular occurrence for many. The severity of a relapse can vary depending on treatment, how quickly treatment is given and individual triggers. The more severe and frequent a relapse the more severe and frequent they will become, as if the mind/brain establishes a 'relapse setting'¹⁹.



Medication regimes are complex

The Bipolar Commission identified over 26 medications that someone with bipolar could take for their condition. These often have a range of adverse effects that impact someone’s physical health and ability to function, including weight gain, feeling sluggish and tired, loss of concentration and tremors. Many people take more medication for these side effects which in turn can lead to additional side effects. Expert witnesses told us that gold-standard treatment such as lithium is under-prescribed, and many GPs told us they don’t feel confident reviewing bipolar medications.

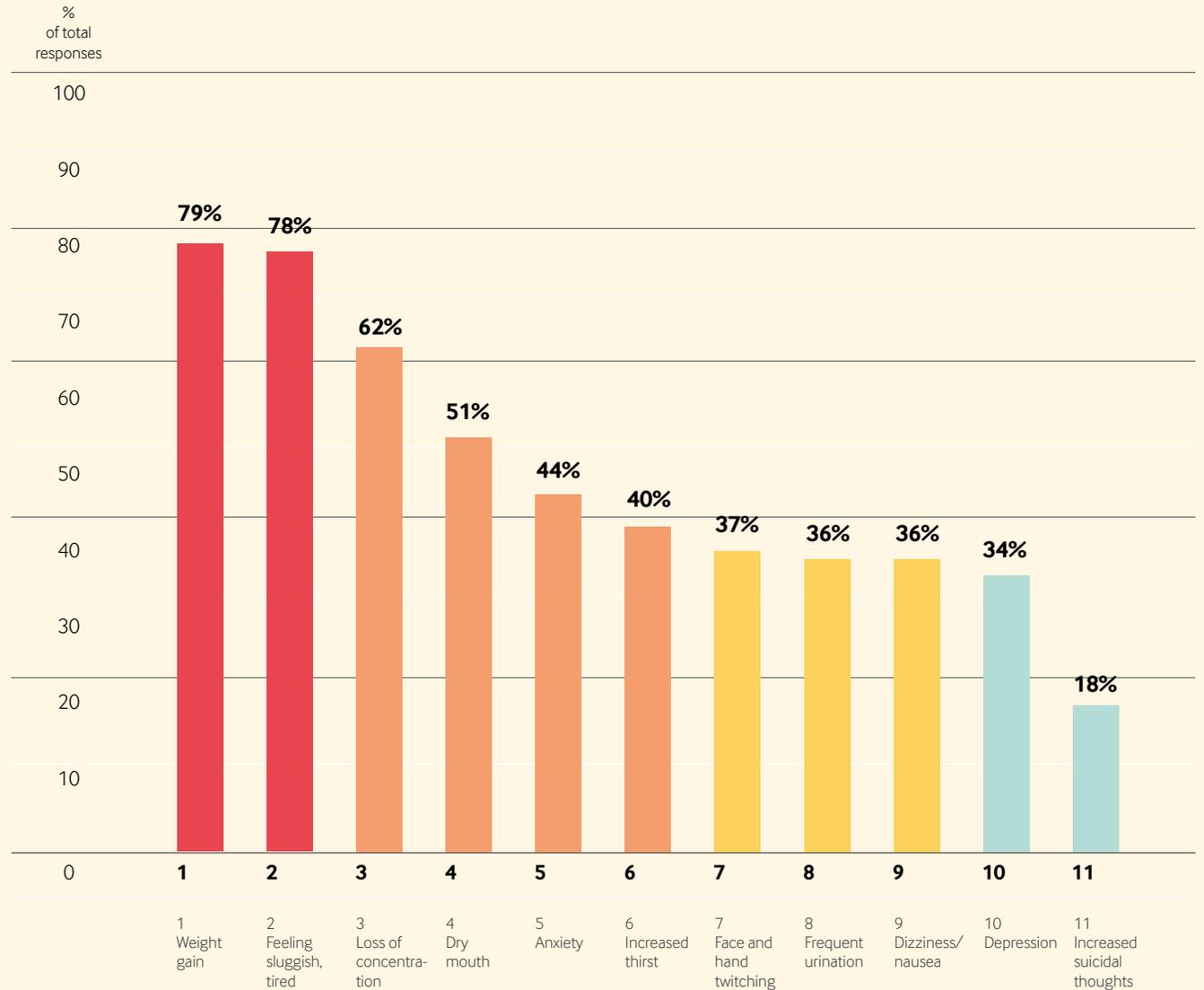
There is an almost infinite number of combinations and dosages someone with the condition can take. Like most conditions, people with bipolar often struggle to maintain their prescribed medication regime consistently. This can result both in relapses and overmedication. Anecdotal evidence from patients and clinicians report that overprescribing is a major issue for the community

“ The medication has lots of side effects, including slowing me down, and if I’m tired my speech becomes slurred.

I saw the same doctor for three years who helped me try difficult combinations and doses of medication before we got it right.

Sadly she retired and now I see doctors who don’t know me. **MP**

What side effects are people with bipolar getting from medication?





It takes an average of 9.5 years for people to get a diagnosis of bipolar



Diagnosis takes far too long

There is an average delay of 9.5 years between people first contacting a health professional about symptoms and getting an accurate diagnosis of bipolar²⁰. 60% of people said this delay had a significant impact on their life.

A wide range of factors are causing this delay, including: a lack of psychiatrists; misdiagnosis; patients not presenting previous episodes of hypomania to primary care; clinicians not asking about previous periods of hypomania; a reluctance by patients to get a diagnosis of bipolar which still carries stigma.

Bipolar type 2 takes longer to diagnose

The type of bipolar someone has affects the severity and type of moods they experience. The most common types of bipolar are: type 1, where someone experiences depression, hypomania and mania; and type 2, where someone experiences long periods of depression and hypomania.

There were significant variations in bipolar types 1 and 2. Bipolar 2 took longer from first contact with mental health services (11.1 years) to diagnosis than bipolar 1 (8.2 years). This is reinforced by the findings of Professor Daniel Smith at Edinburgh University that found that 30-40% of people with treatment resistant depression have bipolar²¹.

Another study found that over 3 in 20 patients with depression in primary care have unrecognised bipolar which can lead to harmful patient outcomes²². Expert witnesses tell us that this is because

'unipolar' depression is about 10 times as common as bipolar²³, and that they can be very difficult to tell apart²⁴.

We are yet to find evidence of differences in diagnosis by ethnic groups

There was no significant difference between white British and black British or other minority groups on time to diagnosis from first high mood, time to diagnosis from first low mood and time to diagnosis from first contact with mental health services. However, these reports should be read with caution because of the small sample size for the black British group (34/2458 respondents).

There are variations in experience between men and women

Comparing diagnosis times, the Bipolar Commission found a statistically significant difference between men and women. The time between a first episode of depression and diagnosis was longer

for men (mean 14.8 years) compared to women (mean 13.9 years). The time between a first episode of high mood and diagnosis was longer for men (12.2 years) than women (10.4 years). This was statically significant. There was no difference in time between men and women from first contact with mental health services to diagnosis (9.5 years).

This suggests that men take longer to present their symptoms (especially high mood) to a medical professional but the diagnosis journey within the health service takes a similar length of time. Appendix 1 (on page 26) highlights the additional burden bipolar has on women, including the impact of hormones at different stages of life.

Despite spending huge resources, the NHS delivers shockingly poor outcomes for people living with bipolar. The missing pieces of the jigsaw? A true understanding of the complex nature of the condition in the NHS and society generally, and the development of a dedicated care pathway providing specialist treatment and support.

“ I struggled from the age of 15 but didn't get a diagnosis of bipolar type 2 until I was 27. My emotions were either numbed, or I was out on all night benders.

If I'd received a diagnosis earlier, I could have lived the life I wanted, the life my peers were living. **AK**

The case for a bipolar care pathway



Bipolar needs to be treated as seriously as other severe and life-limiting physical and mental health conditions. The unique combination of manic and depressive symptoms combined with complex medication management and lifestyle factors makes specialist care vital to successful outcomes.

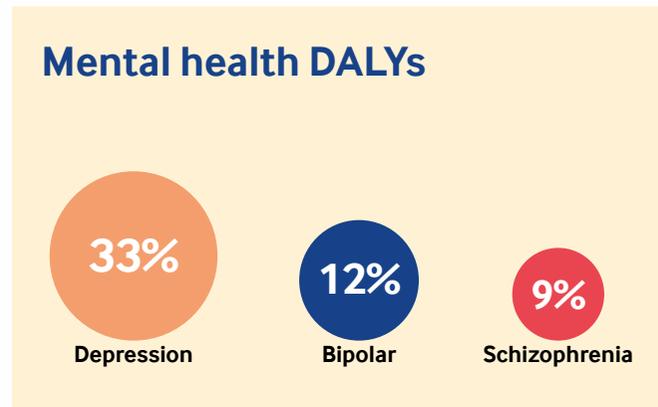
Why is it not given as much investment and support as other long-term conditions?

A holistic economic impact study by the London School of Economics for the Mental Health Foundation published in March 2022²⁵ revealed two facts that shine a light on the enormous burden of disease for bipolar.

“ I want to be treated like an individual by someone who really understands bipolar. Not by different doctors every time who have only just skimmed through my notes. **CR** ”

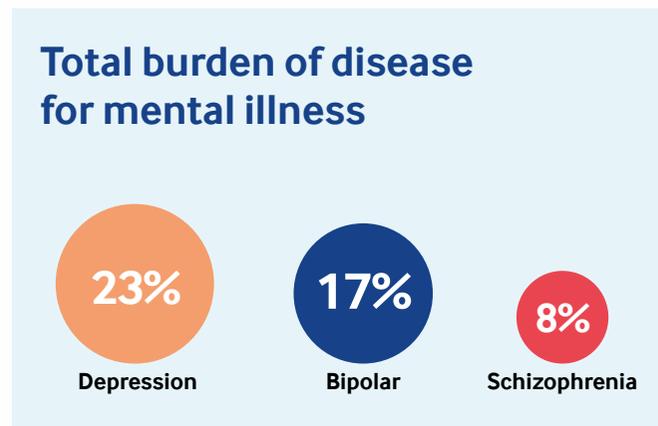
The impact on the individual

A DALY is a value attached to disability-adjusted life years - a measure of overall condition burden, expressed as the number of years lost due to ill-health, disability or early death. Bipolar accounted for 12% of mental health DALYs, compared to 33% for depression and 9% for schizophrenia.



The impact on society

The total burden of disease for mental illness in the UK is £117.9 billion a year. Bipolar accounted for 17% (a massive £20 billion), compared to 23% for depression and 8% for schizophrenia.



To be clear, we agree that people with schizophrenia need and deserve their own dedicated care pathway. We are not asking for funds to be diverted from their services to fund ours. We are simply highlighting both the unfair disparity and that specialist services for complex mental health conditions work.

The NHS is pouring costly resources into people with bipolar but systematically failing them. Episodic care is not working. GPs are overstretched. Treatment is delayed. Relapse rates are high. The burden of disease is insufferable – as evidenced by the high suicide rate.

Many elements of an ideal service model already exist in pockets of excellence across the UK – as detailed on page 22.

