ENHANCING UNDERSTANDING AND REDUCING THE STIGMA OF MAJOR MENTAL HEALTH CONDITIONS

October 2024

CONTENTS

ACKNOWLEDGEMENTS

We sincerely thank Flóris Roland Balta (Hungary), Thasnim Begum (The UK), João We would like to thank Flóris Roland Balta (Hungary), Thasnim Begum (The UK), João Carrapa (Portugal) Margot De Beukeleer (Belgium), Marten Fröbisch (Germany), Aadt Klijn (The Netherlands) Arvid Nilsson (Sweden), Falk Schuster (Germany) Maria Manuel Silva (Portugal), Mark Smith (Wales) Janika Regelin (Finland), Adem Sofilic (Croatia), Kees de Wit (the Netherland) Yaëllie Fishel (Belgium) for sharing their personal experiences, which were invaluable and fundamental to this report.

We thank Nigel Olisa, Executive Director and Cecilia Angulo, Projects and Communications Manager from GAMIAN-Europe for managing the project and publishing this report.

The report was written by Chiara Samele and Norman Urquía of Informed Thinking who also facilitated the workshop. Amaia Urquía Samele conducted the social listening exercise. The report was reviewed by Peter Keri, President of GAMIAN-Europe, Jacinta Hastings, Board Member of GAMIAN-Europe, and Mark Smith from Time to Change Wales.

This project was supported financially by grants from Boehringer Ingelheim, Johnson & Johnson, TEVA and Otsuka, who had no influence on the content of the report.

EXECUTIVE SUMMARY

This report and its associated public campaign tackle head-on the pervasive stigma and discrimination faced by individuals with major mental health conditions (MHCs). To improve the understanding of these conditions this report explores:

- Previous and ongoing efforts to reduce mental health stigma and discrimination through public awareness campaigns
- Delves into the many personal experiences of what stigma and discrimination look like in day-to-day life, and
- Recent conversations about major mental health conditions via social media

Part one of the report reviews the key literature on mental health stigma and discrimination, the different types, reviews public awareness, the evolution of mental health perceptions over time (including improvements in how depression and anxiety are perceived), and persistent stigma in specific conditions like schizophrenia, eating disorders, and Post-traumatic stress disorder (PTSD).

Part two of the report explores the personal experiences and strategies of individuals with major MHCs in managing stigma, particularly in their social interactions and relationships. It explores:

- Experiences of stigma: The difficulties of stigma and discrimination from different sectors of society, such as the workplace and healthcare systems
- Disclosure strategies: How individuals decide when and how to disclose their MHCs, balancing the risks that come with stigma with the need for openness
- Romantic relationships: The challenges of disclosing MHCs in romantic contexts and the impact of timing on relationships
- Trust and safe spaces: The importance of building trust and finding supportive environments, such as people who can empathize and safe online forums
- Self-stigma: The internalization of societal prejudices and its impact on self-worth and help-seeking
- A way forward: Highlighting the importance of being heard, understanding major MHCs, and being recognised as more than just a diagnostic label(s)

Part three of the report analyses discussions about major MHCs on X (formerly Twitter) between Aug 2023 and Aug 2024. It focuses on:

- The volume and nature of Tweets: The frequency and content of tweets related to various MHCs, including PTSD, bipolar disorder, borderline personality disorder, eating disorders, and schizophrenia
- A sentiment analysis: The general sentiment expressed in these Tweets, categorizing them as neutral, negative, or positive. It highlights how diagnostic labels are sometimes misused pejoratively, while positive tweets often aim to educate or offer support
- Representations of major MHCs: Insights from personal experiences concerning the misconceptions, and representation of different major MHCs. It also explores how specific conditions, like PTSD and schizophrenia, receive varied levels of engagement and sentiment

Overall, the report highlights the persistent and multifaceted nature of stigma surrounding major MHCs. Personal experiences reveal the complexities of disclosing major MHCs and managing social interactions, while social media discussions show a mix of supportive and derogatory sentiments.

These findings underscore the critical need for continued and more targeted public campaigns/ education, enhanced support systems, and more compassionate communication to foster a more inclusive understanding of major MHCs.

It is important to know that people with mental health conditions have the right to be accepted, to receive empathy and support and to be viewed with compassion and love to aid their healing and recovery so that they can lead a full and prosperous life, free of stigma and discrimination.

