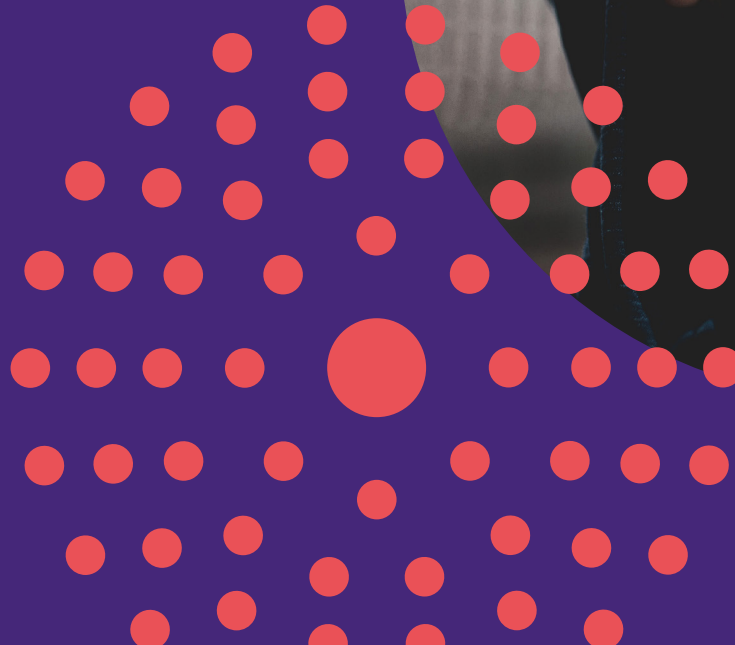
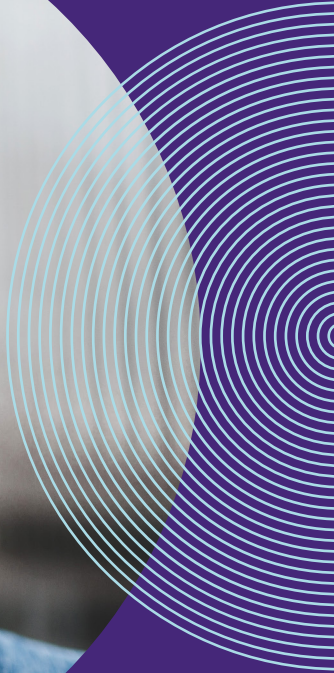
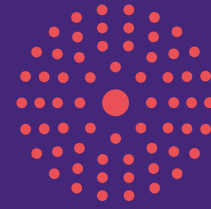
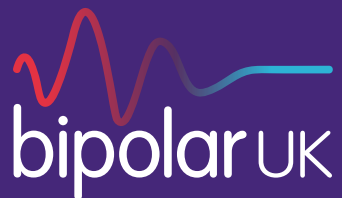


# A continuing crisis

The impact of Covid-19  
on the bipolar community.

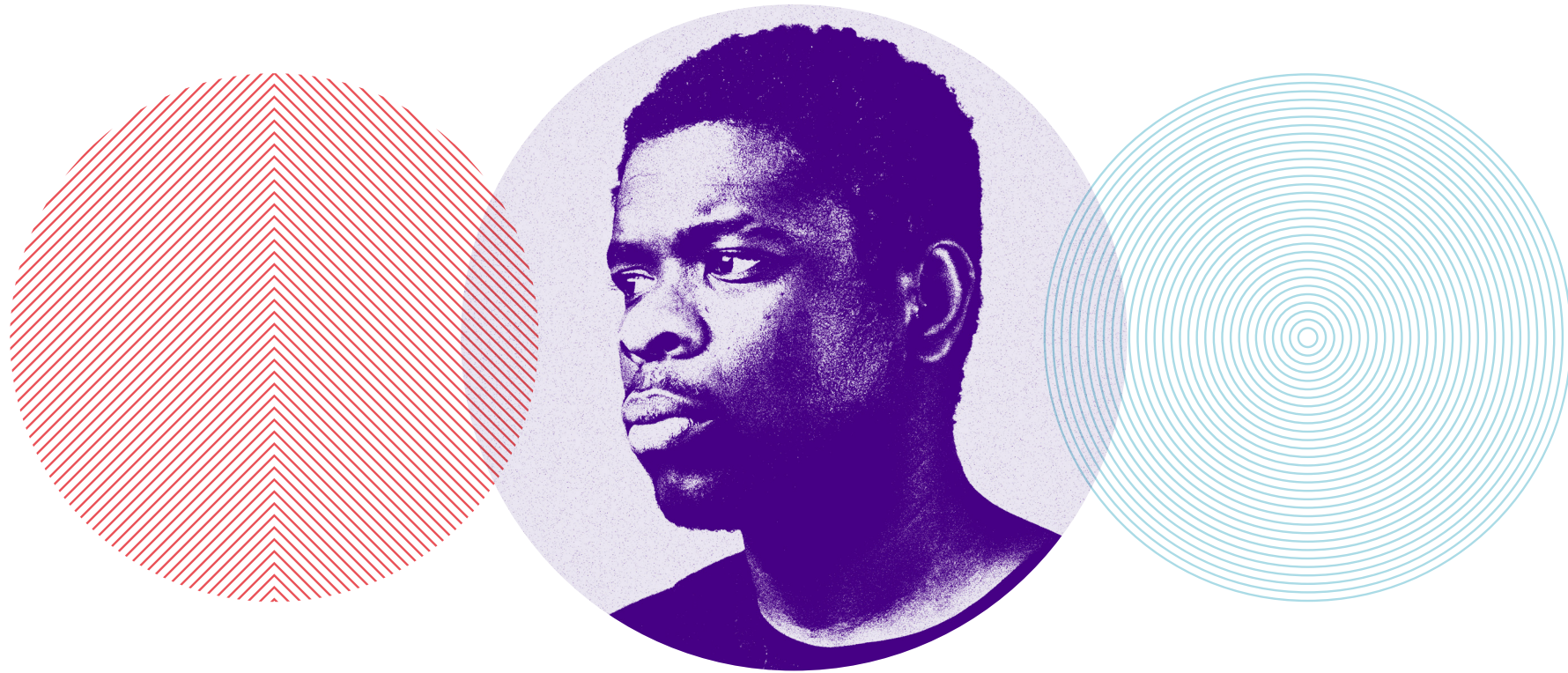
December 2020





I had Covid-19 when I was actively suicidal and everything seemed to be a darker shade of black. I fought for my life.





Bipolar is a severe, long-term mental illness. To assess the impact of Covid-19 on the bipolar community, Bipolar UK originally conducted an online survey between 30 April and 13 May. We received 1,751 responses from our community. A follow-up survey from 7 November to 26 November received an additional 1,096 responses. The surveys asked questions ranging from access to services, to the specific ways in which people's mental health has been affected.

# A summary of our findings.

## From spring to autumn 2020.

### **Mental health is deteriorating. Suicidal thinking is increasing.**

Respondents reported significant increases in depression and anxiety. Almost half said they had relapsed since March 2020.

30.97% reported an increase in suicidal thoughts, 4.03% had attempted suicide during the pandemic and 2.6% had been hospitalisation for suicide attempts. 9.16% have self-harmed.

### **Hospitalisation low but exposure high**

Less than 1% of respondents required hospitalisation for Covid-19.

Wider exposure was higher with 22% of respondents believing a close family member or friend had contracted the virus. Of these, 5% said the acquaintance had died as a result.

### **The mental health crisis is driven by three factors:**

#### **1. A fear of the virus**

Almost half of respondents (47%) said their biggest worry was catching the virus.

#### **2. The challenge of self-managing**

69% said it was harder, if not impossible, to avoid triggers.

#### **3. Reduced access to mental health services**

15% said it was still impossible to access their psychiatrist.

When those without support pre-Covid-19 are factored in, almost a third of respondents were without any clinical mental health support.

### **Christmas fear**

Within our survey, five times as many people affected by bipolar are dreading Christmas compared to those that are excited for it.

While a staggering 36% aren't bothered or are indifferent, suggesting Christmas cheer won't provide a pick me up.

### **Conclusion**

The pandemic has had a severe impact on mental health.

More than five times as many people affected by bipolar have been hospitalised for suicide attempts as for Covid-19 itself over the last eight months.