The Bipolar Commission is calling for fair funding to roll them out. With the NHS on its knees, a dedicated bipolar care pathway makes sense economically for individuals with the condition and society as a whole.

Schizophrenia has its own dedicated Early Intervention in Psychosis care pathway. **Bipolar doesn't. Yet...**

- Twice the number of people have bipolar compared to the number of people with schizophrenia²⁶
- The overall condition burden of bipolar is 33% higher than the condition burden of schizophrenia²⁷
- The total burden of disease for bipolar is more than twice the burden of disease for schizophrenia²⁸
- Psychiatrists spend on average 23% of their time with patients with schizophrenia and 18% with patients with bipolar²⁹



What the data tells us...

While it is impossible to calculate an exact number, it is estimated that over a million adults in the UK have bipolar²⁹. That's roughly 30% more than the number of people who have dementia³⁰. And 50% more than the number of people who have schizophrenia³¹, which has its own dedicated Early Intervention in Psychosis care pathway for which funding is ring-fenced.

Bipolar affects young people

The Adult Psychiatric Morbidity Study (APMS)³² in 2014 found that 16-24 year olds were eight times more likely to screen positive for bipolar than those age 65 or older. The peak age at onset of bipolar is 19 years³². 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.

The prevalence of bipolar could be increasing

Taking into account that people with bipolar on average died 10-15 years younger³³, those aged 55-64 were still half as likely to screen positive as the youngest cohort. That would represent a doubling of the bipolar population in less than two generations and strengthen the rationale for incentivising preventive approaches that are currently feasible but largely underexploited.

Expert witness provided two explanations for this. First, that the Mood Disorders Questionnaire (MDQ) that has been used to track prevalence tends to record false positives for young people and false negatives for older people. Second, that lifestyle triggers are increasing and there is a growing trend towards higher levels of mental illness amongst younger generations. The Commission believes the truth lies somewhere between the two and hopes the updated APMS (due to be released in 2024) will reveal a more definitive answer.

The cost of bipolar is enormous

Overall, bipolar costs the UK economy roughly £20 billion a year³⁴ and the healthcare cost for someone who has had a relapse is estimated to be £5,553 over six months compared to £1,765 for someone without a relapse - so an excess of £3,788 per relapse³⁵. At least 50% of people with a bipolar diagnosis relapse each year – costing the NHS an estimated additional £1 billion a year.

Bipolar patients are also significant users of other mental health services that aren't tailored to their needs. Expert witnesses and academic studies estimated that between 20 and 30% of patients using Early Intervention for Psychosis and Improving Accesses to Psychological Therapies had diagnosed and undiagnosed bipolar³⁶.

Bipolar can be life shortening

People with bipolar live an estimated 10-15 years less than the average population³⁷. This is due to both 'natural' deaths such as cardiovascular disease and cancer and higher rates of 'unnatural deaths', such as suicide, accidents and homicides.

Research shows that bipolar has a similar impact on mortality to schizophrenia³⁸, which as we've already said has its own dedicated Early Intervention in Psychosis care pathway.

Bipolar seriously increases the risk of suicide

Having bipolar increases the risk of suicide by 20 times³⁹. Up to 20% of people with bipolar will go on to take their own life⁴⁰. 10% of Bipolar Commission survey respondents claimed they had attempted suicide in the last 12 months. A review of coroners reports in 2019 found that 5% of all suicides in the review sample had a bipolar diagnosis⁴¹. When undiagnosed cases are taken into account it could be more than double that figure.

Each suicide costs society an average of £1.6 million⁴² through service response, potential lost income, and the emotional distress to loved ones. This suggests bipolar suicides per year cost the UK between £436m and £872m.



9 in 10 people with bipolar have experienced suicidal thoughts



1 in 10 people with bipolar attempted suicide in the past six months



What people with bipolar tell us...

All the primary research by the Bipolar Commission was collected through more than 100 one to one interviews and over 7,000 survey responses from people living with bipolar. It provides further evidence and insight into this tremendous burden of disease and underlines the devastating impact the condition has on individuals and families.

Bipolar devastates finances

People with bipolar reported losing an average of £22,492 in savings linked to bipolar episodes and estimated that they had missed out on an average of £109,343 in lost income. One-fifth of respondents reported out-of-control debt which is a concern.

Bipolar holds people back in the workplace

Over half of our physical health and hospital survey respondents said they had been hospitalised for their bipolar. 63% of our survey respondents told us they had lost a job, 72% hadn't applied for a job, 44% hadn't applied for a promotion, 35% thought they'd been overlooked for a promotion because of their bipolar.

Bipolar can cause homelessness

15% of people with bipolar tell us they lost their home because of the condition and 12% were made homeless. Moving area also exacerbates the condition as people have to change GP and psychiatrist and restart the often time-consuming referral / assessment process all over again.

Bipolar can affect education

Nearly three-quarters of respondents had been to college or university, which is above the national average, although 32% had left a university course early. While this may not be only due to their bipolar, it is much higher than average.

Bipolar has a negative affect on family and friends

Beyond the individual with a diagnosis, there's a substantial financial impact on the families of those with bipolar: 40% reported reduced earning potential because of their loved one's bipolar and those in work take an average of 11 days off sick each year (almost twice the national average⁴³). Effective management of bipolar would be a huge boost to the economy from all angles.

Bipolar destroys family life and friendships

People with bipolar reported that they believed their bipolar had a significant negative impact on an average of five close friends and family members. Common stressful scenarios when someone is unwell include being on the receiving end of unpredictable, often upsetting behaviour, helping to rectify mistakes on prescriptions and care plans, negotiating with creditors to get unwanted debts written off, calling crisis teams and visiting loved one during hospital admissions that can last for months. People with bipolar are more likely to live alone⁴⁴. The proportion of survey respondents who said they were divorced (15%) was nearly double the average for England⁴⁵ (7.8%).

“ 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

Bipolar and its treatment causes obesity

44% of respondents had a BMI above 30 which means they are classified as clinically obese.

This is over 50% more than the national average⁴⁶ and is one of the biggest reasons why people with bipolar die younger, mostly due to the increased risk of cardiovascular disease⁴⁷.

79% and 78% of respondents stated respectively that weight gain and feeling sluggish and tired was a side effect of the medication.



2 in 3 people with bipolar are overweight or obese

**27% = overweight
44% = obese**



Bipolar carries specific risks for women

64% of women told us they had had periods of hypersexuality and reported sexual assaults, unplanned children, vulnerability to sexually transmitted diseases, traumatic abortions and relationship and marriage breakups as a result (see Appendix 1 on page 26).

Bipolar is traumatic

Severe manic and depressive episodes are terrifying experiences frequently compounded by the medical response: 57% of respondents to the hospital patient survey said they had received medication by injection (often a sign of high-level intervention), and 50% said they had been physically restrained.

Only 50% of respondents said hospitals were a place of safety and 30% said they had developed post-traumatic stress due to a hospital admission.

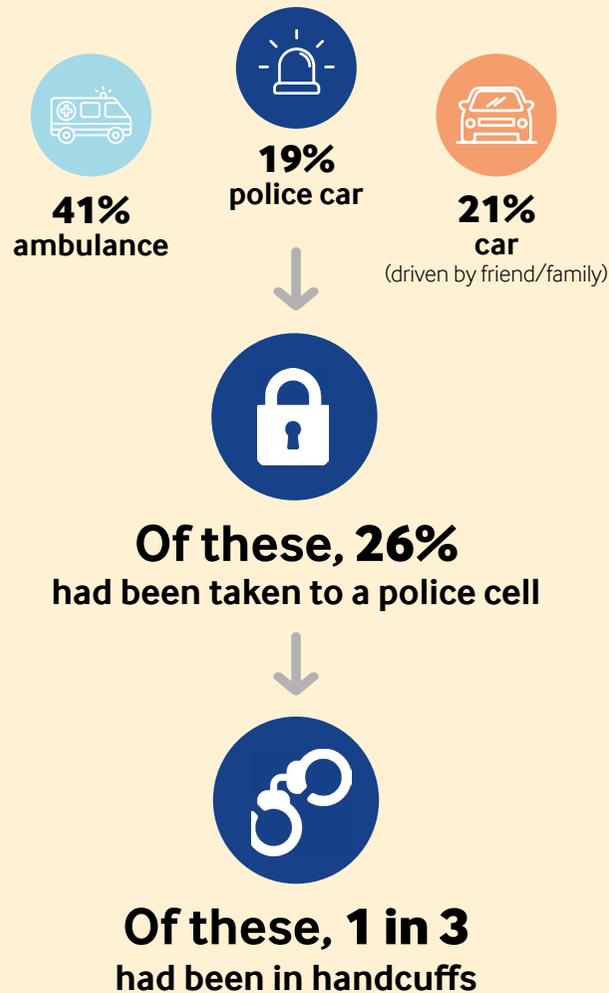
Bipolar can make someone feel like a criminal

One in five people with bipolar who ended up in hospital were taken there in a police car. Of these, 26% had been taken to a police cell. Of these, one in three had been in handcuffs. Even if charges aren't pressed and this was a last resort to keep someone safe, the trauma makes recovery more difficult and consumes considerable police resources.

“ 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**

How do people with bipolar in crisis get to hospital?



“ 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 current 'episodic care' model isn't working



The Adult Psychiatric Morbidity Study⁴⁸ found 60% of people living with bipolar get no dedicated treatment or support for the condition. 54% of people are living with bipolar and have yet to be diagnosed. Diagnosis is far from the end of the journey.

The lack of a dedicated care pathway or services for bipolar means that diagnosis and treatment for the condition defaults to an episodic care model. This is where ongoing support is provided in a primary care setting and where patients (with or without a diagnosis) are only referred to secondary care when they need specialist treatment, usually in crisis. These issues are even more amplified by the lack of a dedicated early intervention (for the first episode) and preventive (in those at risk) care pathways that can modify the course of this disorder and benefit many young people.

The Bipolar Commission has heard from countless lived-experience witnesses who say the term 'crisis management' is a better way to describe their experiences than 'episodic care'. Primary care globally has struggled with the integration of mental disorders (or any chronic condition). NHS GPs and mental health services are under severe pressure and have to deal with multiple competing patient needs and NHS demands. Also, given the challenges around the diagnosis of bipolar and the long delays in accessing mental health services after referral, diagnosis and ongoing management can often be difficult.

“ Living with bipolar before my diagnosis was a living hell. I said things I didn't mean, spent money I didn't have and took risks I wouldn't normally take. Diagnosis helped me make sense of everything. **GW** ”



6 out of 10 people living with bipolar get no dedicated treatment or support for the condition

The result of this lack of dedicated care is that it currently takes an average of 9.5 years from first presenting symptoms to a clinician to getting a diagnosis⁴⁹. This compares to the two-week diagnosis target after a first episode of psychosis⁵⁰. This is particularly tragic as 84% of people with bipolar tell us that a diagnosis is helpful, in and of itself.

People with bipolar have lots of appointments but still relapse

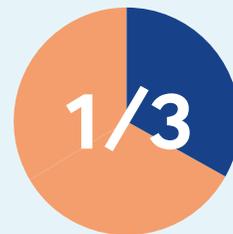
Once a diagnosis has been made, people with bipolar have frequent contact with NHS services (an average of 34 appointments with GPs, psychiatrists and Community Mental Health Teams over three years) – but they are still becoming unwell (98% told us they have had at least one relapse and over 50% told us they had relapsed in the previous year).