BACKGROUND AND INTRODUCTION

Over the past decade, awareness of mild to moderate common mental health issues, such as depression, anxiety and panic disorder has grown. There has been an increasing acceptance of certain mental health issues but there remains a concerning lack of understanding of what mental illness is.[1] This is despite numerous campaigns to raise awareness and promote a better understanding of this.

According to Jong (2023), there still exists a need for greater awareness and understanding *'of what mental illness is and can be; that mental illness is different from 'normal' emotional pain and hardship experienced during life's ups and downs, which does not ordinarily result in a psychiatric diagnosis.'* [2]

The continued stigma regarding major mental health conditions (MHCs) is still strong. Conditions such as bipolar disorder, eating disorders and schizophrenia among many, are debilitating and decrease people's life chances and opportunities for normal life. The stigma and discrimination often associated with them, coming from many sectors of society, are major obstacles to recovery and a key source of inequality and poor outcomes for people with major MHCs[3 4 5] These issues must be tackled and addressed without delay to reduce inequality and improve social justice for those experiencing major MHCs.

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AIMS

The purpose of this project is to:

1. Gather key information to increase awareness and education of the general public, key stakeholders, and decision-makers about the nature and impact of major MHCs, and;
2. Identify ways to combat stigma and discrimination by challenging stereotypes, misconceptions, and discriminatory behaviours associated with major MHCs.

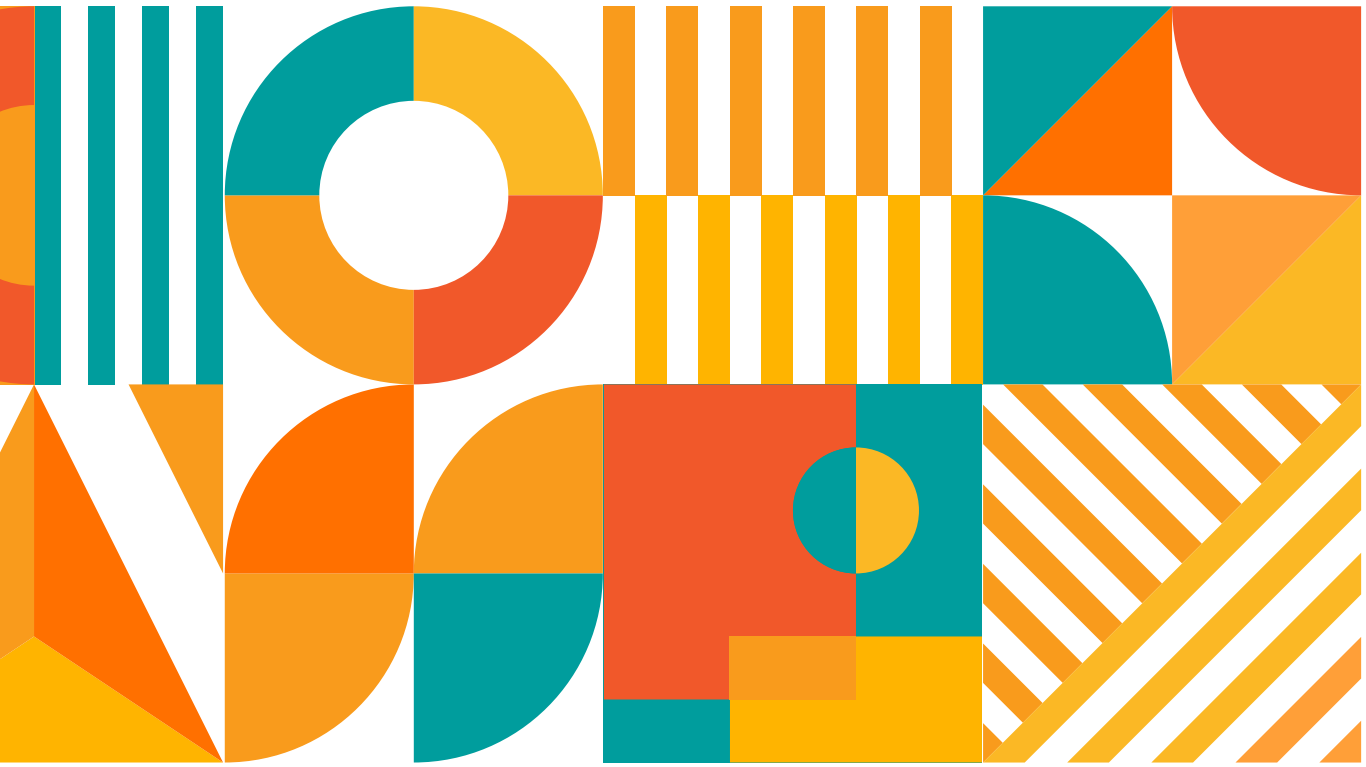
WHAT WE DID AND HOW

We gathered information from three different sources to address our project aims. The first included a brief literature review of the stigma and discrimination concerning major MHCs using desk research to search for key publications published over the past two decades.