The sustained dips in mood, high levels of relapse and continued increases in suicide attempts and completions suggests that the mental health impact of Covid-19 poses a risk comparable to the virus itself.

As such, it demands a similar level of response.

# Recommendations.

## A proportionate response.

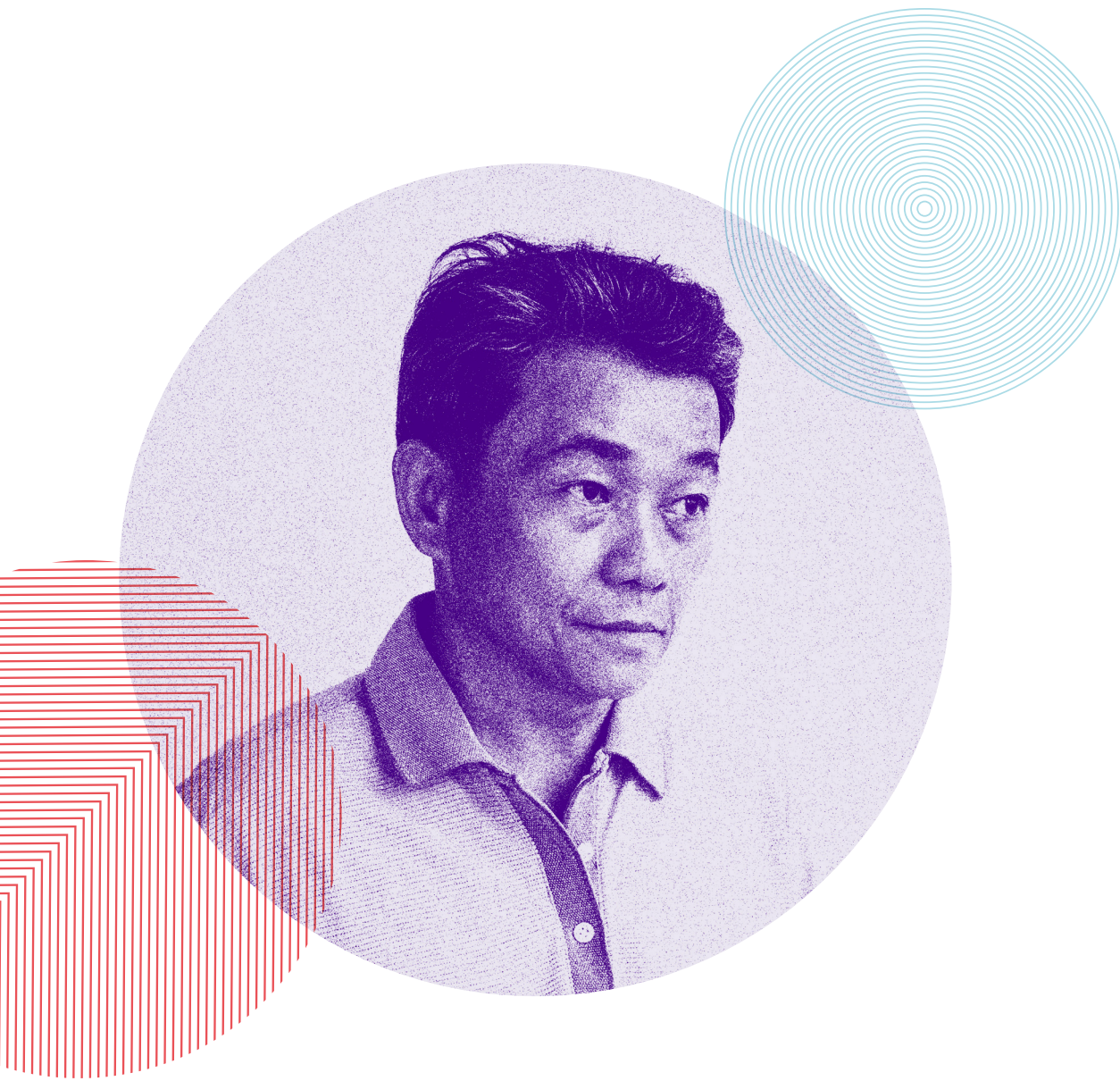
The response to the mental health crisis caused by the pandemic needs be proportionate to the scale of the pandemic itself.

### Immediate priorities

- Everyone with a bipolar diagnosis is written to by their GP about the risks of relapsing during Covid-19, providing advice on staying well and signposting to Bipolar UK. All aligned with existing communications to save time and money.
- Increased access to specialist mental health services so everyone who needs support can find it. This needs to include those who are struggling to stay well but aren't yet in crisis.
- To conduct further research into access to services and treatment for people living with bipolar to investigate whether these findings are representative of everyone living with bipolar.

### Longer term priorities

- Improve diagnosis rates to empower people seeking out knowledge and support. Separating bipolar from other serious mental illnesses in the Quality Outcome Framework could help facilitate this.
- Ensure that specialist bipolar services are included within the new integrated primary and community model.
- Integrated Primary and Community Mental Health Teams to invest in psycho-education courses for everyone with a diagnosis, helping everyone with bipolar to develop tools for effective self-management.
- Expand the use of personal health budgets for mental health so people with bipolar can access the support they need, when they need it.



## Bipolar is a severe, long-term mental illness.

It's characterised by significant mood swings  
— from manic highs to extreme lows.

One in fifty people live with the condition.  
This equates to over a million people in the  
UK alone.

Having bipolar increases the risk of suicide by  
10 to 30 times the average<sup>1</sup>.

<sup>1</sup> Bipolar disorder does increase the risk of suicide by approximately 20 times that of the general population (e.g. Pompili M, Gonda X, Serafini G, Innamorati M, Sher L, et al. (2013) Epidemiology of suicide in bipolar disorders: a systematic review of the literature. *Bipolar Disord* 15: 457–490).

# A second survey. An ongoing crisis.

To assess the impact of Covid-19 on the bipolar community, Bipolar UK originally conducted an online survey between 30 April and 13 May. We received 1,751 responses from our community.

A follow-up survey from 7 November to 26 November received an additional 1,096 responses.

## Who did we survey?

Over 90% of respondents to both surveys are living with a diagnosis. It takes on average 8 years to get a bipolar diagnosis meaning thousands of people with the condition miss out on treatment and support<sup>2</sup>. The remaining 10% either do not have a diagnosis but believe they may have bipolar (2%), or are close family or friends completing the survey for someone who was too ill to do so themselves (8%). (See Q1 below.)

As the survey was distributed through the Bipolar UK website and eNewsletter, it was subject to a self-selection bias.

The respondents skewed older (average age was 51 years old), female (67% of respondents), more likely to have a diagnosis and some awareness of the condition, and a better understanding of health services available to them by virtue that they have accessed our services already.

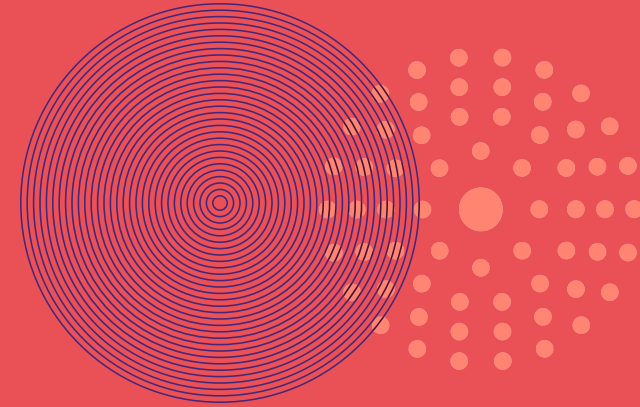
## What did we ask?

A wide range of questions – from access to services, to the specific ways in which people's mental health has been affected.

<sup>2</sup> Improving diagnostic delays in bipolar disorders in clinical practice.  
<https://onlinelibrary.wiley.com/doi/full/10.1111/bdi.12827>

# Impact of Covid-19 on people affected by bipolar.

## The full report.



### Exposure to Covid-19

The direct physical impact of the virus on people living with bipolar remains relatively low, compared to its wider impact on mental health.

Eight months into the pandemic, only 14% of respondents described having had symptoms, with 2% having had a positive test. Less than 1% had required hospitalisation. Though this doesn't take into account the members of our community who have contracted the virus but were asymptomatic and not tested.