And in spite of these frequent appointments, many people reported a total absence of psychoeducation or focus on relapse prevention.

Lifestyle factors are the biggest reason both for bipolar relapses and shorter average life expectancy⁵¹, mostly due to the risk of cardiovascular disease. Despite this, people with a bipolar diagnosis commonly tell us they are given a prescription with very little, if any, information about side effects, cardiovascular risk or guidance on how to manage the condition.

People with bipolar have an average of 34 appointments with GPs, psychiatrists and 'Community Mental Health Teams' over three years

98% of survey respondents had relapsed at least once since they were given a diagnosis yet:



hadn't been offered any psychological therapies on the NHS



hadn't been offered any psychoeducation to help manage the condition well



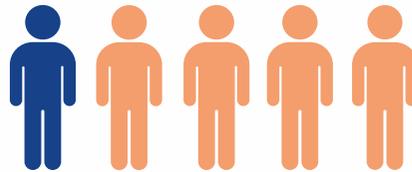
hadn't got a care plan or safety plan



“ I am so self-conscious about my belly. I hate being overweight. I wish the doctor had told me about the weight gain risk before I started taking the medication. Then I might have stopped this happening. Now it’s so hard to lose. **HA**

“ After I got a diagnosis, the gap in healthcare services was significant. There wasn’t any support in the community and the waiting list for psychological therapy was a year. All I got was the out-of-hours emergency number. **MP**

“ 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 with bipolar were offered or had received any group-based education

Physical health assessments aren’t working

NICE Guidelines state that GPs need to monitor the physical health of people with bipolar at least annually⁵². 79% of respondents reported that they had had a physical health assessment in the last five years (46% in the last year), but the Commission found little evidence that these physical health assessments are improving physical health outcomes or prompting any lifestyle changes.

Only 20% of respondents reported being told that their medication increased their risk of cardiovascular disease and, of those who had been told, only 30% were offered any support to reduce that risk, such as healthy eating, smoking cessation and exercise on prescription. The Commission also found no evidence that these reviews were routinely connected to medication reviews which patients felt were intrinsically linked to physical health.

People with bipolar have poor physical health

Unfortunately physical health outcomes for people with bipolar are still a big issue. 44% reported they were obese and data suggests people with bipolar are dying 10-15 years younger than the general population⁵³, mostly from cardiovascular disease.

Despite the risk factors only a minority of our respondents report being given access to advice and support on diet, exercise and smoking cessation. Research suggests implementing current good practice on physical health interventions would add four years to the life expectancy of people living with bipolar⁵⁴.

People with bipolar have a strong desire to be healthy

Positively there was a strong desire by people living with bipolar to improve their physical health. The health intervention most people with bipolar voted for was a free personal trainer, followed by a therapist and weight loss classes.

Patients reported only getting specialist support (such as admission to hospital) once they became severely ill. This creates a vicious cycle in inpatient units where only the most unwell are admitted, resulting in high coercion, a stressful ward environment, high staff turnover, legal rights routinely not observed and unacceptable levels of abuse. Because of the lack of beds, there is also intense pressure to discharge people which can in some cases lead to a revolving door scenario with premature discharge soon followed by relapse and return to hospital.

This is both dangerous and tragic, as the more severe the bipolar episode the increased likelihood and severity of a follow-up episode. The current system traps many people with bipolar in regular severe relapse cycles. If those same patients had been admitted earlier as voluntary admissions when their symptoms were less severe, then their stay would have been shorter and their chances of relapse or readmission lower.

And to take the thinking one step further, if those same patients had been given ongoing specialist support and attended psychoeducation course with a focus on relapse prevention, they might have avoided going into hospital altogether. Research shows that the younger someone is when they are given a psychoeducation course, the significantly more effective it is⁵⁵.

Crisis services aren’t working

Despite investment, crisis services are not working. Only 22% of people living with bipolar who reached crisis said they had used the service and 50% said they did not know about them or had chosen not to use them. A further 20% either said they came and were not helpful, or were not available when called.

The current 'episodic care' model isn't cheap



In 2020/21, the NHS in England alone spent £114 million on hospital admissions, £1.6 million on outpatient appointments and £890,000 on A&E treatment for those with a known diagnosis⁵⁶ and much care provided out of hospital of bipolar.

Expert witnesses told The Commission that the HES data seriously under-records bipolar. With only 44% of people with bipolar having a recorded diagnosis⁵⁷, the true figure could be significantly higher.

Our community across the UK also reports seeing a GP four times a year and psychiatrists on average twice a year. Diagnosed and undiagnosed bipolar puts an enormous burden on primary and secondary care.

Despite legislators saying that significant investment in mental health has been a priority, 63% of psychiatrists believe that care for people with bipolar has got worse (27%) or stayed the same (36%) over the last ten years, compared to 20% who say it has got better.

Bipolar accounts for **17%** of the total burden of disease for mental illness but gets only **1.5%** of the research funding

Bipolar research is woefully underfunded

The Bipolar Commission also investigated the level of research spend going into bipolar. In 2016 the James Lind Alliance conducted an extensive Priority Setting Partnership exercise to identify the top research priorities for bipolar⁵⁸. It identified crucial unanswered questions about bipolar at a time when new technologies and approaches to understanding bipolar (including brain imaging and digital mood management systems) were becoming available.

The top ten questions included lack of basic knowledge about the condition including what causes bipolar, and what the most effective treatments are, and why. The Commission found that the majority of these questions remain unanswered and are as relevant today as in 2016.

Research into bipolar is chronically underfunded, even compared to other mental health conditions. Research published by the mental health research charity MQ in 2018, found that bipolar only received 1.5% of the total mental health research funding spent from 2014 to 2017⁵⁹.

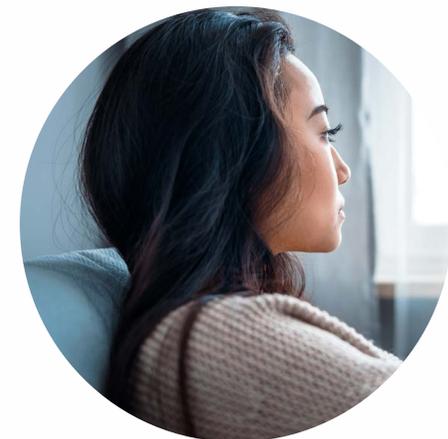
This is despite the fact that bipolar accounts for 17% of the total burden of disease for mental illness⁶⁰. What's more, bipolar only received a third of the research funding of autism and 18% of the research funding spent on schizophrenia⁶¹ despite it affecting nearly double the number of people⁶².

There are barriers to setting up clinical trials

More than 50% of people living with bipolar believe research into better treatments and medication should be a top priority. Despite the high level of demand, the Commission found the episodic care model for bipolar makes recruitment and delivery of clinical trials more challenging and expensive.

The lack of a national or even regional register of bipolar patients means participants need to be recruited through the already-stretched 6,000 plus GP practices, community mental health teams or existing patient networks such as Bipolar UK.

Additional clinical supervision also needs to be factored in as often the clinician responsible for the day-to-day management of someone's bipolar condition lacks the expertise and capacity to monitor trials.



The solution – in theory



In 2020 Bipolar UK asked people affected by bipolar what they wanted to have a fulfilling life. 882 people responded. Living a life that is not defined by bipolar and maintaining good relationships with friends and family came top, followed by being able to live independently and have choice and control over their lives.

These modest ambitions, as reflected in the evidence collated in this report, remain a distant goal for many.

Bipolar-friendly society

There is widespread confusion and there are many misconceptions around what bipolar is and is not. We all have a responsibility to be curious, to ask the right questions, to listen and to start to understand this unique condition.

While anti-stigma campaigns, such as Time To Change (2007-2021) have started a conversation, nearly nine out of ten people with mental health problems still say that stigma and discrimination have a negative effect on their lives. This means some people might avoid going to the GP with symptoms, preferring not to seek a diagnosis. In turn, this means they may be more vulnerable to social isolation, poor housing, unemployment and poverty – all of which can make their mental health worse.

Many of the lifestyle triggers people with bipolar described - losing sleep, changing jobs, moving house, separating from partners, demanding work schedules, long haul flights – could all be described as the cut and thrust, or even glamour, of the faster pace of modern life. This is perhaps why bipolar prevalence rates appear to be rising.

We need a 'bipolar-friendly' society where everyone – education providers, employers, friends, families, policy makers, politicians – understands bipolar symptoms and triggers (such as stress, jetlag, constant change, disrupted sleep) and allows people with bipolar to thrive.

Bipolar-friendly organisations

As a long-term condition bipolar is a protected characteristic under the Equality Act 2010. The huge burden of disease experienced by people living with bipolar suggests having or not having the condition is one of the biggest determinants of someone's opportunities.

Bipolar therefore needs to be integrated into all Equality, Diversity and Inclusion work and should be a key consideration for all directors and managers responsible for this within their organisation. This includes promoting reasonable adjustments to help people avoid triggers and using all possible funds, such as Access to Work, to overcome the disadvantages people face. Reasonable adjustments could include taking 'guilt-free' sick leave when someone's experiencing a mild low or high mood to prevent a full-blown relapse, or coming into work late so they can catch up on sleep.

Getting people with bipolar into work and investing monies to support them to remain in work would provide a positive outcome both for their mental health but also for the exchequer. It would provide vital respite for overstretched mental health services. This support should take a holistic approach and consider treatments and support that might be paid for by the health services, such as personal trainers or even therapists.

Bipolar-friendly funding

People with bipolar need a fair deal when it comes to funding and support. That means getting their full share of the mental health research and services budget. This should be based on the burden of disease, calculated by The London School of Economics as 17%⁶³. This 17% figure should be used by mental health commissioners and research councils to ring-fence a minimum spend on bipolar services and research.

For spending to match disease burden in monetary terms, that would mean:

Of the £115 million spent on mental health research each year in the UK, bipolar should get £20 million a year but is currently getting £1.9 million a year⁶⁴.

Of the £14.3 billion NHS England spends on mental health services in England, bipolar services should get £2.4 billion a year.⁶⁵

Devolved Administrations should get similar proportions.

In England this increased figure could be paid for from the £2.3 billion⁶⁶ real time additional annual funding going into mental health services and a reprofiling of spend away from more generic, less appropriate services that people with bipolar must currently use. Given the already high level of out-of-pocket health expenses for people with bipolar and the close link between welfare and work, innovative funding models should also be explored to share the cost of treatment. The Commission does not believe that the funding should be taken from notional savings from bed closures. Good community and inpatient care go hand in hand for people living with bipolar.

Funding needs to be available to better understand and develop targeted interventions for specific groups whose risk of relapse is proven to be higher – eg. women with bipolar at times of hormonal change, and teenagers with bipolar in the family, especially when they're leaving home for university at 18.

It's also crucial for funding to be made available for studies to better understand the main risk factors for bipolar. This research should look at the interplay between the genetic, environmental and lifestyle factors using large-scale population cohorts such as UK Biobank.