The second involved a workshop with people diagnosed with major MHCs and their experiences of stigma and discrimination.

The third included a social listening exercise to explore conversations over the past year on social media, specifically on X (formerly Twitter) that used diagnostic terms for major MHCs in posts.

A glossary is included in the appendix listing the definitions and acronyms of the major MHCs used in this report.



PART ONE

A BRIEF REVIEW OF THE KEY LITERATURE

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This brief literature outlines key areas concerning stigma and discrimination towards MHCs and what it is not. It highlights public awareness of MHCs (attitudes and behaviours) over the past two decades, any changes following anti-stigma campaigns, what levels of stigma continue to persist for various psychiatric diagnoses and the latest developments to reduce stigma and discrimination.

WHAT ARE STIGMA AND DISCRIMINATION?

Stigma in the context of mental health is considered a combination of a lack of understanding (ignorance), negative attitudes and behaviour that discriminates against people with major MHCs.[6] Mental health stigma is a product of decreased pity, anger, fear, empathy and the belief that people with mental health problems are responsible for their symptoms.[7]

Discrimination often results from stigmatising attitudes and involves treating people with MHCs unfairly or denying them opportunities because of their condition.

Research has identified three types of stigma related to MHCs:[8]

Public stigma
Negative attitudes held by the general public towards those with MHCs

Self-stigma
Internalized shame and negative self-perceptions held by individuals with MHCs

Structural stigma
Institutional policies or practices that limit opportunities for people with MHCs

PUBLIC AWARENESS AND IMPACT OF STIGMA AND DISCRIMINATION

Public misconceptions about major MHCs have been well documented, including that they are rare (affecting only a minority of the population), untreatable and permanent, that they can lead to violence and that people with MHCs cannot function in society.

The 2023 Eurobarometer survey of 26 501 people, from the 27 Member States of the European Union found that 76% of respondents agreed that people with MHCs were perceived as less capable and contributed less to society.[9]

The same proportion (76%) agreed that people with MHCs receive fewer opportunities at work, finding housing and with social activities. Around 69% agreed that people with MHCs are perceived as less sociable.

Such attitudes, together with stigma and discrimination towards people with MHCs contribute to considerable inequalities including reduced life expectancy, poor access to healthcare, exclusion or limited opportunities to education and employment, victimisation, poverty and homelessness.[10 11 12]

WHAT ARE MAJOR MENTAL HEALTH CONDITIONS (MHCS)?

Table 1 below lists some of the main elements of MHCs and what they are not. Much of what it is not is based on public misperceptions or beliefs, with a limited understanding of what MHCs are.

Table 1: What MHCs are

A complex health condition that changes a person's thinking, feelings, or behaviour, causing distress and difficulty in functioning[13]
Potentially influenced by genetic, environmental, and developmental factors[14]
Associated with changes in brain structure, chemistry, and function[15]
Diagnosable using established criteria in manuals like the DSM and ICD[16 17]
Treatable with various interventions, including talking therapy, recovery-oriented approaches and medication[18]
Often involving significant changes in thinking, emotion, and/or behaviour
A medical condition, like heart disease or diabetes[19]

It is also important to understand the differences between mild to moderate and major MHCs. Table 2 compares these in terms of symptom severity, impairment of daily activities, chronicity, treatment needs, associated risks, and social impact.