Wider exposure through the network was high, with 44% believing they knew someone who had contracted Covid-19. This included 22% of respondents who believed a close family member or friend had caught the virus.

### Covid-19 fatalities

Sadly, 17% of people knew someone who had died of Covid-19, including 5% of respondents who had lost a close family member or friend.

These high losses could be due to the older demographic of the respondents, though it still represents a tragically high figure.

For those affected by bipolar, the stress and anxiety brought on by exposure to cases and the loss of loved ones is an additional trigger to a population already at high risk of relapse.

# A devastating impact.

## Our Mood Scale assessment.

To assess peoples' mental health, the survey used the Mood Scale developed by Bipolar UK to help people track their moods.

The scale ranges from extremely low mood (recurring suicidal thoughts) at 0 through to extremely high (mania, psychosis, hallucinations) at 10 (see Q3 below). The midway figure 5 indicates a balanced mood. People not living with bipolar, and people effectively managing bipolar, tend to rate their mood as 4 to 6.

The first wave of the survey was shortly after the first lockdown period, so participants were asked to retrospectively rate their mood. This included pre-crisis (early March), early crisis (late April/early May) and then, as part of the second survey, as restrictions were heightened across the UK throughout autumn.

The second survey also coincided with positive announcements of several new vaccines that could combat the virus.

### Our findings

Since spring 2020, respondents' moods had improved slightly but remain significantly worse than pre-Covid-19 levels.

The number reporting being in the balanced mood range (4-6) initially fell from 69% to 42% during the first lockdown. This has now risen back up to 52%. This still suggests that around 48% of people living with bipolar might now be unwell and require additional support.

This is reflected in a follow-up question where an astonishing 47% of respondents confirmed that they had relapsed over the last eight months (see Q6).

In starkest terms: these findings suggest over half a million people living with bipolar either have or are at high risk of relapse and hospitalisation. This puts enormous pressure on individuals, families and the NHS

# An increase in suicide and self-harm.

Suicide ideation remains high and is having a devastating effect. Of the 1,484 respondents who agreed to answer questions on the topic in spring 2020, and the 917 who answered in the follow up survey in the autumn, 30.97% reported an increase in suicidal thoughts since the pandemic started in March (see Q7 below).

While that figure remained static in both surveys, the sustained impact of those suicidal thoughts is destroying lives. The number of people who have attempted suicide has increased from 1.15% to 4.03%. Those requiring hospitalisation for suicide attempts has increased from 0.61% to 2.62%. Family members completing the survey again reported four suicides, the same as in the spring but, alarmingly, with almost half the sample size.

While a major concern in itself, self-harm is often a pre-cursor to suicide. With this in mind, the number of respondents self-harming is worryingly high at almost 10%.

## Alarming rates

These numbers are higher than expected, even for people living with bipolar who already experience horrendous rates of suicide. Though it must be noted, identifying changes in the rate of suicide for the purposes of this survey is difficult because of the sample size. None the less, four reported suicides in an eight month period from a sample of 917 is judged to be extremely high.

The UK's Office of National Statistics (ONS) records approximately 11 suicides per 100,000 people in the general population in a given year<sup>3</sup>. Having bipolar increases the risk of suicide by 10 to 30 times. Best estimates therefore suggest that for every 100,000 people living with bipolar, 83 will tragically lose their lives to suicide every year.

With this sample size of just under 1,000, we would expect no more than one suicide in an entire year. Suicide was raised as a major concern when the first report was published in June 2020. It is clear from the follow-up survey that, since then, the situation has worsened still.

<sup>3</sup> <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesintheunitedkingdom/2019registrations>

# An escalating mental health crisis.

## Three key factors.

The mental health crisis being experienced by people affected by bipolar is being driven by three key factors: a fear of the virus, the increased challenge of self-managing during lockdown and reduced access to vital mental health services.

### 1. Fear of the virus

When asked what their greatest worry was (see Q8 below), almost half of those answering the second survey (47%) said that it was a fear of catching coronavirus itself.

This compares to 30% who were most worried about relapsing (experiencing a severe manic or depressive episode), 17% worried about the wider impact on the world, and 13% worried about the financial impact.

These are very similar to the figures in spring 2020, though worries about relapsing have increased.

Fear of the virus is understandable, given ubiquitous government messaging, the high fatality rate, and the number of fatalities within peoples' families and wider networks.

Respondents' attitudes to actions to stop the spread of the virus reinforce these notions. The vast majority were either in favour of the tough lockdown restrictions in November or pushing for tougher ones (see Q9). Only 20% have said they go too far, despite the extra burden it is placing on their mental health.

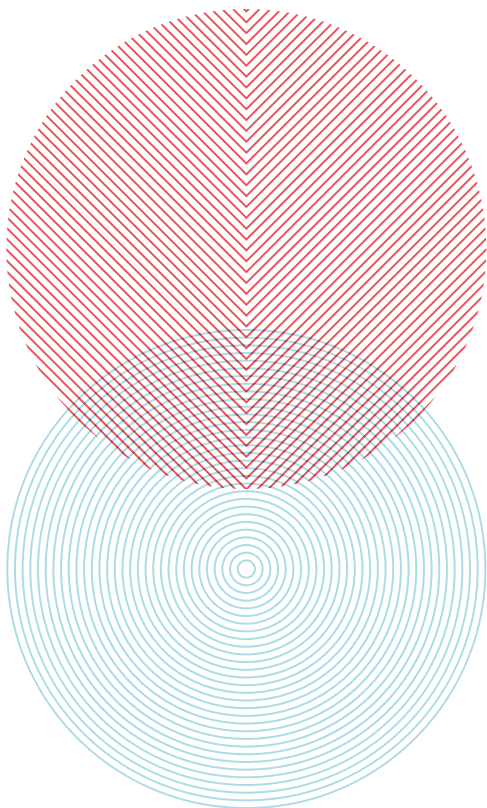
### 2. The challenges of self-managing

Effective self-management has become much harder during lockdown. Reducing the risk of relapse requires routine, sleep, mood monitoring, exercise, private time and space, medication, a good support network of friends and family, and the avoidance of triggers such as stress and over excitement.

Overwhelmingly, respondents say managing many of these factors has become harder, if not impossible (see below Q4C). 69% said it was harder or impossible to avoid triggers. Seeing friends and family was particularly difficult, with 23% saying it was impossible. This will likely contribute further to loneliness as people living with bipolar are more likely to live alone.

Mood is also harder to predict and monitor. Respondents were asked to rate from 1 'not at all' to 7 'very much so' different aspects of their mood and self-management routine (see Q5 below). Weighted averages for maintaining a routine have moved from 4.7 before the pandemic to 3.8 during it.

Anxiety has also played a part in driving moods to become more unpredictable. Perhaps not surprising given the fear of the virus, compliance with Public Health England guidelines on handwashing and social isolation came top with over 50% saying they very much followed it. In contrast, mood monitoring, a key self-management tool, came bottom with 64% saying they didn't do it at all.



### 3. Reduced access to mental health services

Accessing vital mental health services was difficult before Covid-19 and has been become significantly harder during the pandemic (see Q4A below).

Of those surveyed, 64% reported access to GPs, often the first line of defence against relapsing, was harder, much harder or impossible to access. Combined with those that didn't use a GP before, 11% didn't have any access to primary care during the pandemic.

Perhaps most worrying is access to specialist mental health services. Use of these services prior to Covid-19 was already low; but combining those that now find it impossible with those that didn't use them before Covid-19 makes for stark reading. Following the pandemic, 38% do not have access to a psychiatrist, 48% haven't got access to a community mental health team, and 56% haven't got access to a crisis team.

For hundreds of thousands of people the NHS has essentially ceased to exist when it comes to their mental health needs. These are the emergency mental health services needed to keep people safe during periods of suicidal thinking, hypermania and psychosis. This limited access will result in higher rates of suicide and worsening episodes.

Given the increased need and demand for support, it's disappointing that only less than 5% of respondents said they found mental health services easier to access – especially when considering the increased use of digital technology for communicating.

#### Access to medication

One area of hope has been around prescription medication. 61% of respondents said there was no change in being able to access medication and only 1% saying it was impossible (see Q4A below).