“ I'm too embarrassed to tell my colleagues that I have bipolar. I don't want them making assumptions about me or wondering if I'm well enough to handle a project. JP



We need to create a dedicated bipolar care pathway where early diagnosis, relapse prevention, holistic medication reviews and psychoeducation are priorities.

Bipolar-friendly services

We need to create a dedicated bipolar care pathway where early diagnosis, relapse prevention, holistic medication reviews and psychoeducation are priorities.

The pathway must put the patient-psychiatrist relationship at its heart. Both patients and clinicians want a greater emphasis on the role of the psychiatrist and continuity of care – as seen in many other countries including Sweden, France, Australia and the US. It is time to get rid of the unhelpful ‘Severe Mental Illness’ or SMI’ umbrella label and build a network of bipolar and mood disorder ‘specialists’ to mirror many other areas of medicine (eg, surgeons or oncologists) where specialising in a relatively narrow area of expertise is widely regarded as best practice. Creating a network of centres of expertise in bipolar has been shown to benefit patients and save money .

Everyone with bipolar should have the right to a named psychiatrist (or an alternative clinician of their choice who has specialised knowledge of bipolar) with regular assessments and access at the point of need. Increased uptake of technological advancements, such as the use of online Zoom appointments and technology to track mood can help make this a reality. These teams could be organised into regional bipolar or mood disorder centres of excellence which would increase expertise, speed up diagnosis and reduce relapse and suicide rates.

The Bipolar Commission has found overwhelming evidence this specialist treatment for people with bipolar is the most cost-effective way to support people with the condition. The Kessing study in Denmark⁶⁷ for instance found that by spending the equivalent of £2,550 per patient per year on specialist care, there is a saving of £2,715 from reduced hospital admissions, and dramatically improved outcomes for people living with the condition.

Bipolar-friendly early detection and prevention

Young people in the UK must wait about 9-10 years before their bipolar symptoms are recognised and cared for⁶⁸. This is at odds with the game-changing role of preventive and early intervention approaches for bipolar that are gaining traction worldwide. The term ‘at risk of bipolar’ could be ground-breaking in enabling effective self-management before medication is required. We demand a national investment in prevention and early intervention for bipolar that can benefit the lives of many young people and society as a whole.

Bipolar-friendly NHS leadership

Implementing this model will require both clinical and lived-experience leadership at every level of the NHS. Given significant diagnostic overlap with depression and anxiety, this could be within the broader remit of mood disorders.

The Commission is calling for a National Clinical Director for Mood Disorders and a clinical lead for Mood Disorders in each trust. This should be supplemented by Lived Experience Champions, who are either living with bipolar and or have close friends and family with the condition. Their role would be to champion the implementation and quality of specialist services for people living with bipolar and ensure no decision is ever made about them without them. We are also calling for all NHS Mental Health providers to sign up and commit to becoming bipolar-friendly.

Bipolar-friendly diagnosis

Everyone with bipolar has a right to a timely accurate diagnosis. It is shocking that people wait on average 9.5 years⁶⁹ to get one. We are proposing a national campaign to encourage understanding of bipolar symptoms and providing tools to help patients present those symptoms to GPs and psychiatrists. The Commission believes this campaign should be focused initially on people with depression and the family members of those with a diagnosis of bipolar.

We would also welcome the use of a ‘working diagnosis’ or a ‘designated at risk of bipolar’, to allow people to be prescribed non-pharmaceutical approaches to self-management, such as a ‘sleep hygiene’ course, exercise on prescription and mood tracking (with Bipolar UK’s Mood Scale and Mood Tracker app).

“ For years I took antidepressants and had counselling for depression, but struggled with low moods. 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.

When I was 50, I saw a psychiatrist who diagnosed bipolar type 2, put me on a mood stabiliser and adjusted the dose of the antidepressant. Everybody around me noticed the difference straight away. It’s really helped iron out my moods. **AT**



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

“ 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**



Bipolar-friendly hospitals

The chronic underinvestment in inpatient units has resulted in late admissions, worse relapses and traumatic hospital experiences. The Commission is calling for a moratorium on bed closures and the development of a sustainable long-term investment programme to improve the hospital experience.

The long-term goal must be to maintain bed availability and increase the proportion put aside for voluntary admissions. Advance Choice Documents⁷⁰ should be at the core of treatment. Inpatient units should be where every mental health professional wants to work, the communities they serve should be proud of them and no one should be afraid to send a loved one there.

Bipolar-friendly NICE Guidelines

The NICE Guidelines on Bipolar⁷¹, which emphasise episodic care and maintenance in primary care, were compiled in 2014 and last updated in 2020 before Covid-19. The Commission is calling for that guidance to be reviewed again to take account of the learning from the pandemic and the mounting evidence of the benefits of specialist treatment and support, including early intervention and prevention.

The Bipolar Commission took inspiration from Early Intervention services for Psychosis programmes that improved outcomes for people living with psychosis. More recently the Optima Service⁷² in the South London and Maudsley Trust which has proved the efficacy of a similar intensive programme for bipolar and the Outreach And Support in South London for Bipolar At Risk is the first NHS service set up to prevent the onset of bipolar in the UK⁷³.

Bipolar-friendly self-management programmes

Everyone living with bipolar has the right to basic advice on how to manage the condition well. The Commission is calling for a national roll out of group psychoeducation programmes, such as the award-winning Bipolar Education Programme Cymru (BEPC). As for Improving Access to Psychological Therapies (IAPT), the Commission believes everyone with bipolar should be invited to participate in it.

Bipolar-friendly data collection

Establishing a national register of everyone with a diagnosis of bipolar through primary care will speed up diagnosis by focusing on those with depression and families of those with a bipolar diagnosis. It will gather vital evidence to inform future decisions. It will also allow clinicians to support patients with on-going relapse prevention and healthy lifestyle measures, and allow easier recruitment for clinical trials to improve future care.

The Commission also proposes the formation of an internationally recognised benchmark for bipolar diagnosis, relapse, prescribing, psychological therapies and suicide rates. This would allow countries and healthcare models to compare outcomes and rapidly identify and disseminate the best care models globally.

Bipolar-friendly detention collection

Another issue recognised by the Commission is that the records taken when someone is detained under the Mental Health Act do not include their diagnosis. Many do have a diagnosis of bipolar which could be noted. And for those who only get a diagnosis after having been sectioned, the inclusion of 'undiagnosed' and 'suspected bipolar' categories under 'condition' would provide statistically vital information, such as readmission of people who were later diagnosed with the condition.

This would increase understanding of the nationwide mental health crisis - knowing which specific mental health conditions are driving the increase in detentions would place us in a much better position to tackle the problem, and prevent much suffering and NHS expenditure.

The solution – in practice



People with bipolar are asking for something very simple, an expert in bipolar and who will work with them for years to manage their condition and be available at the point of need.

Improving access to psychiatrists was consistently the number one priority for people living with bipolar. Psychiatry-led models in many developed countries, including Sweden and Germany, suggest this would lower both the relapse and suicide rates in the community⁷⁴. And psychiatrists and patients were aligned in their views.

515 psychiatrists responded to a joint Bipolar Commission / Royal College of Psychiatrists survey on bipolar treatment and care (one in 25 psychiatrists who are practicing in the UK). They agree that improving access to secondary care is a priority.

41% of patients and 37% of psychiatrists said that the psychiatrist should be the primary clinician responsible for supporting someone to

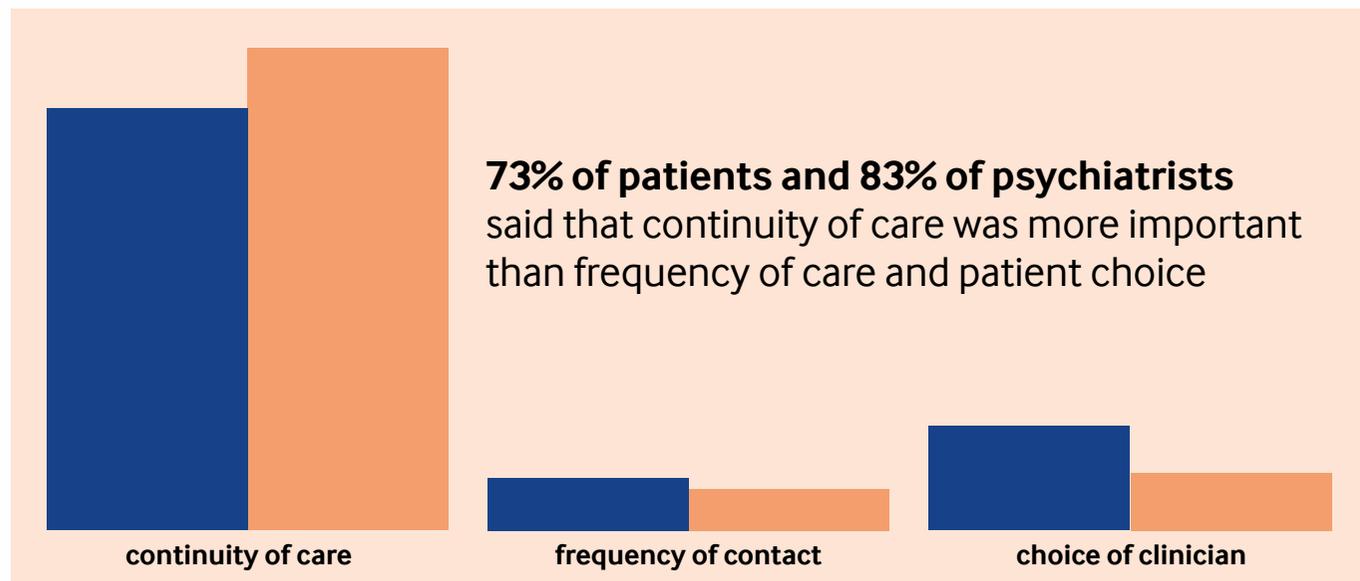
Psychiatrists agree that improving access to secondary care is a priority

manage their bipolar. This compares to 16% and 8% respectively who said the GP should be the primary clinician (the current model). The remaining respondents would prefer a combination of community mental health teams, community psychiatric nurses and therapists.

More than two in three psychiatrists did not endorse the current episodic model of care - 69% wanted to see patients regularly regardless of whether they are unwell or currently stable. 58% of psychiatrists would like to see their patients with bipolar more often. The majority of psychiatrists (57%) also said they believe patients with bipolar should each have a named psychiatrist.

The Bipolar Commission has found overwhelming evidence that specialist treatment for people with bipolar is the most cost-effective way to support people with the condition.

The Kessing study⁷⁵ in Denmark for instance found that by spending the equivalent of **£2,550 per patient per year on specialist care, there is a saving of £2,715 from reduced hospital admissions, and dramatically improved outcomes for people living with the condition. A study from France this year confirmed the economic advantages of a specialist network⁷⁶. Similar findings have been replicated in the UK.**



What do people with bipolar want?

- 73%continuity of care
- 9%frequency of contact
- 18%choice of clinician

What do psychiatrists want?

- 83%continuity of care
- 7%frequency of contact
- 10%choice of clinician

How continuity of care works for Trevor



I was diagnosed with bipolar a couple of years ago following three episodes of hypomania where I ended up in hospital three times.

I've always had a lot of energy and a tendency to be at the high end of the scale.

What I hadn't experienced was the depths of a depressive episode, which I experienced in hospital for the first time.