Table 2:

Distinction between mild to moderate and major mental health conditions (MHCs)

Aspect	Mild to Moderate MHCs	Major MHCs
Symptom Severity	Less intense symptoms that cause some distress or impairment	More intense, intrusive symptoms that markedly interfere with functioning
Impairment	Some impairment, but able to carry out most daily activities	Severe impairment in occupational and social functioning
Duration	Maybe shorter-term or episodic	Often chronic and persistent
Treatment Setting	Usually manageable in primary care settings	Typically requires specialist mental health services
Comorbidity	Less likely to have multiple co-occurring conditions	Higher rates of comorbid physical and mental health conditions
Risk	Lower risk of self-harm or harm to others	Higher risk of self-injury, suicide, or harm to others
Social Impact	Less severe social disadvantage or disability	Often associated with significant social disadvantage and disability
Diagnostic Criteria	May not meet the full criteria for major disorders	Meets criteria for major disorders like schizophrenia, eating disorders or bipolar disorder

CHANGES IN AWARENESS

Awareness about MHCs has changed over the past two decades. In the past, several campaigns to reduce stigma and discrimination like the UK Time to Change programme (2008-2019), for example, found improvement in knowledge and attitudes towards MHCs.[21]

Similarly, in the US, the 2018 National Stigma study found a decreased rejection and desire for social distance towards people with depression compared to previous years in 1996 and 2006, showing some reduction in prejudice and discrimination towards depression.

Similarly, previous European campaigns have attempted to improve mental health literacy and reduce stigma and discrimination. These campaigns largely took place between 2009-2014. Some used social contact with people with MHCs to combat stigma and improve relations, considered one of the best ways to reduce stigma and discrimination.[22] The anti-stigma campaign in Sweden, 'Hjärnkoll', for example, used a multi-faceted approach including employing 350 trained ambassadors with their lived experience of an MHC to engage in various activities and events to increase social contacts. Improved mental health literacy (e.g. more open-minded, intended behaviour and pro-integration) was found in each of the annual surveys conducted (over 5 years) on random samples of the population.[23]

The first year of the COVID-19 pandemic also increased awareness of MHCs following a growth in depression and anxiety globally.[24]

PERSISTENT STIGMA TOWARDS CERTAIN MAJOR MHCS[1]

Despite these positive changes and the growing use of social media certain types of MHCs continue to be stigmatised and discriminated against. For example, attitudes, knowledge and the desire for social distance from people with schizophrenia have worsened over the past two decades. In Germany, over the past 30 years, public fear and uneasiness towards people with schizophrenia have increased, and the desire to help has declined.[25] This is in part explained by the media's tendency to sensationalize and negatively portray those with schizophrenia as violent or dangerous which adds to misconceptions about this condition.[26]

The consequences of these stereotypes hugely impact people with MHCs regarding their symptoms, help-seeking, treatment outcomes and quality of life (such as employment, social and relationship opportunities). Those living in European countries with less stigmatising attitudes had better help-seeking and treatment utilisation rates.[27]

There have been concerns raised about the stigma and discrimination faced by young people at risk of developing psychosis, highlighting the need for greater awareness and education.[28] This includes greater awareness of the impact of 'internalised stigma' or 'self-stigma' is where a person with an MHC internalises or takes on negative stereotypes about MHCs with regards to themselves.[29] Self-stigma also declines when the general public is more comfortable speaking to people with an MHC.[25]

Other stigmatised groups include people with eating disorders, for example, anorexia or bulimia. Often these are misperceived as a personal choice (or volitional attribution) which is not the case.[30] One survey showed no change in this belief over 10 years (between 1998-2008) and that people with eating disorders were to blame for their illness, more so than people with major depression.[31]

Bipolar disorder carries common stereotypes and misconceptions including being dangerous, unpredictable, and a term to refer to mood fluctuations that everyone experiences.[32]

[1] Not all major MHCs are included in this report due to limited time and resources, but are equally relevant in terms of importance.

Families and mental health professionals can also hold stigmatising attitudes towards people with bipolar disorder[33], and other MHCs. Families themselves, however, can also experience stigma, particularly parents who may be blamed for a relative's MHC.[34]

Misperceptions of personality disorder are similarly stigmatising. A common stereotype for someone with this MHC includes a person who purposefully misbehaves, is manipulative, dangerous and/or attention-seeking.[35] [36] Instead, people with borderline personality disorder (BPD), for example, can experience psychosocial difficulties, including problems with regulating emotions, self-image, interpersonal relationships and suicidality.[37]

Structural stigma has a significant negative impact on diagnosis, treatment access and quality of care for people with borderline personality disorder.[38]

Another MHC associated with significant stigma is post-traumatic stress disorder (or PTSD). Common stereotypes include being dangerous/violent, unhinged, weak or damaged.[39] Again, such stereotypes impact seeking help or treatment to avoid being labelled mentally ill, although veterans with combat-related PSTD considered this less stigmatising than other MHCs.[39]

While stigma towards depression has improved over the past decade stigma and discrimination regarding major depression persist. In the workplace, for example, employees with major depression can experience direct discrimination from employers and colleagues.[40] This can include a lack of support/understanding/respect, abuse and exploitation, and avoided or shunned.[41]

LEVELS OF STIGMA AND PSYCHIATRIC DIAGNOSES

More generic terms have been used in stigma research and anti-stigma campaigns to encompass all MHCs, although this often overlooks many of the different mental health diagnoses which carry different levels of stigma. Levels of stigma and discrimination vary according to different types of psychiatric diagnoses with some carrying more than others.