Additionally, 40% said there was also no change in being able to access or change their medication – a vital service when increased anxiety and poorer self-management meant changes to dosages are necessary.

Alongside this, almost 50% said there was no change in their continued ability to access information on self-management, though 20% didn't use it before the crisis.

#### The bigger picture

The huge discrepancies between access to primary and secondary care highlights both a historic and current underfunding of specialist mental health services and its static funding model. It underlines how unresponsive mental health services are to the needs of the community they aim to serve.

Contrast this to the ability of supermarkets, logistics and delivery companies which successfully scaled up their activity to respond to increased demand during the pandemic. Imagine if after eight months of the pandemic, 15% of customers still found it impossible to get an online food delivery as people currently state is the case for a psychiatrist.

And while training up a delivery drivers is a lot quicker than training up a psychiatrist, the pandemic suggests there is a long term skill shortages, an inability to surge capacity and structural barriers to innovating new service models.

That said, some mental health providers have evidently risen to the challenge and managed to do so and should provide inspiration to others.

#### Christmas fear

Within our survey, five times as many people affected by bipolar are dreading Christmas compared to those that are excited for it.

While a staggering 36% aren't bothered or are indifferent, suggesting Christmas cheer won't provide a pick me up.

# From here, where?

## Conclusion and recommendations.

With the sustained dip in mood, high levels of relapse and the continued increase in suicide attempts and completions, the mental health impact of Covid-19 poses a risk comparable to the virus itself. As such, a similar level of response is required

Despite more than five times as many people affected by bipolar being hospitalised for suicide attempts as for Covid-19 itself, the respondents maintain tough attitudes to lockdown.

This suggests that the risks of relapsing are underappreciated by people living with the condition. Isolation from friends and family, as well as a struggle to access vital services accentuates this further.

Our findings suggest that mental health services have essentially disappeared for hundreds of thousands of people affected by bipolar – at the exact time they need them most. It is no surprise that so few people affected by bipolar are looking forward to Christmas

# Recommendations.

The response to the mental health crisis caused by the pandemic should be on a scale proportionate to the pandemic itself.

## Immediate priorities

- Everyone with a bipolar diagnosis is written to by their GP about the risks of relapsing during Covid-19, providing advice on staying well and signposting to Bipolar UK. All aligned with existing communications to save time and money.
- Increased access to specialist mental health services so everyone who needs support can find it. This needs to include those who are struggling to stay well but aren't yet in crisis.
- To conduct further research into access to services and treatment for people living with bipolar to investigate whether these findings are representative of everyone living with bipolar.

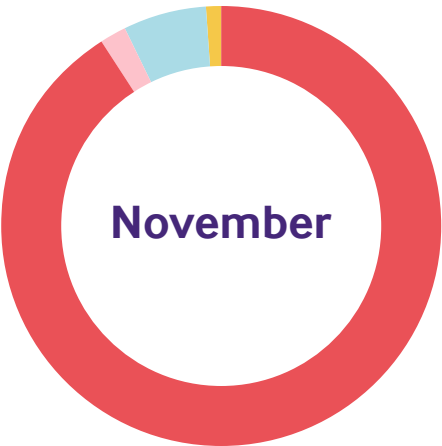
## Longer term priorities

- Improve diagnosis rates to empower people seeking out knowledge and support. Separating bipolar from other serious mental illnesses in the Quality Outcome Framework could help facilitate this.
- Ensure that specialist bipolar services are included within the new integrated primary and community model.
- Integrated Primary and Community Mental Health Teams to invest in psycho-education courses for everyone with a diagnosis, helping everyone with bipolar to develop tools for effective self-management.
- Expand the use of personal health budgets for mental health so people with bipolar can access the support they need, when they need it.

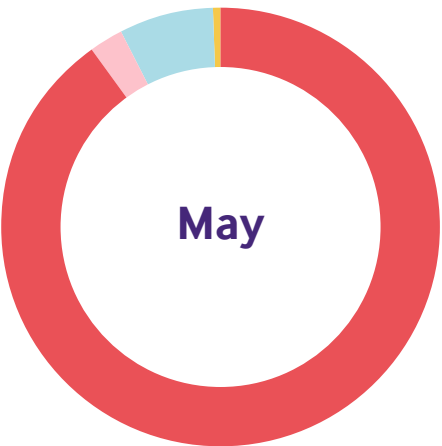
# Q1

## Are you living with bipolar?

Responses add up to over 100% because some respondents could tick multiple boxes



	Responses	1,092
<div></div> I am living with bipolar and have a diagnosis	91.94%	1,004
<div></div> I think I might have bipolar but I don't have a diagnosis	2.20%	24
<div></div> I have close friend or family member with bipolar	6.68%	73
<div></div> I think a close friend or family member has bipolar but they don't have a diagnosis	0.92%	10

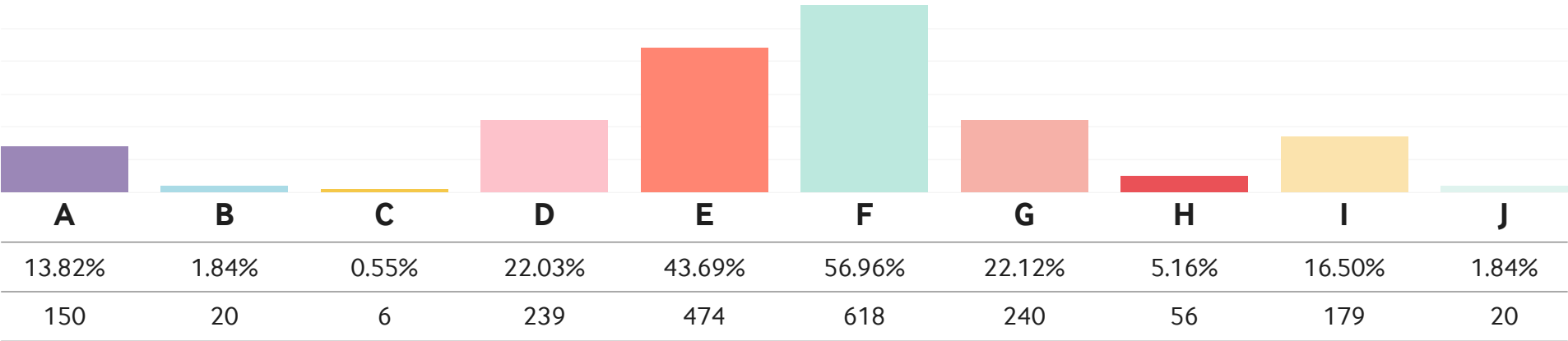


	Responses	1,744
<div></div> I am living with bipolar and have a diagnosis	90.19%	1,573
<div></div> I think I might have bipolar but I don't have a diagnosis	3.04%	53
<div></div> I have close friend or family member with bipolar	8.20%	143
<div></div> I think a close friend or family member has bipolar but they don't have a diagnosis	0.46%	8

# Q2

## Have you been affected by Covid-19?

Total Respondents: 1,085



- A - I have had Covid-19 symptoms
- B- I have tested positive for Covid-19
- C - I was treated in hospital for Covid-19
- D - I have had close friend / family member who has had Covid-19
- E - I know someone who has had Covid-19
- F - I have not had any Covid-19 symptoms
- H - I have a close friend / family member who has died of Covid-19
- I - I know someone who has died of Covid-19
- J - I have long term Covid-19 symptoms ('long Covid')