I am now back working as a medical researcher which I think is down to the fact that I had very good treatment in our local hospital and that I get ongoing exceptional support from the Community Mental Health Service.

I see my consultant every three to six months. I see my CPN [community psychiatric nurse] every month, although up until about six months ago I was seeing him every two weeks. I've also got a number to call if I've got any concerns. This means I can discuss my medication with my consultant and ask my CPN about everything else without having to wait.

It took some time to get the medication sorted. I tried various antipsychotics. The first one I tried numbed me out so much, I just wanted to lay on the sofa and do nothing.

It has taken the best part of a year and a half to get my medication sorted. My consultant was really patient getting the medication right, tweaking it slowly over time.

The fact that my consultant knows me is invaluable. He always asks about my work, my family. He wants to get to know me.

Likewise, my CPN does a great job in terms of understanding me and my specific needs. And he's helped me understand what I need to do to self-manage the condition well.

For all our family, me becoming unwell and getting a diagnosis of bipolar has been a seismic shift in terms of our outlooks and perspectives. My wife comes to all my appointments. That's been a big support – for me and for her.

I go to my local Peer Support Group every month hosted by Bipolar UK. It's helpful to meet other people with the condition, regardless of whether they're currently struggling or thriving. It's great to have people like you from different backgrounds, sharing their stories and supporting each other. That mutual understanding is invaluable.

One of the other things I've got out of the group is that I appreciate how very lucky I am. Not everyone has regular appointments with a consultant and ongoing support from a CPN.

Far from it. I don't know where I'd be without them.



The specialist care model is already working in some parts of the UK



As well as the undeniable proof that rolling out nationwide programmes can work for mental health conditions, pockets of excellence across the UK show that specialist care is effective for people with bipolar too. These include:

London - The OPTIMA mood disorders service

This is a specialist programme for people with bipolar who need frequent hospital admissions. An audit comparing data on hospital admissions and home treatment team (HTT) contacts in patients three years after discharge from the programme found that the average monthly rate of hospital admissions after OPTIMA was significantly reduced compared with the rate prior to the programme⁷⁷.

This highlights the effectiveness and importance of individually-tailored, specialist care for patients with bipolar following discharge from hospital.

Newcastle - Specialist Adolescent Mood Disorders Service

This specialist service provides second opinions for children and young people up to the age of 18 for the most complex and high-risk cases of depression and bipolar across the UK. Since the service was launched in early 2013, there have been 238 referrals of whom 84 young people had a diagnosis of bipolar. Of these, 77 were outpatients when referred and following intensive, specialist care 74 (96%) avoided admission to hospital⁷⁸.

This is a success for the individual (being an inpatient as an adolescent is often terrifying for the young person and their family) and the NHS (adolescent inpatient care is expensive, costing between £500 and £1,300 a bed a day⁷⁹).

Birmingham - Specialist Mood Disorders Clinic

This specialist mood disorders clinic provides assessment and evidence-based treatment recommendations for people with difficult to treat bipolar who have very often needed frequent acute care services, and for young people in whom there is concern that they are developing bipolar⁸⁰.

Alongside this, a Mood on Track programme specialist secondary care service offers individuals with all types of bipolar a cognitive-behavioural psychological intervention designed specifically for bipolar which involves sessions on mood monitoring, medication, self-management and relapse prevention. After completing the group sessions, people are offered 6-8 individual sessions and then an ongoing support group. In a qualitative evaluation⁸¹ six months after the course, scores of depression and anxiety were significantly reduced, and mood difficulties were less impactful on daily functioning.

Newcastle - Regional Affective Disorders Service

This is a specialist service for adults in the North East of England with difficult-to-treat mood disorders. The service includes an initial detailed and expert assessment, second opinions, advice on treatment option, in-patient and day-patient care, psychoeducation and ongoing advice by phone, email or letter. 12 months after the initial assessment, more than 50% of patients reported that they were 'much' or 'very much' improved, again strengthening the case for specialist care⁸².

Cardiff – Reproductive Mental Health Programme for women

The Cardiff University Psychiatry Service (CUPS) provides a second-opinion service offering advice on the diagnosis and management of bipolar in women and on the risks associated with women's reproductive health, such as the menstrual cycle, pregnancy, perimenopause and hormone therapy. Research shows women are very keen to access specialist advice on these issues⁸³.

London - Outreach and Support in South London Service for Bipolar At Risk states (OASIS-BAR)

One service in South London is taking specialist services to a whole new level by showing that the onset of bipolar is potentially preventable altogether^{84,85}. OASIS is an NHS-funded, multidisciplinary (team leader, consultant and junior psychiatrists, clinical psychologists, mental health professionals), transitional (for those aged 14-35 years) community mental health service for young people at clinical high risk for bipolar.

The programme uses specific assessment tools to reliably detect bipolar at risk features in young people who might be at clinical risk and more vulnerable to developing the condition. The aim is to prevent the onset of a first episode of bipolar and, if an illness does develop, to reduce the duration of the untreated disorder and optimise pathways to care. This type of specialist care has already demonstrated real-world implementability in the NHS, good prognostic accuracy and clinical utility for young people^{86,87}.

Time and again specialist services are proving to be effective – for individuals, for society, for the economy. The Commission advocates an urgent review of these individual centres of excellence and a national strategy to roll them out across the UK. national strategy to roll them out across UK.

Conclusion



Having bipolar carries an enormous burden, both for the individual with the condition and for the friends, family, society and health service around them.

The condition constitutes 17% of the total burden of disease for mental illness and costs the UK economy a massive £20 billion a year⁸⁸. Yet it receives far less attention than schizophrenia or depression which are both benefitting from the introduction of the UK's two flagship mental health programmes: Early Intervention in Psychosis (EIP) for people with schizophrenia and Improving Access to Psychological Therapies (IAPT) for people with depression.

A seismic shift in mindset is needed

Members of the Commission were shocked at how many policy documents and strategies, national and local, totally ignore the needs of the 2% of the population who have bipolar⁸⁹. The condition is 'the forgotten twin of schizophrenia' as Professor Guy Goodwin says in the foreword of this report – *even though it affects twice as many people*⁹⁰.

It is striking that the Bipolar Commission's findings reveal a high level of agreement between clinicians and patients. Both told us that promoting continuity of care should be a top priority, with the NHS focusing on building relationships rather than providing units of clinical time.

People with bipolar want a single clinician who knows them, who is an expert in bipolar and who will work with them for years to manage their condition. Clinicians also want to be able to provide continuous care.

What the community needs now

What we need is a true understanding of the complex nature of the condition across the NHS and society generally, and the development of a dedicated care pathway to provide specialist treatment and continuity of support over a lifetime – from first telling a GP about symptoms and receiving a diagnosis to getting ongoing specialist support from clinicians who focus on personal recovery and managing triggers and relapse, with first-class inpatient care available if needed.

So much suffering and waste of talent could be avoided – and money saved – if the emphasis were switched to prevention: prevention of relapse and prevention of premature death. We need to move away from tick box exercises, increased frequency of contact and crisis management towards building long-term patient-clinician relationships that encourage holistic self-management.

We understand this is moving in the opposite direction of travel...

In England⁹¹ the current direction of travel set out in the NHS Long-Term Plan and The Community Mental Health Framework for England is welcome in providing a bigger role for the voluntary sector and localised decision-making.

But expert witnesses tell us that the direction of travel is also towards more generalised services that treat individual symptoms and distress rather than conditions themselves. The data collected by the Commission indicates strongly that this generalised approach does not work for people living with bipolar.

Unless we can ensure a fair proportion of funding goes to specialist bipolar services, the extra funds risk further entrenching local service models which are fundamentally failing people living with bipolar.

...but the NHS urgently needs a flagship intervention for bipolar

Our inspiration comes from the success of the EIP and IAPT programmes which were both rapidly and successfully upscaled and rolled out across the UK to provide specialist services for specific groups (people with schizophrenia and depression).

Expert witnesses told us that these two programmes provide both a model and a precedent of what a successful dedicated bipolar pathway could and should look like. It gives hope that when a clear need is identified and the NHS has the will to tackle it, the system can respond and deliver real improvements in care.

As well as offering immeasurable benefits to patients and their families, frontline clinicians suggest that targeted programmes can bring wider benefits too: while vacancy rates and staff turnover

within NHS Mental Health Services are high across the board, Early Intervention in Psychosis is an exception, struggling less to recruit and retain staff.

No longer the 'forgotten twin'

The million-plus⁹² people living with bipolar in the UK deserve a fair share of funding and resources and should be able to access services tailored to their needs.

The success of the EIP and IAPT services demonstrates that specialist support targeted at a specific group of patients really does work. With the current state of the NHS and so many individuals and families suffering, now is the time to introduce a care pathway that will dramatically reduce costs and improve life outcomes for everyone with bipolar.

If someone with bipolar gets a diagnosis quickly and proper treatment and support over a lifetime, they're much more likely to be well enough to stay in education or the workplace. They will cost the NHS less. They will need less support from social and criminal justice services. The impact on their families will be smaller.

“ Our community has been let down by health services for too long. The case for introducing a specialist care pathway for people with bipolar couldn't be clearer.

Simon Kitchen, CEO, Bipolar UK



The Bipolar Commission is calling for:



- ✓ **Better understanding of bipolar in society**
- ✓ **Quicker diagnosis of bipolar**
- ✓ **All suicide prevention policies to include bipolar**
- ✓ **Access to specialist bipolar treatment and support**
- ✓ **Optimum bipolar medication management**
- ✓ **Investment to improve inpatient care significantly**
- ✓ **Fair funding for bipolar research and treatment (17%)**
- ✓ **Bipolar-appropriate NHS services**

Better understanding of bipolar

- National awareness campaign to increase understanding of bipolar symptoms, specifically targeting people with depression who have had previous episodes of hypomania and those with mental health symptoms for which the treatment isn't working
- A letter to everyone with a 'Severe Mental Illness' or 'SMI' or who's taking antidepressants to improve understanding of pre-cursors and symptoms of bipolar – ie: 'treatment-resistant' depression, previous episodes of hypomania, on-going anxiety, depression and/or a family history of bipolar – to prompt them to ask the question 'could it be bipolar?'
- Ensure that understanding of bipolar symptoms is included in both training and continuous professional development in primary care – Bipolar UK is keen to work with the Royal College of GPs to support with the roll out of this training

Quicker diagnosis of bipolar

- Anyone who has made a suicide attempt should be automatically screened for bipolar
- Rapid assessment for anyone with bipolar symptoms to start appropriate treatment within six months (to work towards parity with national targets for psychosis⁹³)
- Incentivise primary care to implement NICE Guidelines and consider bipolar in all mental health assessments
- Incentivise psychiatrists to specialise in bipolar to increase the speed and accuracy of diagnosis
- Ensure that secondary care is set up to provide quicker diagnosis – which means more psychiatrists and shorter waiting times for a referral
- Pilot a self-referral to secondary care model trial (building on the model of youth mental health services)