People with more debilitating or major MHCs are more likely to experience greater levels of stigma and discrimination compared to those with common mental health conditions, such as depression and anxiety.[42] [43]

One research study developed a hierarchy of stigma for MHCs.[43] They found schizophrenia and antisocial personality disorder to be the most stigmatised, with depression and generalised anxiety disorder being the least (see Figure 1). The researchers call for the need for anti-stigma campaigns to feature specific psychiatric diagnoses, such as schizophrenia and generalised anxiety disorder (GAD), which should include input from people with lived experience.[44]

Figure 1: Hierarchy of stigma by major MHC
(adapted from Hazell et al. 2022)[44]

CONTINUED ACTION AGAINST STIGMA AND DISCRIMINATION

Efforts to end stigma and discrimination towards people with MHCs continue.

Examples of this include, The Lancet Commission which produced a report co-produced with people with lived experience from across the world to evidence the negative impact of stigma and discrimination; considered at times worse than the condition itself.[45] This Commission confirms social contact between people with MHCs and those without remains the most effective intervention, and calls for greater inclusion to ensure those with mental health conditions have equal life opportunities (e.g. for employment, education, healthcare, relationships etc.).

The European Commission is developing its future actions to guide the European Union to address mental health stigma and discrimination, and the World Health Organisation is drafting its Mosaic toolkit to reduce stigma.[46]

At the time of writing, some of the ongoing mental health awareness campaigns are continuing efforts to end mental health stigma and discrimination and encourage people to talk about their mental health difficulties. For example, in Ireland, the annual See Change Green Ribbon campaign aims to spread awareness about all mental health difficulties to help end mental health stigma and discrimination.[47] Co-ordinated by Shine (formerly Schizophrenia Association of Ireland) is a countrywide campaign run throughout September with substantial media and social media coverage. Events include social media campaigns and supporting workplaces, organisations and the general public are encouraged to wear the green ribbon (distributed free) to start having open and honest conversations about mental health.

Time to Change Wales is running a series of mental health campaigns that also aim to end mental health discrimination and the shame surrounding MHCs. The "If It's Okay Campaign" collects testimonials from people struggling with their mental health to understand their stories and experiences and overcome the shame of living with these difficulties.[48]

PART TWO

EXPERIENCES OF STIGMA AND DISCRIMINATION: KEY FINDINGS FROM THE WORKSHOP

EXPERIENCES OF STIGMA AND DISCRIMINATION: KEY FINDINGS FROM THE WORKSHOP

Twenty-four people with lived experience of a major MHC took part in a virtual workshop discussion to explore the different levels of stigma experienced. Table 3 lists the number of participants by gender, country of residence and their MHCs. Participants came from 14 different countries across Europe, the United States and Israel.

Table 3:
Number of participants by gender, country of residence and MHC

Gender			
Male	13	Female	11

Country of residence	
Hungary	3
Belgium	2
UK (England and Wales)	4
Croatia	2
Germany	2
The Netherlands	2
Portugal	2
United States	1
Romania	1
Israel	1
Poland	1
Turkey	1
Finland	1
Sweden	1

Mental health condition (MHC)*	
Schizophrenia	6
Bipolar Disorder	5
Depression (includes MDD)	4
PTSD	3
Schizoaffective Disorder	2
Anxiety	2
Borderline Personality Disorder (BPD)	2
Obsessive-Compulsive Disorder (OCD)	1
Autism	1
Attention deficit & hyperactivity	1

*Several participants had multiple conditions

Participants had experience with a range of major MHCs and two neurodevelopmental disorders (autism and ADHD). Six participants had multiple MHCs and/or neurodevelopmental conditions.

The quotes below are accompanied by participants' diagnoses to highlight the different experiences each encountered.

WHO DO YOU TELL?

Participants were asked who they told about their MHCs. This revealed issues around their anticipation of the types of stigma they might expect from different groups of people. This anticipation affected the strategies they might use when talking about their condition.

