

# Mapping the Gaps in Wales

The impact of incomplete data on bipolar diagnosis and care



Far too many people with bipolar are falling through the cracks because services can't be properly designed to meet their needs - largely due to a shocking lack of data. Addressing these gaps is a vital step towards building a healthcare system that can provide timely diagnosis and specialist care.



**Simon Kitchen, Bipolar UK CEO** 

## **Mapping the Gaps in Wales**

## The impact of incomplete data on bipolar diagnosis and care

Bipolar UK set out to investigate how many people in Wales are being sectioned under the Mental Health Act with a diagnosis of bipolar - and what kind of care and support is available to them.

Our aim was to build a clearer picture of the systems in place and identify whether people living with bipolar were being recognised and supported by the services that are meant to help them. Our investigation focused on two areas: the availability of data on bipolar in NHS Wales and the provision of specialist services.

We submitted Freedom of Information (FOI) requests to seven Health Boards in Wales. We asked how many individuals with bipolar had been detained under the Mental Health Act in recent years and whether specialist services were available for people with the condition.

We found that, in some cases, data was patchy, and diagnosis was recorded under broad umbrella terms like "other" or "diagnosis not recorded". This makes it difficult to determine exactly how many people with bipolar were being admitted or detained.

We also discovered that whilst each Health Board in Wales offers Early Intervention in Psychosis (EIP) services, very few offer any form of dedicated, ongoing support for people with bipolar. There is currently no national bipolar care pathway in Wales, and no consistent approach to diagnosis, treatment or follow-up.

This lack of data, combined with an absence of dedicated services, means that many people with bipolar are falling through the cracks.



After I got a diagnosis of bipolar, I didn't get any support other than prescriptions from my GP, and the waiting list for therapy was a year. All I got was the out-of-hours emergency number."

Without accurate data on who is being diagnosed or sectioned with bipolar, Health Boards cannot measure demand, plan services or ensure continuity of care. As a result, people are too often caught in a cycle of misdiagnosis, emergency intervention, and insufficient follow-up support.

Our investigation highlights the urgent need for a more coordinated, data-informed and specialist approach to bipolar care in Wales.

This means improving the way bipolar is recorded in mental health systems - ensuring that it is clearly distinguished in clinical data and commissioning plans.

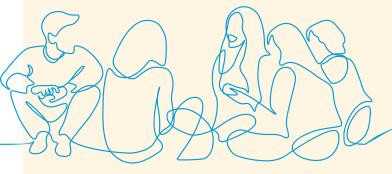
In the longer term it means implementing a dedicated bipolar care pathway. As an interim measure it means making better use of existing structures, such as EIP services, so that people with bipolar are diagnosed quicker and receive appropriate care from the earliest stages of illness.



# The Bipolar Commission recommends:

- standardising quality data collection
- adapting EIP services to incorporate bipolar
- developing a dedicated bipolar care pathway

Making these changes could have a significant impact for the NHS and the economy, whilst ensuring everyone with bipolar receives the care they need



#### **About bipolar**

Bipolar is a serious and lifelong mental illness affecting around 2% of the adult population – around 55,000 people in Wales. The condition is characterised by intense episodes ranging from depression to mania or hypomania.

- The employment rate among people with bipolar is estimated to be between 40-60%<sup>1</sup>, significantly lower than the average employment rate of 74%<sup>2</sup>.
- The London School of Economics has estimated that the total cost of bipolar to the UK economy is £20 billion a year – 17% of the total burden of mental illness<sup>3</sup>.
- Bipolar is linked to a 20-fold increased risk of suicide<sup>4</sup>, with research estimating that one in five people with the condition will take their own lives<sup>5</sup>.
- People with bipolar are 50% more likely to be obese and more likely to die 10–15 years younger<sup>6</sup> than the general population from all causes, including cardiovascular disease and cancer.

#### Bipolar is a neglected condition

Unlike conditions such as first-episode psychosis and eating disorders, there is no specialist care pathway for bipolar. Most people with bipolar don't have access to psychoeducation to learn how to self-manage the condition and prevent relapse. Many only get help once they are in crisis.

This reactive, episodic approach to diagnosing and managing bipolar leads to unnecessary suffering, hospitalisations, and increased suicide risk, and places huge strain on the NHS.

### **Bipolar in Wales**

We're already supporting hundreds of people across Wales through:

- Peer support groups in Cardiff, Pontypridd, Merthyr Tydfil, Chepstow and Swansea
- Peer support line and eCommunity Conversations for anyone affected by bipolar
- Campaigning and policy work to drive national change

The average time to receive a diagnosis after first reporting symptoms is 11.9 years in Wales<sup>7</sup>

It's estimated that 56% of people with bipolar don't have a diagnosis<sup>8</sup>

Research suggests that preventable bipolar relapses alone cost the NHS an extra £1 billion a year<sup>9</sup>



## **Key Findings and Recommendations**

Our Freedom of Information (FOI) requests to seven Health Boards in Wales and wider engagement with NHS data sources, revealed three key findings.

#### Finding #1. There's a lack of quality data

People living with bipolar often experience severe episodes requiring inpatient care, including detention under the Mental Health Act. We asked the seven Health Boards in Wales to provide us with sectioning data by diagnosis over the previous five years. Many datasets list "diagnosis not recorded" which

TABLE 1. Availability of sectioning data by diagnosis in Wales

HEALTH BOARD	DIAGNOSIS-SPECIFIC DATA PROVIDED?
Aneurin Bevan UHB	(2022/2023 onwards)
Betsi Cadwaladr UHB	X
Cardiff & Vale UHB	
Cwm Taf Morgannwg UHB	×
Hywel Dda UHB	$\bigcirc$
Powys THB	$\bigcirc$
Swansea Bay UHB	igstar

means it is impossible to understand how many people with bipolar are being detained or treated for bipolar in hospitals, how long they stay, how frequently they are readmitted or how often their condition leads to crisis interventions.