All suicide prevention policies to include bipolar

- Bipolar should be included in all suicide prevention strategies and plans
- People with bipolar should automatically be given psychoeducation so they understand their increased risk of suicide. They should get support from mental health teams to produce self-management plans to lower the risk of relapse and safety plans to protect them if they do relapse
- Everyone with bipolar should have access to ongoing peer support to help them live well and find common strategies to keep safe
- A national push to improve bipolar diagnosis rates will help to lower suicide rates
- Clinicians should encourage patients to try lithium, which has proven suicide-reduction qualities⁹⁴, before other medications. For a third of people with bipolar it can reduce the risk of suicide to the national average⁹⁵
- 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 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





Access to specialist bipolar treatment and support

- Roll out best-practice early intervention and on-going relapse prevention services in regional specialist mood disorder clinics across the UK with patient choice as to who oversees their care – GP or psychiatrist – regardless of whether they move out of area
- Give everyone with bipolar the right to develop a long-term relationship with a named clinician who knows them and who is an expert in bipolar
- Recruit enough extra specialist psychiatrists to ensure ongoing support is possible
- Explore the idea of training CPNs as specialist bipolar nurses (equivalent to specialist diabetes nurses)
- Ensure everyone with bipolar can access specialist psychological therapies, such as CBT and group-based psychoeducation with psychologists or CPNs
- Give every woman with bipolar the right to access specialist knowledge and support, especially about the stages of life where risk of relapse is higher – eg. pregnancy and menopause
- Use technology to improve continuity of care and allow people to self-manage (online appointments, courses, peer support)
- Review NICE guidelines for bipolar to take into account latest evidence to prioritise holistic approach over a lifetime – ie. specifying regularity and quality of:
 - medication reviews
 - physical healthcare checks
 - psychoeducation
 - specialist psychological therapies
 - peer support in every community or online

“ I’d say the 12-week psychoeducation course I did soon after my diagnosis with a psychologist has probably saved my life. **PM** ”

Optimum bipolar medication management

- Ensure that a clinician who specialises in bipolar oversees all prescriptions and medication changes to maximise both mental and physical health
- Improve clinician understanding and better use of available treatments, particularly lithium, lamotrigine and lurasidone
- Expand use of precision medicine to reduce overprescribing (eg. making use of the new technology of skin biopsies and prick tests)
- Improve patient understanding of medication and side effects

Investment to improve inpatient care significantly

- Speed up and improve the pathway to hospital admission at point of need with improved liaison psychiatry services
- Record detentions under the Mental Health Act by diagnosis
- Introduce immediate moratorium on bed closures
- Increase budget for new hospitals and introduce specialist bipolar residential centres for voluntary admissions to treat relapses early and reduce detention rates
- Reduce thresholds to increase voluntary admissions and lower detentions
- Offer everyone psychological therapy and/or psychoeducation during and/or after each admission

Fair funding for bipolar research and treatment (17%)

- Introduce a national register of everyone with bipolar in the UK to ensure easier recruitment for clinical trials and to gather accurate diagnosis data
- Recruit specialist mental health nurses, psychiatrists and occupational therapists
- Establish a clinical research network with a strong focus on prevention and early intervention for bipolar that can prioritise early interventions for the next generation

Bipolar-friendly NHS services

- Incentivise every clinician to sign up to a ‘Bipolar Pledge’
- Appoint a National Clinical Director of Mood Disorders
- Appoint a clinical lead in every NHS trust mandated with improved healthcare for people with bipolar (known as ‘Bipolar Champions’)
- Guarantee the voice of lived experience champions in every policy meeting / on every committee
- Integrate bipolar into Equality, Inclusion and Diversity policies
- Introduce innovative funding models for NHS to ensure early diagnosis / specialist services

“ My aunt has bipolar and she’s been in and out of hospital for the past 26 years. She didn’t have children. She’s overweight. She doesn’t work. When she becomes unwell it’s really hard to get hold of her crisis team. I was terrified when I was diagnosed with bipolar at 18. ”

I thought my life was over. But now I’ve met lots of people with the condition who work, who have children. I’ve realised that if I’m determined to find the right combination of medication, support and self-management techniques I can live a good life. **HA**

Appendix 1: The impact of bipolar on women



By Dr Clare Dolman, co-chair of the Bipolar Commission, a trustee for Maternal Mental Health Alliance and a trustee for Action on Postpartum Psychosis. She has a diagnosis of bipolar type 1.

Although the general prevalence of bipolar disorder is similar among men and women, there are definitely gender-related differences. For instance, rapid cycling, mixed episodes and bipolar 2⁹⁶ have all been reported to be more frequent in women. Other associated conditions that are seen more often in women with bipolar than men include anxiety, migraines, obesity and panic disorders⁹⁷.

The need for information

This is an under-researched area but an obvious candidate to explain why women with bipolar are affected differently to men is the difference in our hormonal makeup and how that interacts with the condition. And yet when, as part of the Commission's work, we asked women with bipolar whether any health professional had ever given them any information on how hormones might affect their bipolar, an astonishing 86% of them said 'No'.

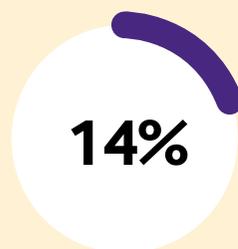
More than 1,000 women with bipolar responded to our survey and revealed how much hormonal events in their lives affect their ability to manage their bipolar successfully and how little help they get with this aspect of their condition. For example, 75% told us that menstruation affected their bipolar symptoms to some extent and, of those in the relevant age bracket, 55% said perimenopause or menopause had affected their bipolar.

There has been a woeful lack of academic research into this association between hormonal changes due to menstruation or menopause and exacerbation or triggering of bipolar episodes so it is difficult to back it up with robust data, but there is one time of life when hormones and bipolar interact to sometimes catastrophic effect which has been more thoroughly researched and the link has been indisputably confirmed: around childbirth.

We now know that women with bipolar have a risk as high as 50% of having a serious episode around childbirth, and 25% will suffer a postpartum psychosis, a potentially life-threatening episode that usually requires hospitalisation for several weeks (Di Florio 2013⁹⁸). How this is caused biologically is not yet known but the timing of episodes – usually within days of the birth when major hormonal upheaval is taking place – has led researchers to conclude that hormones must be implicated.

More than **1,000 women** with bipolar responded to our survey

Lack of information for women with bipolar:



been given information by a clinician about how hormones can affect their bipolar

Need for information for women with bipolar:



say menstruation affects their bipolar symptoms



risk having a serious episode around the time of childbirth



(age 40+) say perimenopause or menopause affects their bipolar symptoms

“ I was told hormones had nothing to do with my bipolar when I suggested it to a psychiatrist. **CV** ”



Menstruation

So considering the strength of this association, it is not surprising that hormonal shifts at other times of a woman's life also affect the course of her bipolar. Our survey results demonstrate this clearly:

- Some women told us about repeated severe episodes triggered by their menstrual cycle that landed them in hospital
- 75% said their menstrual cycle affected their bipolar symptoms to some extent
- 17% said their menstrual cycle affected their bipolar symptoms significantly

This mother told us the experiences of her daughter:

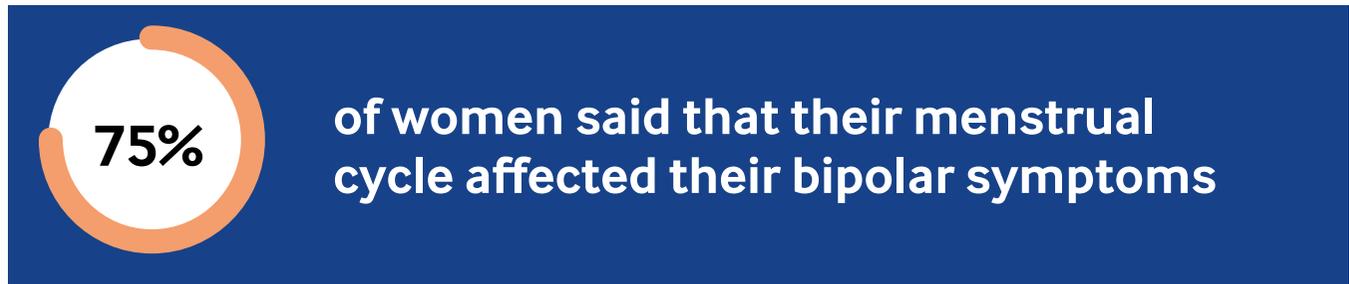
“ She was sectioned after starting a new stressful NHS job, ... her relationship broke down and she became unwell and hypomanic. She went back into hospital 3 times after becoming first ill.... We paid privately to see a female doctor who specialised in woman's health and hormones, who clearly showed me that my daughter's episodes were being triggered by the change in hormones as the menstrual cycle begins. It suddenly made real sense. **JB**

For the women affected, this is not an occasional problem:

- 52% said it's happening often
- 30% said it's happening every month
- More than a third - 37% - said they haven't told their doctor about it

Lack of understanding about the interaction of hormones and bipolar was cited as a reason for not seeking medical help, as this respondent said:

“ No one has admitted to me that my diagnosis of bipolar was anything to do with hormones!! But I believe it was ALL to do with hormones. Sectioned aged 40 years in a psychosis having a period. Sectioned another two times having a period. **HH**



Childbirth

The time of life when a woman with bipolar is at highest risk of having a severe episode which could endanger her life is when she gives birth, specifically in the first few days and weeks afterwards⁹⁹. However, in our survey, 45% of respondents did not know this fact. Even more worryingly, 75% of them did not know they were entitled to preconception advice from a specialist perinatal psychiatrist.

This is shocking considering the campaign that has been waged for the last ten years (by Bipolar UK and other charities, notably APP - Action on Postpartum Psychosis and the Maternal Mental Health Alliance which brought together the relevant Royal Colleges to shine a light on the huge gaps in necessary specialist treatment for women with perinatal mental health issues). There is still a huge job to do to raise awareness among GPs and other health professionals about the perinatal services available.

With mental health services configured as they are currently, women with bipolar do not see a psychiatrist regularly but are discharged from secondary care if deemed 'well enough' at a particular moment in time. This 'episodic' model of healthcare does not suit a fluctuating mood disorder which can be triggered by a myriad of different things, including hormonal changes over the course of a lifetime.

Continuity of care is essential

A woman can start experiencing debilitating symptoms which have a significant impact on her job and home life with no one with any mental health knowledge to turn to. The sooner she gets specialist help, the better yet less than 40% of people with bipolar tell us they think GPs are knowledgeable about the condition. This is not to criticise GPs, who are overburdened and not trained in this area. It is vital that women with bipolar have continuity of care from a specialist who understand the nuances of the condition and their specific needs. This is why the Bipolar Commission is calling for a named psychiatrist for everyone with bipolar.

Recent research done in the UK¹⁰⁰ suggests that women who experience mood worsening at one reproductive cycle event are more likely to experience such symptoms at other events. If replicated and confirmed, this could be important information for women with bipolar who are sensitive to monthly hormonal changes as it may be a significant clinical indicator of risk at times like childbirth or menopause which could trigger an episode of severe illness. Similarly, women who suffer a postpartum psychosis should be warned that the perimenopause could trigger a serious episode after years of being well.

“ I track my mood. It's very clear that 7 days before my period starts my mood is badly affected. I've tried to highlight this with my mental health nurse & psychiatrist. I feel it's been ignored or dismissed. **SP**



Menopause

Our survey asked women with bipolar about their experiences around menopause and it was worrying that only 35% of them knew that this could be a time of higher risk for them (and many of them said they only knew this through watching Bipolar UK's educational webinars). Of those in the relevant age bracket:

- over half - 55% - said perimenopausal or menopausal symptoms had impacted their bipolar
- 28% of those said the impact was significant
- a third (32%) said that, although they were experiencing symptoms linked to perimenopause, they had not been to their doctor about them.