Participants experienced a cycle of stigma and ways to avoid it. Participants were careful about exposing themselves to judgements and described a range of decisions around disclosure in different situations. They often felt uncertain about who they might be able to tell and what the reaction might be.

There was a distinction between disclosing and sharing information. 'Disclosing' an MHC was more akin to formally revealing previously hidden information where there might be consequences and 'sharing' was a more informal and mutual exchange of information.

Participants used different strategies for managing how they shared information about their MHCs, including testing the waters and selective disclosure to avoid stigma. Table 4 provides an overview of the strategies used by participants for sharing their mental health condition.

Table 4: Strategies used by participants to disclose their MHC(s)

Condition	Strategy	Quotes
Depression	Openness	*'I felt the need to tell [my boss].'* *'I'm very open with my mental health. In every case, let's say like that, it's appropriate in a situation where I reveal my circumstances, and I have never been rejected for it.'*
Schizophrenia	Relabelling Sharing in safe spaces	*When people ask, "why don't you have a normal job"? I say that I experienced psychosis, and that's what's really happening.'* *'I tell my friends and my family.'*

Table 4: Strategies used by participants to disclose their MHC(s)

Condition	Strategy	Quotes
MDD	Choosing a safe space	*'I've become more selective about who deserves, or needs to know about my mental health. I don't want to put myself in that position where I have to deal with the stigma, the bullying, or just the indifference…'*
Combined: Autism and schizophrenia	Partial withholding	*'I have autism and schizophrenia, nowadays I tend to avoid mentioning schizophrenia'.*
Schizophrenia	Withholding	*'I used to be quite open about it, mainly because I like to be open about anything, and I like to tell the truth. I am unable to lie, I don't want to, but I gained such unpleasant experiences and career obstacles and stuff…'*
Combined: PTSD, ADHD, BPD, depression	Withholdin	*'I don't usually share, because I don't want to, and it leads to these points where I have to explain, and explain I just say that I have conditions, and I don't open up from that… not everyone needs to know my stuff.'*

Being open or not sharing

Participants often struggled with finding the best time to share information about their mental health diagnosis in potential romantic relationships. Some chose to be open and tell people as soon as possible as this was a more honest basis on which to start a relationship. Others felt that withholding their diagnosis was a dishonest way to start a relationship.

> *'In love relationships, I feel obligated to share my vulnerabilities or else I would feel as if I am lying or cheating them.'* (P9, complex PTSD)

Others were open as a way of filtering out any intolerant people. Once they were aware of others' prejudices, they could steer away from them.

> *'I say it right away. Because if people are going to be judgmental, then I want to know as soon as possible. I don't want to invest in this relationship. I don't want to hang out with someone who wouldn't accept me if they knew about my mental health issues.'* (P21, PTSD, BPD and GAD)

However, the open approach could close off any early potential relationships and leave a person with an MHC isolated or single.

> *'As they learnt about my PTSD, BPD and GAD they were unsure. They said that their main obstacle was my illness.'* (P21, PTSD, BPD and GAD)

Some participants preferred not to share, particularly if they had more complex and multiple MHCs.

> *'I don't usually share, I don't want to, it leads to points where I have to explain and explain… I have a complex post-traumatic stress disorder, and I'm chronically depressed, and I have anxieties, borderline personality disorder, then a of couple years ago I was diagnosed with ADHD on top of it, and even the professionals have problems understanding.'* (P15, PTSD, BPD, ADHD, depression, anxiety)

Being vague and relabelling

If the conversation came up one strategy used was to be vague about the details of their MHC to avoid negative judgment.

> *'I just say that I have conditions, and I don't open up from that… not everyone needs to know my stuff.'* (P15, PTSD, BPD, ADHD, depression, anxiety)

Because of the very negative stereotypes regarding schizophrenia, some participants are campaigning to abolish the term and to rename it, 'Psychosis susceptibility' as an alternative name for schizophrenia'.[49]

Building trust and safe spaces to share

Some participants might wait until they have built some familiarity with people before sharing information about their MHCs and past traumas as they can be personal.

> *'I will not tell you before I actually really trust you. It takes me really long time to trust somebody so much that I can tell them* [about my MHCs].' (P21, PTSD, ADHD, BPD).

Once some participants had established friendships, they were more comfortable talking about their mental health. Others took a cautious approach especially when looking for a partner.