# Q3

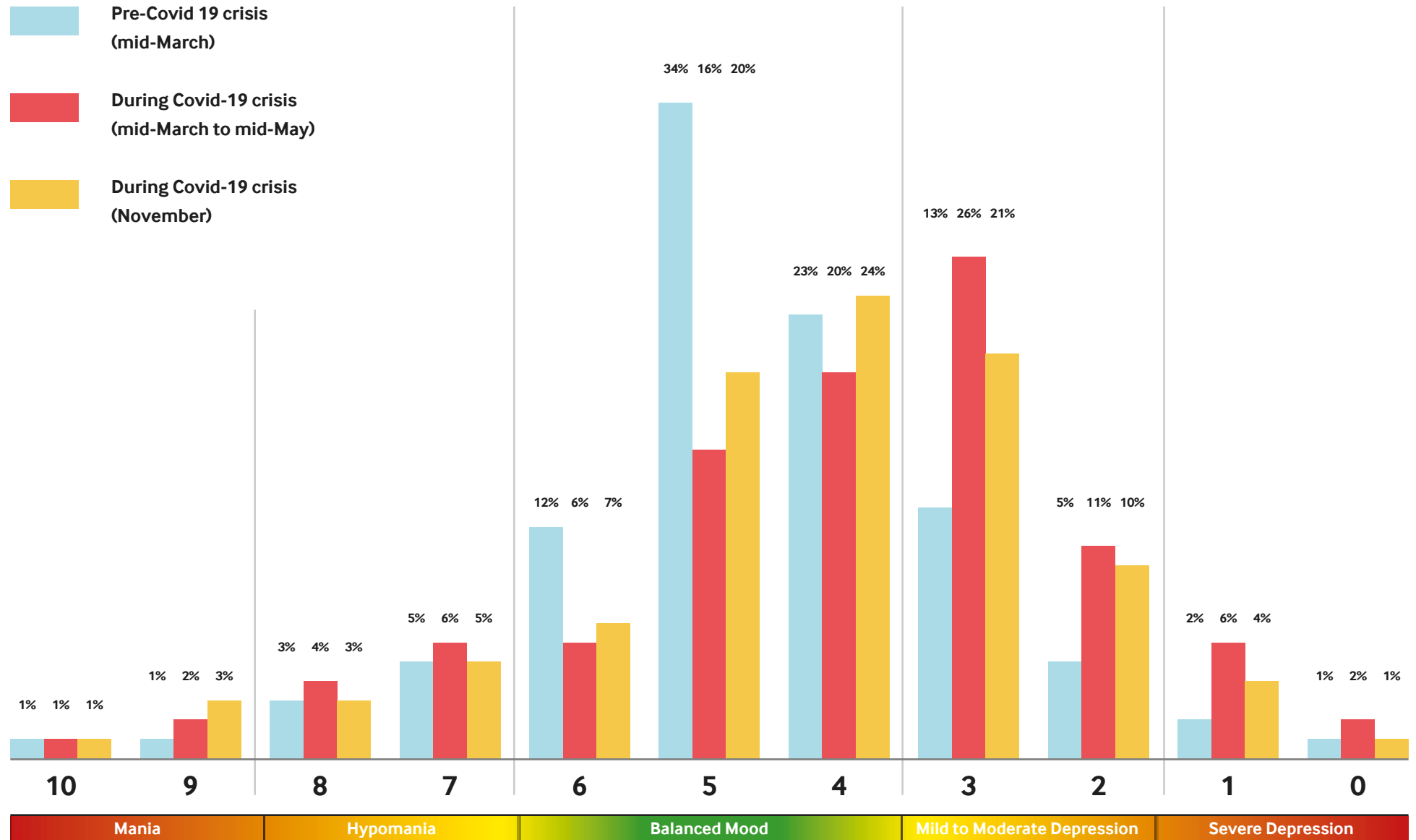
## Generally, where would you place your mood at the beginning of March (so shortly before the Covid-19 crisis and subsequent lockdown)?

### 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

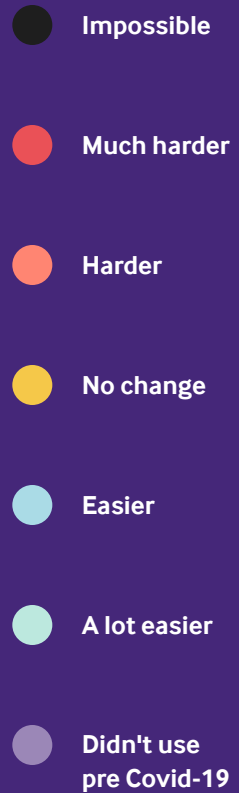
# Q3



Total respondents / Start of lockdown: 1,733 / During lockdown: March, May 1,714 / During lockdown: November 1,081