The recognised treatment for menopausal symptoms is hormone replacement therapy (HRT)¹⁰¹ yet in our survey only 31% of women had been offered it. This is a serious missed opportunity as of those who are taking HRT, 64% said it had helped them, with 21% saying it was 'extremely effective'.

Lack of knowledge in primary and secondary care

Unfortunately, the majority of women told us that they received poor understanding and treatment from their GPs or other healthcare professionals as illustrated by this respondent:

“ Mum first became unwell with bipolar symptoms when she was 51 - triggered by menopausal hormone changes. Her GP prescribed antidepressants which triggered hypomania, mania and psychosis. **AS**

It is unsurprising, then, that 88% of women think that healthcare professionals need more training in this area. Professor Arianna Di Florio, a clinical psychiatrist and prominent researcher on women and mood disorders, gave evidence to the Commission and agreed that more training was badly needed:



I have designed and lead an optional module on the effects of reproductive events on the brain for medical students. My students are always surprised by the multiple links between reproduction and the brain and believe that the module should be compulsory to all medical students – as the content is not covered elsewhere in the curriculum.

Similarly, in my clinical practice – I lead a UK-wide women's mental health second opinion clinic – I know that many of my colleagues have not received adequate training on the effect of reproductive events beyond childbirth (for example the effect of the menstrual cycle and reproductive aging) and on more severe conditions such as bipolar disorder. Probably, such lack of training opportunities, and consequent lack of awareness, reflects in part the severe lack of research evidence in this area, sustaining a vicious circle of poor information and stigma.

Professor Arianna Di Florio



Professor Di Florio also pointed out that, observed from her clinical experience, hormonal fluctuations could interfere with the effectiveness of psychiatric medications. This is also backed up by the small amount of research that exists (for example a 2019 review showed a close relationship between premenstrual exacerbation of mood symptoms and a significant decrease in lithium levels in the days before having a period in women with bipolar – despite stable oral doses¹⁰²). Again, research on this issue is badly needed.

Parenting issues

Stigma is a particular problem for women: not only are they stigmatised for having a severe mental illness, they are further stigmatised if they are a mother with mental illness or want to be. In our survey 47% said they worried that people would judge them for wanting to be a parent with bipolar.

“ As a single parent, once I was diagnosed, I was terrified I would lose my daughter, because I had a diagnosable mental illness. I felt a lot of judgement from society about being a single parent, and enormous pressure to mask symptoms and appear stable and competent. This pressure has brought on episodes of bipolar depression. **TK**

We also found examples of the how societal stigma against discussing 'women's problems' such as menstruation and menopause has meant that women's real suffering is not being addressed. Although there have been advances in reducing societal stigma against mental health issues (particularly anxiety and depression) over the last few decades, evidence given to the Commission demonstrates that there remains very little understanding of the unique symptomatology of bipolar and the particular ways in which it impacts women.



Hypersexuality

Another matter which affects women with bipolar more than men is their greater exposure to domestic violence and sexual assault¹⁰³. When someone is experiencing a manic or hypomanic episode, their sex drive is often heightened, causing them to behave in an uncharacteristically sexualised way. Another common symptom of this state is a greater inclination to take risks and to feel extremely outgoing and keen to express love for everyone around them.

For women, especially in their teens and twenties before they get a diagnosis or any treatment for their bipolar, this can make them extremely vulnerable to being sexually exploited and abused. Our survey was the first time any evidence on the extent of this problem was gathered and it provoked a heartrending outpouring of distress, shame and guilt at how hypersexuality linked to an episode of bipolar illness had sometimes had dreadful consequences for them.

A worrying 64% of women told us they had had periods of hypersexuality and many reported sexual assaults, unplanned children, vulnerability to sexually transmitted diseases, upsetting abortions and relationship and marriage breakups as a result.

One respondent said her hypersexuality had caused:

“ relationship breakdowns, unwanted abortions and sexual abuse, being vulnerable, also drinking heavily when I don't usually. TK

Many women spoke of the shame and guilt they suffered long afterwards as a result of this completely uncharacteristic behaviour; psychological damage that they felt unable to talk to anyone about. Research is needed to confirm the extent of this problem so it can be acknowledged by health professionals and taken into account in treatment plans so that women are able to shed the harmful burden of self-blame and shame.

In conclusion, the Commission's gathering of evidence on how bipolar uniquely impacts women has revealed a disturbing picture of suffering and stigma and a yawning gap in the NHS treatment of these issues.

What women with bipolar need:

✓ More research

Hormonal fluctuations seriously impact the course of bipolar in women and yet minimal research has been done in this area, either on the effects of the menstrual cycle, pregnancy and childbirth or on perimenopause and menopause. As a result, health professionals do not recognise and treat these problems adequately and, due to widespread self-stigma, women themselves are reluctant to ask for help.

✓ Better training

All psychiatrists, GPs, mental health teams, midwives and social workers need to understand the needs of women with bipolar, and this needs to be underpinned by high-calibre research.

✓ Better information

Giving women information when they are first diagnosed means they can be aware of possible triggers and how to avoid or prepare for them.

✓ Anti-stigma campaigns

Encouraging understanding of severe mental illness and so-called 'women's problems' like menstruation and menopause means women will have the confidence to ask for the help they need.

Women with bipolar who have periods of hypersexuality



Appendix 2: The economic impact of bipolar



By Professor Paul McCrone, Professor of Healthcare Economics at the Institute for Lifecourse Development (University of Greenwich)

As highlighted in the main report, a landmark study by the London School of Economics found that bipolar cost the UK economy about £20 billion in 2019 - 17% of the total burden of mental illness¹⁰⁴.

This appendix looks at the economic impact of this headline statistic on society generally, individuals, their families and the NHS. It also includes early analysis of two online surveys carried out by Bipolar UK and the University of Greenwich.

865 people with bipolar responded to survey 1

203 friends and family of people with bipolar responded to survey 2

The economic impact of bipolar on society

A team from the London School of Economics recently estimated the costs of mental health issues in the UK¹⁰⁵. Their report combined estimates for 11 mental health conditions (including bipolar) from the WHO Global Burden of Disease survey with the costs of care for these specific conditions.

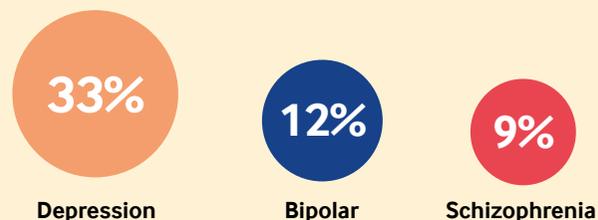
For specialist mental health care, it was not possible to determine the condition to which they applied and so the proportion of the disability burden due to each condition was used to apportion these costs.

Privately funded healthcare was excluded. Considering a third of survey respondents told us they pay for some healthcare costs associated with the condition, this means the figure must be an underestimate.

The report included estimates of productivity loss and informal care from family/friends. It also attached a monetary value to disability-adjusted life years (DALYs) caused by each condition. A DALY is a measure of overall condition burden, expressed as the number of years lost due to ill-health, disability or early death.

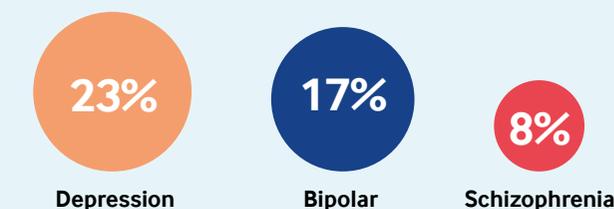
The report found that bipolar accounted for 12% of mental health DALYs, compared to 33% for depression and 9% for schizophrenia.

Mental health DALYs



The total cost of bipolar for 2019 was estimated at £19.7 billion, compared to £9.4 billion for schizophrenia and £26.3 billion for depression. The most comprehensive and up-to-date study on the economic burden of mental illness, it included the cost to the NHS, productivity lost and lost quality of life.

Total burden of disease for mental illness



The cost of bipolar shows no sign of diminishing

Previous estimates of the burden of disease for bipolar used different methods with a more restricted range of costs. These have been reviewed by Sabes-Figuera et al (2010)¹⁰⁶ and Jin & McCrone (2015)¹⁰⁷ who identified a number of studies which report on mental health costs to the UK.

Das-Gupta & Guest (2002)¹⁰⁸ estimated that the total costs of bipolar in 1998 were £2.1 billion (around £3.3 billion in 2021 prices). Of this amount, 86% of £2.1 billion was due to lost productivity costs. McCrone et al (2008)¹⁰⁹ estimated costs in 2007 of £5.2 billion (£7.1 billion in 2021 prices), with 69% due to lost production.

In another study, Young et al (2011)¹¹⁰ estimated the healthcare costs of bipolar to be £342 million in 2009/10 prices (around £441 million in 2021 prices).

Even at its lowest and most restricted methodology, bipolar is consistently shown to place a significant burden on society and shows no signs of diminishing.



NHS costs

Bearing in mind it's estimated that 56% of people don't have a diagnosis¹¹¹, that the HES data may seriously under-record bipolar and that much care is provided out of hospital, the latest figures from NHS England on the costs of bipolar could potentially be significantly higher:

- In 2019/20 there were 6178 admissions to hospital in England where the primary diagnosis was mania or bipolar. The cost of these admissions was about £114 million¹¹²
- In 2020/21 there were 11945 outpatient appointments for people with a primary diagnosis of bipolar. This suggests a spend of around £1.6 million¹¹³
- In 2020/21, there were 4876 A&E visits where the primary or secondary diagnosis was bipolar with a cost of about £890,000¹¹⁴

Both diagnosed and undiagnosed bipolar put an enormous burden on primary and secondary care

The cost of relapse

The healthcare cost for someone who has had a relapse has been estimated by Hong et al at £4083 over six months compared to £1298 for someone without a relapse¹¹⁵. These are 2007/8 figures and inflate to £5553 and £1765 now (so an excess of £3788). At least 50% of people with a bipolar diagnosis relapse each year, costing the NHS up to an estimated additional £1 billion per year.

The cost of suicide and suicide attempts

In 2020 there were 5224 deaths by suicide in England and Wales¹¹⁶. It is estimated that 5-10% of these were by people with bipolar (between 261 and 522 people)¹¹⁷.

The cost of suicide includes the service response (which is relatively low), potential lost production, and the value of the emotional distress to loved ones. Estimates of around £1.6 million lifetime costs have been reported¹¹⁸. This indicates costs of about £436m-£872m for bipolar related suicide.

The economic impact of bipolar on individuals

865 people with bipolar responded to the first 'economic impact of bipolar' survey. The average age of respondents was just under 50. This is older than the national average age and the estimated population profile of people living with bipolar in the UK – the Adult Psychiatric Morbidity Study¹¹⁹ (APMS) in 2014, found that of the 2% of the UK population aged 16 and above who were living with bipolar young people were significantly more likely to screen positive than older people: 3.4% of 16 – 24-year-olds screened positive compared with 0.4% of those aged 65 – 74.