> *'The first thing is not to tell anybody my diagnosis. I try to hide this for a while, especially if I'm looking for a partner. I don't tell them at first time. Maybe if they got to know me, I would tell them…. It's a quite big problem for me.'* (P11, paranoid schizophrenia)

Although some participants waited before sharing many of their close friends noticed things, for example, mood changes and the disclosure did not come as a surprise.

> *'My close friends, they know it … they say, 'Oh yeah, I recognise this with you, because you always go up and down and up and down', so they noticed.'* (P14, bipolar disorder)

Although people talked about building trust with friends and allowing them to share their diagnosis, some also mentioned that conversations with strangers who have similar experiences could also present a safe space. Referring to participation in the workshop one participant noted:

> *'I can be open, like, in situations like this [a workshop], because I know people understand, and we have similar experiences, so now it's okay.'* (P21, PTSD, ADHD, BPD)

Sharing online (where considered safe) presented a level of anonymity which potentially provided a space to share information, receive empathy and support without negative repercussions.

> *'We like to share trauma a lot and you feel this security and community that knows what you're going through and is more understanding. I was hospitalised and I have a WhatsApp group with those people and it's great because we can talk about depression and everything.'* (P20, depression, anxiety, PTSD, OCD, BPD)

EXPERIENCES OF STIGMA

When discussing the negative responses to their conditions, one participant described stigma as ***'an additional sickness'*** that can ***'intensify or multiply symptoms.'***

Participants also described discriminatory attitudes or behaviours from healthcare professionals, where MHCs are treated with less empathy or dismissed.

Stigma from Family

Participants spoke about relatives holding stigmatizing beliefs or being unsympathetic. This was especially difficult for participants as close family was hoped to have been a source of support, but some family members found MHCs difficult to comprehend.

> *'My parents didn't understand my sensitivity and emotions, and their lack of empathy made things even worse.'* (P11, paranoid schizophrenia)

But in some instances, some families were openly hostile making the situation even more difficult for the person experiencing mental health problems.

> *'My family was very much against me, especially my husband and brother who didn't support me, even though they knew I had bipolar disorder.'* (P8, bipolar disorder)

Not being believed or validated

Participants expressed a longing to be believed about their experiences and the need for emotional support and validation.

> *'Before a diagnosis of schizophrenia, I had the diagnosis of depression and I encountered zero empathy… Before, I was not believed despite asking for help.'* (P23, schizophrenia)

Acknowledgement and validation of the experience of MHCs were equally important.

> *'I would have loved validation. I grew up hearing the message that I was difficult to love. It's difficult to get rid of that conviction.'* (P9, complex PTSD)

Self-stigma and internalisation

Exposure to many negative attitudes and prejudices from all quarters of society, including family, and mental health professionals creates a sense of dismay and further isolation for people with MHCs. Some participants internalised these negative attitudes.

> *'A lot of the time you internalise what other people think of you; I felt like I did that.'* (P5, MDD)

This can lead to negative judgments about oneself and self-stigma.

> *'I have that sense of self-stigma at times, where the only person who judges me is me.'* (P19, bipolar disorder, anxiety)

This reveals how external judgments can shape an individual's self-perception and feelings of worth which in turn leads to shame and reluctance to seek help.

> *'It was like some kind of embarrassment to ask for help... It has been really hard to learn to ask for help when it's needed. I needed empathy for myself and for other people to empathize with me...'* (P15, complex PTSD, BPD, ADHD)

More empathy from others and for oneself was important, together with a better understanding of the experience of mental health issues and knowing how to access support.

> *'I wish I had more understanding of myself and how to ask for help.'* (P15, Complex PTSD, BPD, ADHD)

A WAY FORWARD

Being listened to and understanding MHCs

A recurring theme for participants was the importance of feeling listened to and being heard. This was about being acknowledged and included in various circles.