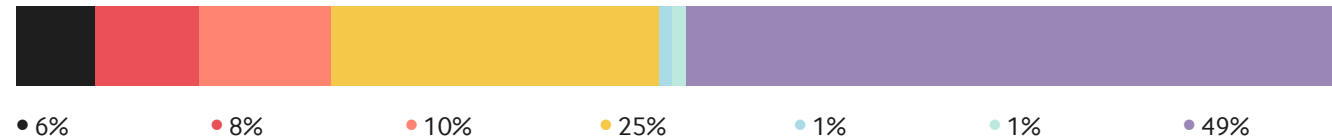
# Q4A

## Has the Covid-19 crisis had an impact on your access to the following ways of helping with your bipolar?



### Accessing crisis team

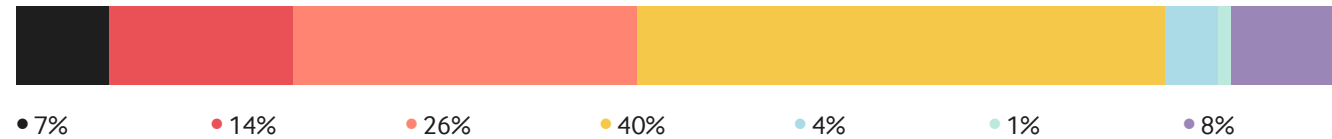
1,059 Respondents



●+●  
**55%**  
can't access

### Accessing advice on making changes to your medication

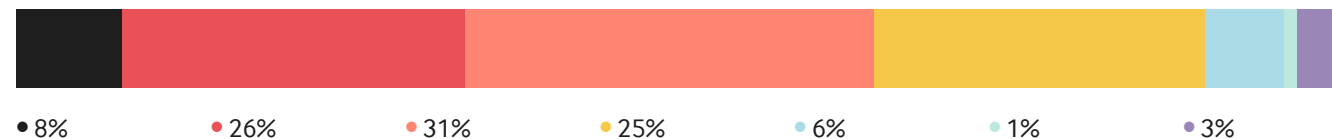
1,078 Respondents



●+●  
**15%**  
can't access

### Accessing GP

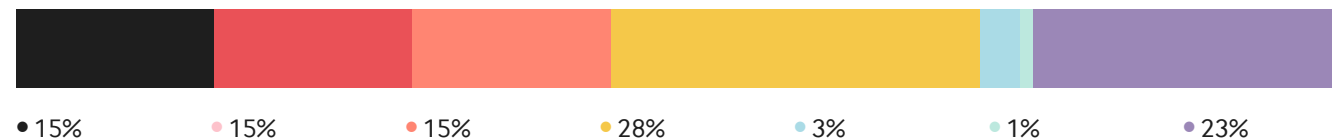
1,081 Respondents



●+●  
**11%**  
can't access

### Accessing psychiatrist

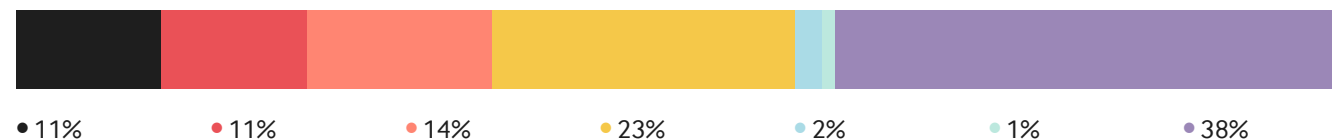
1,071 Respondents



●+●  
**38%**  
can't access

### Accessing other members of the mental health team such as a community psychiatric nurses

1,077 Respondents

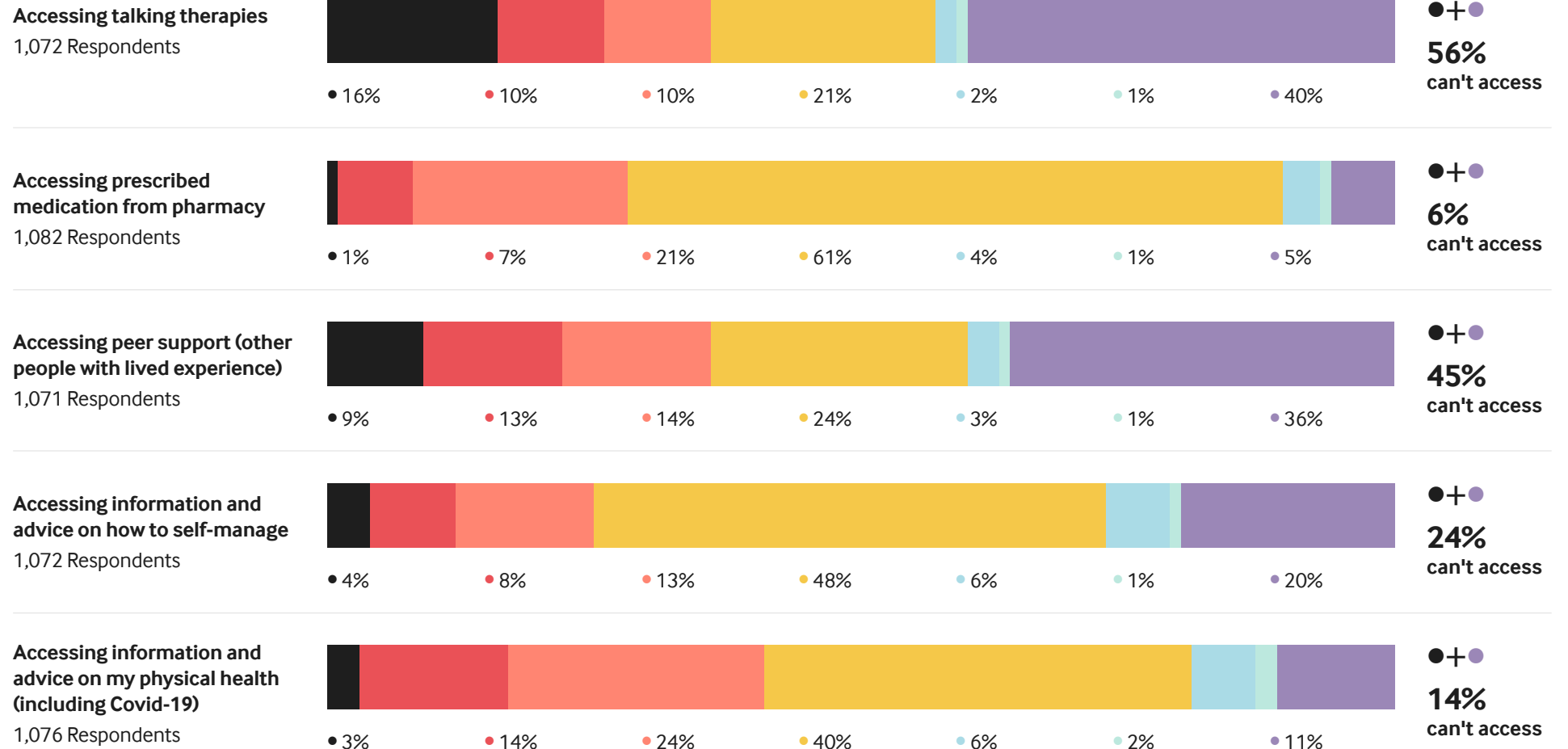


●+●  
**49%**  
can't access

# Q4A

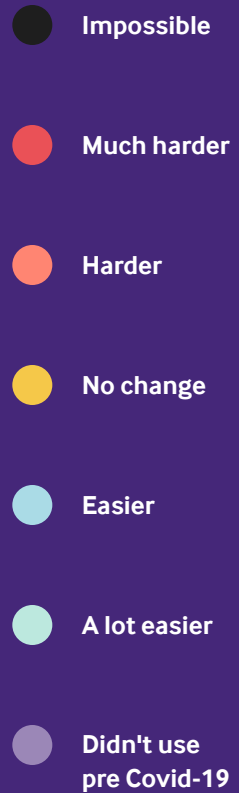
- Impossible
- Much harder
- Harder
- No change
- Easier
- A lot easier
- Didn't use pre Covid-19

## Has the Covid-19 crisis had an impact on your access to the following ways of helping with your bipolar?

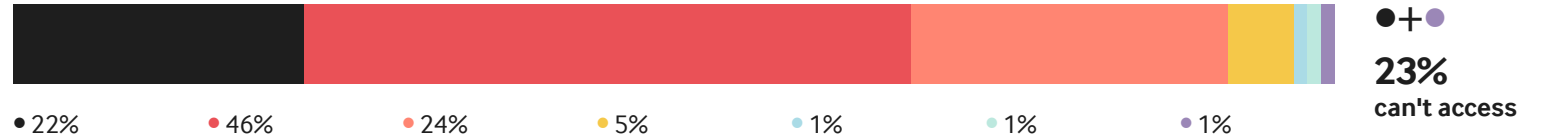


# Q4B

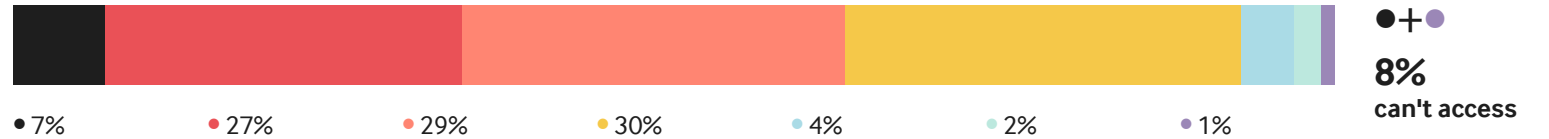
## Has the Covid-19 crisis had an impact on your access to the following ways of helping with your bipolar?



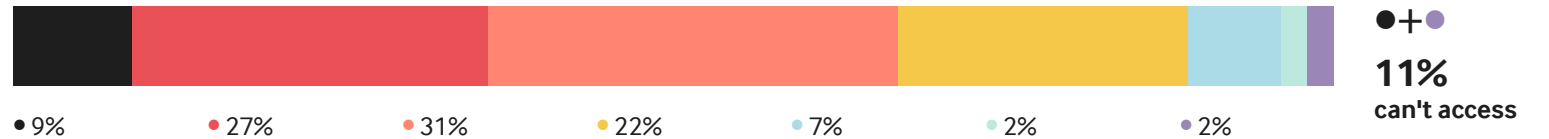
**Seeing friends and family**  
1,082 Respondents



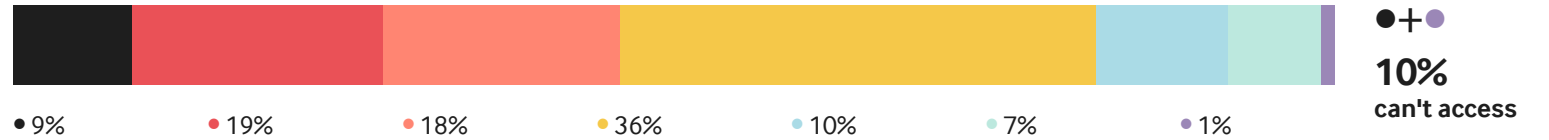
**Getting enough sleep**  
1,070 Respondents



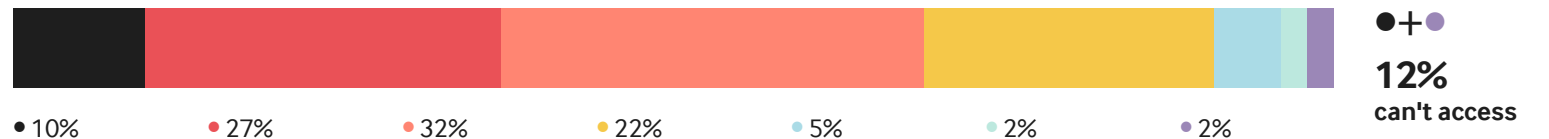
**Getting enough exercise**  
1,078 Respondents



**Getting enough private space and time**  
1,079 Respondents



**Avoiding triggers**  
1,082 Respondents



# Q5

NOT AT ALL

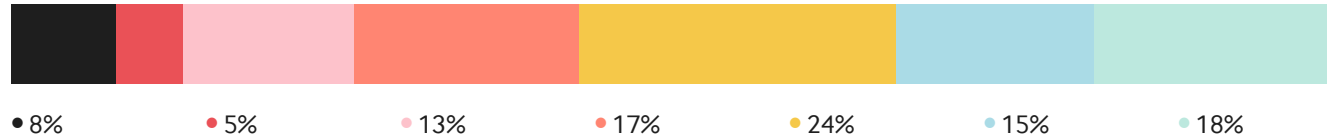
- 1.
- 2.
- 3
- 4
- 5
- 6
- 7.