70% of survey respondents were female. The disproportionate number of females needs to be considered in the subsequent analyses as it is known that there are gender differences in other variables such as use of primary care services. Most respondents (93.3%) identified as being of white ethnicity. This is higher than the average for England and Wales of 84.8%¹²⁰.

Just over a quarter (27.5%) of respondents self-reported they had type 1 bipolar and just over a third (34%) had type 2 bipolar. More than a quarter of respondents (27.7%) said they did not know which type of bipolar they had, which makes this variable hard to interpret.

On average, respondents had first been diagnosed over 10 years previously. The earliest year of diagnosis was 1970 and the most recent was 2022. Slightly more respondents were married (39.1%), in a civil partnership (2.8%) or widowed (2.4%) than were single (31.8%).

The proportion who told us they were divorced (14.7%) was nearly double the average for England¹²¹ (7.8%)

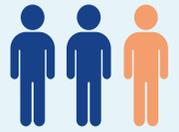
Bipolar, work and money

Reflecting the high burden of disease for bipolar, one quarter of survey respondents with bipolar listed welfare benefits as their main source of income.

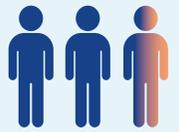
The average amount of money lost due to unemployment among the sample was high. The average was over £100K and this was after excluding an extreme outlier.

Other work-related impacts due to bipolar:

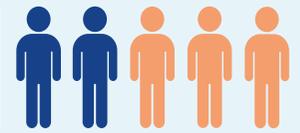
Nearly two-thirds (63%) of the respondents had experienced job loss



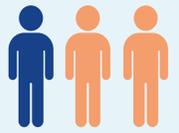
More than two-thirds (72%) had not applied for a particular job



Over two-fifths (44%) hadn't applied for a promotion



Just over one-third (35%) felt that they had been overlooked for promotion



Nearly three-quarters of respondents had been to college or university which is higher than the national average of people with an NQF 4 qualification or higher¹²². But it is notable that one-third of people had left university early.

Just under half (47.3%) of respondents were employed or self-employed. This is relatively high compared to other studies of serious mental illness, especially given that 11% were retired due to age.



In spite of this above-average proportion of people who had been to college or university and relatively high number of people in work, the most common level of income was between £10,000 and £20,000 per year. The average income in the UK in 2020 was £29,900¹²³ according to the Office of National Statistics. This suggests bipolar causes people to earn substantially less each year than the average.

Usually, university attendance correlates with higher earnings as a graduate. With high college and university attendance and active participation in the workforce, why do people with bipolar report such low income?

Although it's a subjective assessment, a very high proportion of respondents stated that their earning potential was negatively affected by having bipolar, with only 3% reporting a positive impact.

This negative impact makes sense when you consider the overwhelming cost of bipolar being attributed to lost productivity. It is unlikely that people with recurrent sick days and time off will be positively considered (or put themselves forward) for bonuses, raises and promotions.

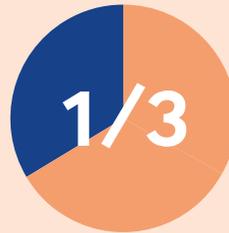
Income and expenditure

Other findings are also worrying given the disproportionately low income and high burden of the condition reported amongst respondents:

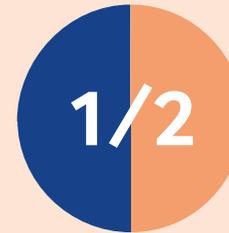
- Around 40% of respondents had to pay for their own prescriptions
- The majority of respondents hadn't applied for a Personal independence payments (PIPs) and one in ten people had applied but had been unsuccessful. Only one-third of people had applied for it successfully, although some of these people had had to apply more than once. These payments were brought in by the government to help people with mental or physical health problems cope with everyday living costs.
- Nearly three-quarters of the sample were not aware of the government's Access to work scheme and only 7% had actually used it. This is a scheme to support people with a mental health condition in the workplace.

Further information on barriers to available support systems would be of particular interest following this study.

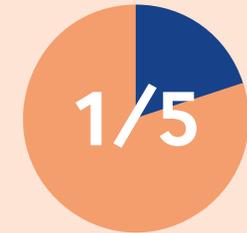
When they're hypomanic or manic, people with bipolar tell us they often buy things they don't need and later regret



One-third did not have any savings



Just under half the sample had some form of debt



One-fifth of respondents reported out of control debt

“ Being hypomanic feels like I'm plugged into the national grid as I have so much energy and an overwhelming compulsion to buy everything - more books and DVDs than I could ever read or watch and loads of clothes I'll never wear. **CT**

“ I've always struggled with money and have never been able to stop my compulsive spending when I'm manic. **SL**

Home ownership

- More than half of respondents owned their property (either solely or jointly)
- More than one-quarter no longer had a mortgage

It's worth noting, however, that respondents to this survey were more likely to be older white women, whose experience may not be representative of people with bipolar overall. We know younger people, for example, are facing difficulties with home ownership, and it is unlikely that a study responded to by a younger demographic would show such stability with home ownership, mortgage and pension savings.

- 12% been made homeless because of their bipolar
- 15% of respondents had lost their home due to bipolar

This again suggests that the high number of homeowners among this sample may not be representative of the wider bipolar community.



Money worries are both caused by and compound bipolar

When asked about triggers for relapse in an earlier survey for Bipolar UK, nearly two-fifths (39%) of respondents told us money worries and nearly one in five (19%) told us that housing issues had been factors. When you consider that these triggers are both caused by and compound bipolar – for example, the stress of unwanted debt accumulated during a manic episode may make another episode more likely – it becomes easy to see how the burden of disease for bipolar is so high.

What healthcare services are people with bipolar using?

It is important to note that we measured the use of healthcare services, but that having bipolar was not necessarily the direct reason for this use. The Health Survey for England produces information on use of GPs¹²⁴. Compared to the general population, survey respondents with bipolar were more likely to have some GP contacts compared to the general population with between six and ten contacts. The majority of respondents with bipolar had seen a GP during the past year with an average of four appointments.

The Understanding Society survey collects information on the use of hospital services¹²⁵. Inpatient use in our sample was 11.6% and this is only slightly higher than in the population (9.1%). In our sample, 63% of the sample had contacts with psychiatrists, other doctors, or both. This compares to 43% of the general population having hospital clinic visits.

40% of survey respondents would like funding for a personal trainer to support them to stay well physically

What healthcare services do people with bipolar want?

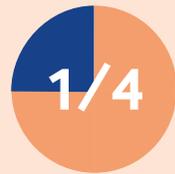
The services that were desired most were GP care and support from psychiatrists. The level of GP care provided and desired was similar, but there appears to be a gap in the provision of care by a psychiatrist. Other services that were seemingly underprovided were psychologist support, complementary healthcare, group therapy, weight loss clinic, day centre, and physiotherapist support. We did not ask how many people had contact with a personal trainer, but it was desired by 40% of the respondents. Considering the impact of bipolar on a person's lifestyle, and that medication side effects often include weight gain, this is not surprising.

The cost of care¹²⁶

The total cost of care over the year was £3907 on average. The most expensive service was inpatient care (despite its relatively low use), accounting for 37.6% of costs. By comparison, GP costs accounted for 3.6% despite the high use of this service.



More than a half of survey respondents had seen a psychiatrist



One-quarter had seen a counsellor



One third were in contact with a community mental health team



One third were in contact with a mental health nurse



When my son had a serious manic episode in 2019, the family wasn't aware that the cause of his behaviour was bipolar because he didn't yet have a diagnosis. He owned his own house, and it was on that basis that we believe the banks provided finance for the purchase of TWO cars, which he bought from the same dealer only three days apart. They set up finance deals with two separate banks – at a total cost of nearly £1000 a month – based on a 48-month repayment scheme.

George also attempted to sell his house, which would have provided him with several hundred thousand pounds, which he would have squandered in weeks. I was so worried about the situation, I persuaded the solicitors he approached to act on his behalf to decline his instruction, which thankfully they did.

His borrowings with his own bank had reached significant levels, which were attracting costly interest rates. Although at the time he was behaving really out of character, I persuaded him to let me go to his bank with him and I paid off his debt, which was just over £13,000. I also got him to agree to ask the bank to block another overdraft facility.

Had the family known at the time that all these decisions were due to manic spending because he was unwell with bipolar, we would have been far more prepared to help my son not to get into these situations in the first place!

The stress and anxiety placed on the family at that time was extreme. We are lucky that in all the circumstances mentioned above, we were able to get my son out of the financial commitments he made, but we realise that so many people aren't as fortunate. **PA**



The economic impact of caring for someone with bipolar

203 people who care for someone with bipolar responded to the second survey. Ages ranged from 20 to 89, with an average age of 57.1. Nearly 70% were female, correlating with the higher number of women who take on the role of 'informal carer' in society generally. Interestingly, only 46% of people they cared for were female, suggesting that men are more likely to receive informal care than women. The average age of the person cared for was 44.7. Nearly two-thirds of carers were married.

Work and money for loved ones

Beyond the individual with a diagnosis, there's a substantial financial impact on the families of those with bipolar. Just over one-fifth of survey respondents were retired due to age and over half were either employed or self-employed. Few carers were only in receipt of benefits, but around one-third had incomes below £20,000 and 40% of survey respondents reported reduced earning potential because of their loved one's bipolar:

- Nearly one in 10 (9.5%) had lost a job
- One in four survey respondents had not applied for a particular job
- Nearly one in five (18%) had not applied for promotion
- A small but significant number (4.5%) felt they had been overlooked for a promotion

In the previous year, respondents took an average of 11 days off sick each year (almost twice the national average¹²⁷) and the number of days lost from work due to caring for someone with bipolar was an average of 6.7. However, the number of lost leisure days due to caring for someone with bipolar was on average 49.8 – almost one day a week.

A huge number of survey respondents (87.2%) self-reported that their mental health had been adversely affected due to caring for someone with bipolar. These findings are worrying, suggesting that carers do not take leisure days for holidays, instead using them to manage their caring responsibilities, which is taking a toll on their mental health.

Five respondents to the survey told us they had lost their home due to their caring responsibilities and two respondents told us they had been made homeless.

In terms of education, nearly 7 in 10 carers (69.6%) had been to college or university. Similar to those with bipolar, it appears that carers are also disproportionately underpaid when their level of education is considered.

The use of healthcare services for carers

The use of services and associated costs were also measured. As with people with bipolar, carers had frequent appointments with GPs with an average of 3.6 a year. The other most frequently used services were practice nurses, counsellors and other doctors. Counsellors were the service with the highest costs, and this is likely to reflect the high rate of mental health effects associated with caring responsibilities. The total costs for carers were £1339 over the year.

Effective management of bipolar would be a huge boost to the economy from all angles.

In conclusion, having reviewed the most up to date studies on the costs of bipolar, I found the figures from the most comprehensive study on the burden of mental illness by the London School of Economics particularly stark. It is substantially bigger than the burden for schizophrenia (which itself is huge) and comparable to depression.

That burden is brought home by our own research which shows how many people with bipolar had lost their job, not gone for promotion or been made homeless by the condition. Both the quantitative and qualitative research highlights the enormous economic and productivity boost of providing effective support and treatment for everyone living with bipolar.

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