This data gap probably also applies to individuals receiving informal care within mental health settings. The fragmented nature of this data prevents NHS commissioners and policymakers from accurately assessing demand for bipolar-specific services. And it makes it almost impossible to evaluate whether existing services are effective or equitable.

#### Recommendation #1. Standardise quality data collection

The NHS needs accurate data to plan services, allocate resources and properly evaluate progress. We are calling for a national effort to improve how bipolar is recorded, reported and monitored across NHS Wales. This includes ensuring bipolar diagnoses are coded clearly in all clinical systems;



separating bipolar from broader categories in public datasets and requiring Health Boards to collect and publish data on prevalence, admissions, detentions, re-admissions, service use and outcomes.

Better data would help policymakers understand the true scale of the challenge, target investment more effectively and hold systems accountable for closing the treatment gap.

TABLE 2. Availability of recorded diagnoses in patients sectioned in Wales \*no specific diagnosis was logged

YEAR	BIPOLAR	PSYCHOSIS	EUPD	TREATMENT-RESISTANT DEPRESSION	OTHER	DIAGNOSIS NOT RECORDED*
2019/2020	328	611	181	207	838	951
2020/2021	155	369	164	217	457	1418
2021/2022	93	309	113	70	225	2204
2022/2023	108	338	130	2	281	2744
2023/2024	112	339	158	0	273	2694

## Finding #2: EIP services are available across Wales but not tailored for people with bipolar

Every Health Board in Wales has an Early Intervention in Psychosis (EIP) service and people with bipolar are being treated in them. Around 50% of individuals with bipolar will experience lifetime psychotic symptoms<sup>10,</sup> and people with bipolar make up between 5-20% of those assessed in EIP services<sup>11</sup>.

While it's true that people with bipolar are being funnelled into the EIP pathway, the services are rarely tailored to their needs. Support is often time-limited to up to three years after discharge and lacks the tools required to help people manage the lifelong, episodic nature of bipolar.

## Recommendation #2: Focus on catching bipolar diagnoses in EIP services

The widespread availability of EIP services offers a practical, interim solution while specialist bipolar services and a national care pathway are being developed. With targeted investment and training, EIP teams could play a central role in identifying and supporting people with bipolar at the earliest opportunity.

This would involve equipping staff to recognise early signs of bipolar, ensuring care plans include psychoeducation and self-management support, improving referral pathways into longer-term specialist care, and strengthening continuity of care post-discharge.

Adapting EIP services in this way would help prevent years of avoidable illness and reduce the likelihood of people with bipolar falling through the cracks of the current system

#### Finding #3. There isn't a bipolar care pathway

Despite bipolar's prevalence, high risk of suicide and hospitalisation and substantial economic and social burden, none of the seven Health Boards we contacted have a standardised care pathway for bipolar.

Rather, some people with bipolar only get access to support from a psychiatrist when they are in crisis. In between episodes, people with bipolar are usually supported by generalist services, such as Improving Access to Psychological Therapies (IAPT) or in primary care, where limited condition-specific knowledge and training can make it difficult to manage bipolar effectively.

TABLE 3. Availability of bipolar specialist care in Wales \*provision is an Early Intervention in Psychosis service

HEALTH BOARD	BIPOLAR	PSYCHOSIS	EUPD	TREATMENT-RESISTANT DEPRESSION	EATING DISORDERS
Aneurin Bevan UHB	X	<b>Ø</b>	X	X	<b>Ø</b>
Betsi Cadwaladr UHB	*		X	X	X
Cardiff & Vale UHB	X			X	
Cwm Taf Morgannwg UHB	X		X	X	
Hywel Dda UHB	X		X	X	X
Powys THB	X		X	X	
Swansea Bay UHB	X			X	

## Recommendation #3. Develop a specialist bipolar care pathway

We are calling on the Welsh Government and NHS Wales to establish a dedicated, specialist bipolar care pathway - similar to the Early Intervention in Psychosis (EIP) model. This should be built on the principles of early intervention, continuity of care, relapse prevention and personal empowerment through psychoeducation and self-management.

The Bipolar Commission and international research, including a landmark study by Professor Kessing in Denmark<sup>12</sup>, have shown that specialist, structured care is not only clinically effective but also cost-neutral.

A structured pathway would not only improve clinical outcomes but also reduce pressure on crisis services, cut hospital admissions and save money in the long term.

#### Conclusion

People with bipolar in Wales need and deserve early diagnosis, specialist treatment, continuity of care and effective self-management advice. This will dramatically reduce the risk of severe bipolar episodes and empower people to lead fulfilling lives with minimal ongoing clinical support. It is win-win for the patient, their family, their employers and the NHS in Wales

# We call on the Welsh Government to make Wales the most bipolar-friendly country in the world by:

standardising quality data collection



adapting EIP services to incorporate bipolar



developing a dedicated bipolar care pathway

## References

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<sup>12</sup>Kessing LV, Kyster NB, Bondo-Kozuch P, The CAG Bipolar Study Group, et al., (2021). BMJ Open. Effect of specialised versus generalised outpatient treatment for bipolar disorder: the CAG Bipolar Trial - study protocol for a randomised controlled trial.



## **Get in touch**

If you would like to find out more about Bipolar UK, or to discuss ways in which we can work together, please get in touch.

Campaign Work: bipolarcommission@bipolaruk.org

Peer Support Services: info@bipolaruk.org

Workplace Support: workplace@bipolaruk.org
Fundraising: fundraising@bipolaruk.org