VERY MUCH SO

## Tell us about your loved one's mood management?

Do you normally have a daily routine?

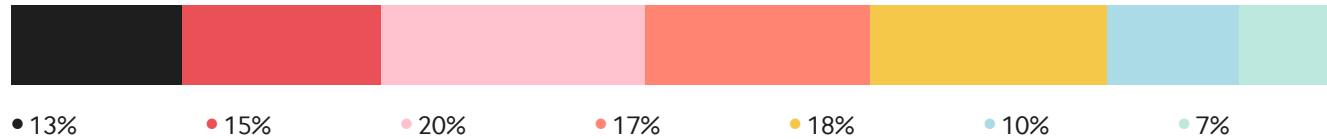
1,083 Respondents



**4.67**  
Weighted Average

How far have you maintained your routine during lock down?

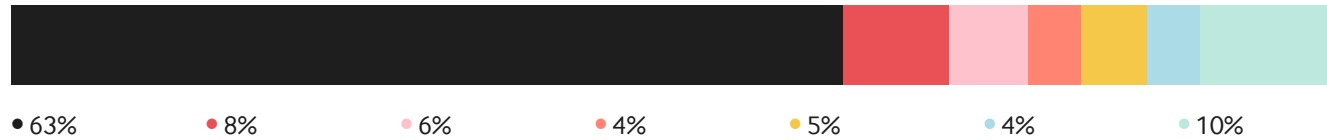
1,080 Respondents



**3.84**  
Weighted Average

Have you used a mood diary or digital platform?

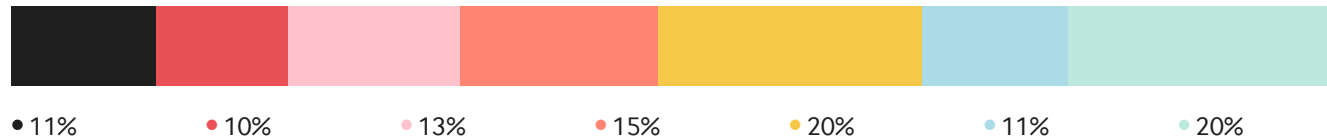
1,080 Respondents



**2.95**  
Weighted Average

Has your mood been more unpredictable than usual?

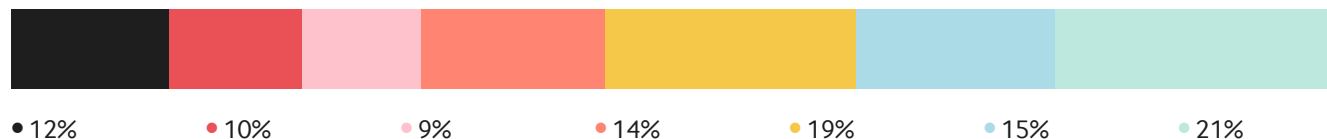
1,079 Respondents



**4.46**  
Weighted Average

How much has anxiety driven your mood to be unpredictable?

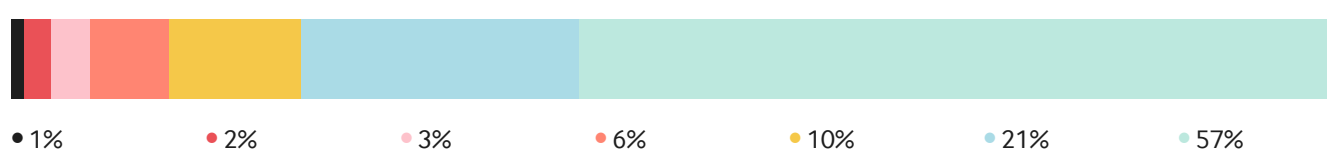
1,084 Respondents



**4.58**  
Weighted Average

Are you able to follow Public Health England (PHE) guidance on handwashing, social distancing and self-isolation?

1,086 Respondents



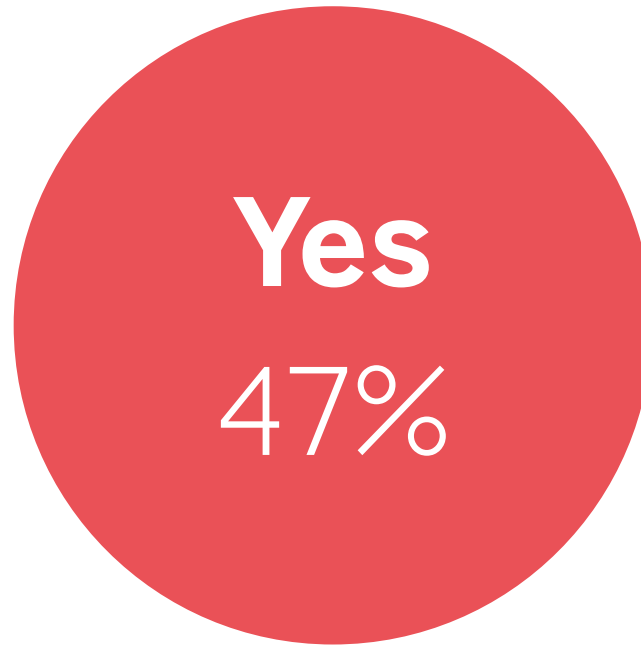
**6.14**  
Weighted Average

# Q6

## Have you relapsed over the last eight months?

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Total Respondents: 578\*



**273 responses**

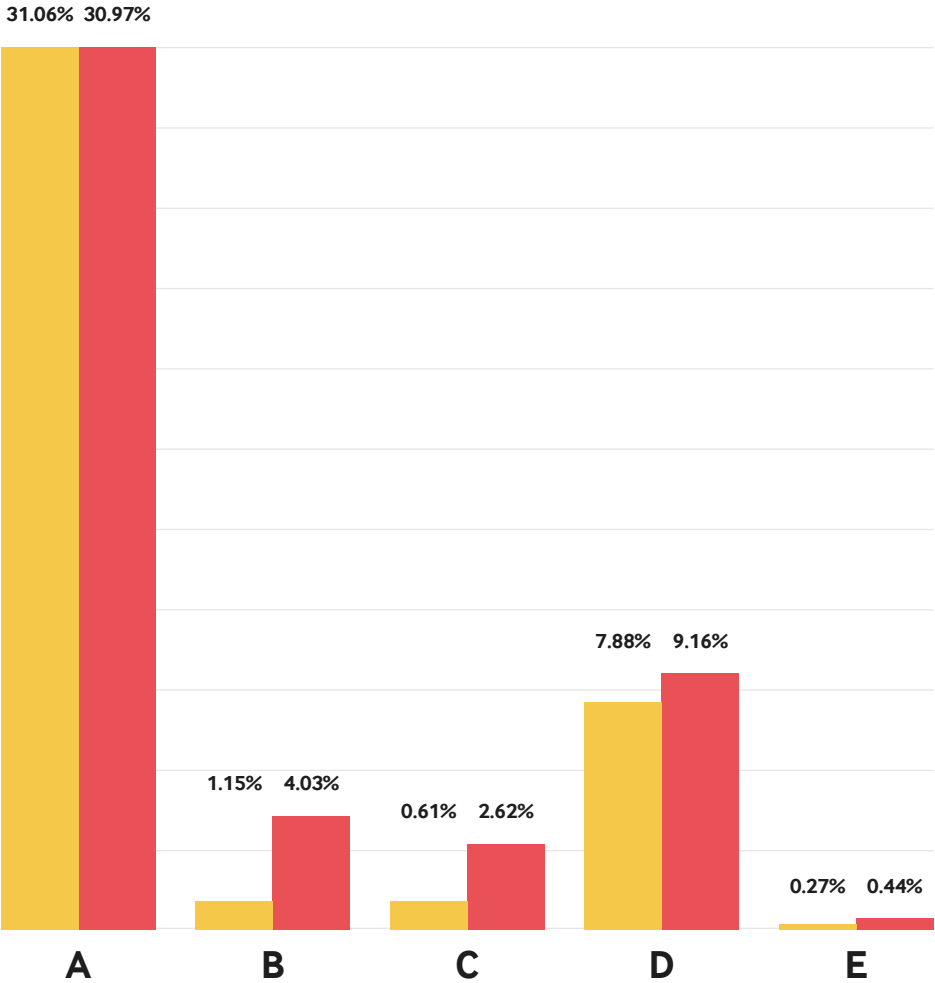


**305 responses**

\* Question added midway through the survey

# Q7

## Has the onset of coronavirus in mid-March made you or your loved one more suicidal and / or more likely to self-harm? (compared to the 6 months prior to first lockdown )



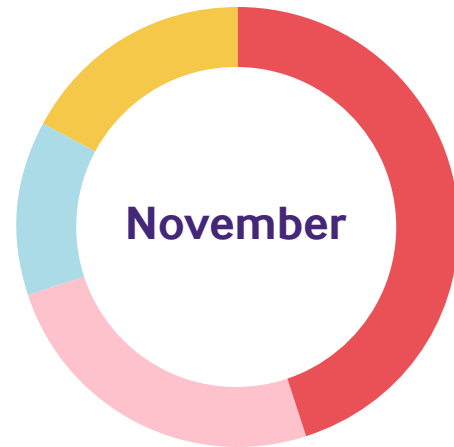
<b>Total respondents March/April:</b>	<b>1,484</b>
A – I/they have had more suicidal thoughts since mid-March	(461)
B – I/they have attempted suicide since mid –March	(17)
C – I/they have been hospitalised since mid-March because of suicidal thoughts	(9)
D – I/they have self-harmed since mid-March	(117)
E – They completed suicide	(4)

<b>Total respondents November:</b>	<b>917</b>
A – I/they have had more suicidal thoughts since mid-March	(284)
B – I/they have attempted suicide since mid –March	(37)
C – I/they have been hospitalised since mid-March because of suicidal thoughts	(24)
D – I/they have self-harmed since mid-March	(84)
E – They completed suicide	(4)

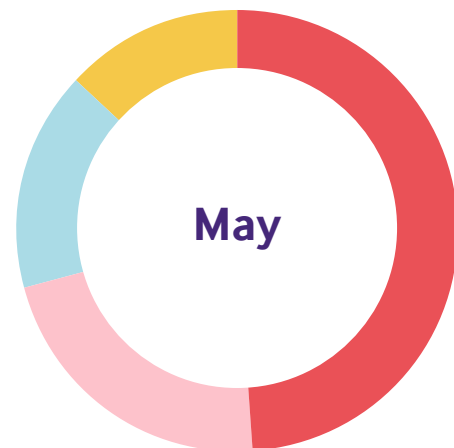
# Q8

## Which of these is your your biggest worry at the moment?

Responses add up to over 100% because some respondents could tick multiple boxes



	Responses	971
<span style="color: red;">●</span> You or your loved ones catching coronavirus	46.53%	423
<span style="color: pink;">●</span> You or your loved one's bipolar relapsing	29.45%	268
<span style="color: lightblue;">●</span> The financial impact of the lock down on you or your loved ones (loss of income or work)	13.16%	119
<span style="color: yellow;">●</span> The wider impact of coronavirus on the world	17.04%	161

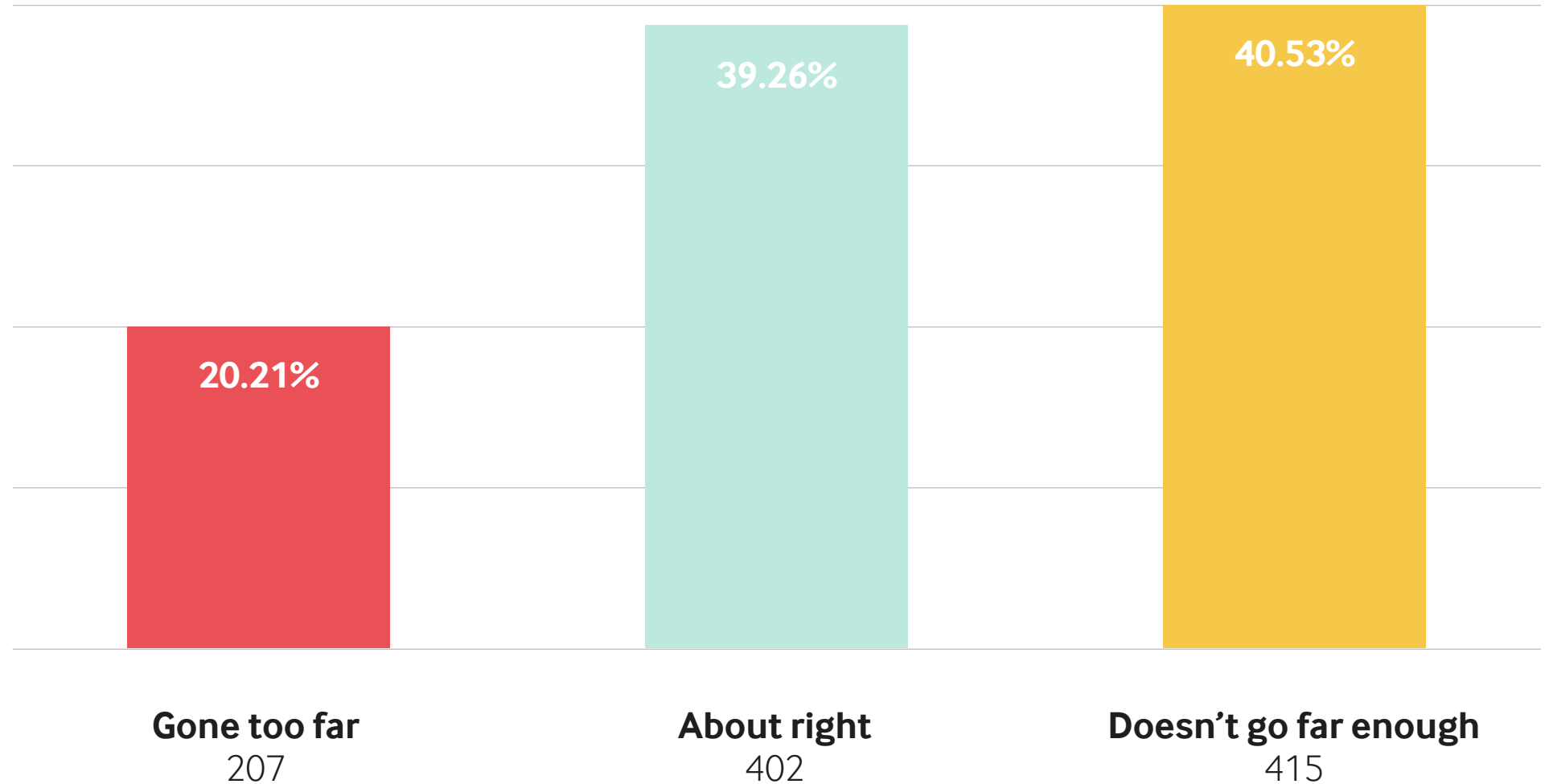


	Responses	1,539
<span style="color: red;">●</span> You or your loved ones catching coronavirus	48.76%	745
<span style="color: pink;">●</span> You or your loved one's bipolar relapsing	22.09%	338
<span style="color: lightblue;">●</span> The financial impact of the lock down on you or your loved ones (loss of income or work)	16.19%	247
<span style="color: yellow;">●</span> The wider impact of coronavirus on the world	13.23%	209

# Q9

## What is your attitude to the lockdown?

Total Respondents: 1,024



# Q10

## How do you feel about Christmas this year?

Total Respondents: 555\*

18

121

200

118

98

**Excited**

3.24%

**Looking  
forward to it**

21.80%

**Indifferent**

36.04%

**Anxious**

21.26%

**Dreading it**

17.66%

\* Question added midway through the survey



Having Bipolar in these times is more difficult than ever! My head's spinning around constantly trying to keep track of what and how to do everything.  
If this is stressing people in general, then imagine how it's affecting people who already struggle daily!



# Contact Bipolar UK

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

## **Bipolar UK**

[info@bipolaruk.org](mailto:info@bipolaruk.org)

[www.bipolaruk.org](http://www.bipolaruk.org)

[www.bipolaruk.org/faqs/mood-scale](http://www.bipolaruk.org/faqs/mood-scale)

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