> *'I would like to be asked, 'How are you?' So, I am seen and heard and don't feel as isolated in the world.'* (P10, depression)

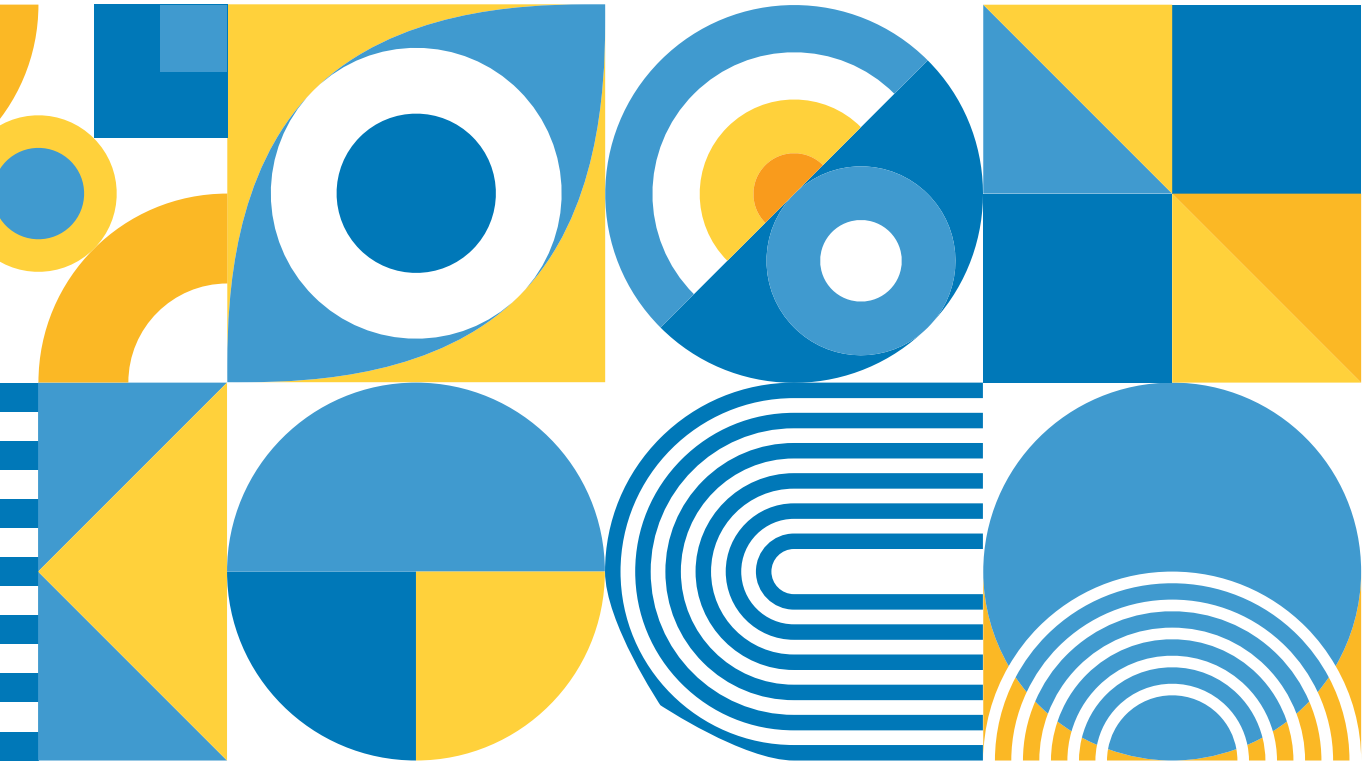
Having information about MHCs and understanding what this involves is another important element to ending stigma.

> *'It's very important to have someone who understands correctly... I know what they're going through, and I can also support them.'* (P12, bipolar disorder)

More than a diagnosis

Participants also discussed the challenge of being defined by their diagnosis rather than their experiences, often overlooking who they are as a person. They emphasized the need to talk about symptoms instead of diagnostic labels to foster a better understanding of MHCs and reduce stigma.

> *'Start speaking about the symptoms, not about the diagnosis... Being scared is easier for people to understand than an anxiety disorder.' (*P20, depression, anxiety, OCD)



PART THREE

SOCIAL LISTENING EXERCISE: KEY FINDINGS

SOCIAL LISTENING EXERCISE: KEY FINDINGS

Social media has become an important outlet for people with MCHs. Online support groups on social media platforms can help reduce feelings of isolation and provide a sense of community. A key feature of social media is chatting, which has become an important method of communication among social media users. This may not always be beneficial, although it is unclear whether social media, particularly in terms of heavy use can lead to mental health problems in young people, for example.[50]

To understand some of the conversations over social media about major mental health conditions we explored Tweets posted on X (formerly Twitter) regarding these.

Tweets in English posted between 31 August 2023 and 31 August 2024 were gathered based on whether they included any reference to 7+ major mental health conditions. These included: PTSD, eating disorders (binge eating disorder, bulimia, anorexia), personality disorder (BPD/EUPD), bipolar disorder, major depressive disorder and schizophrenia.

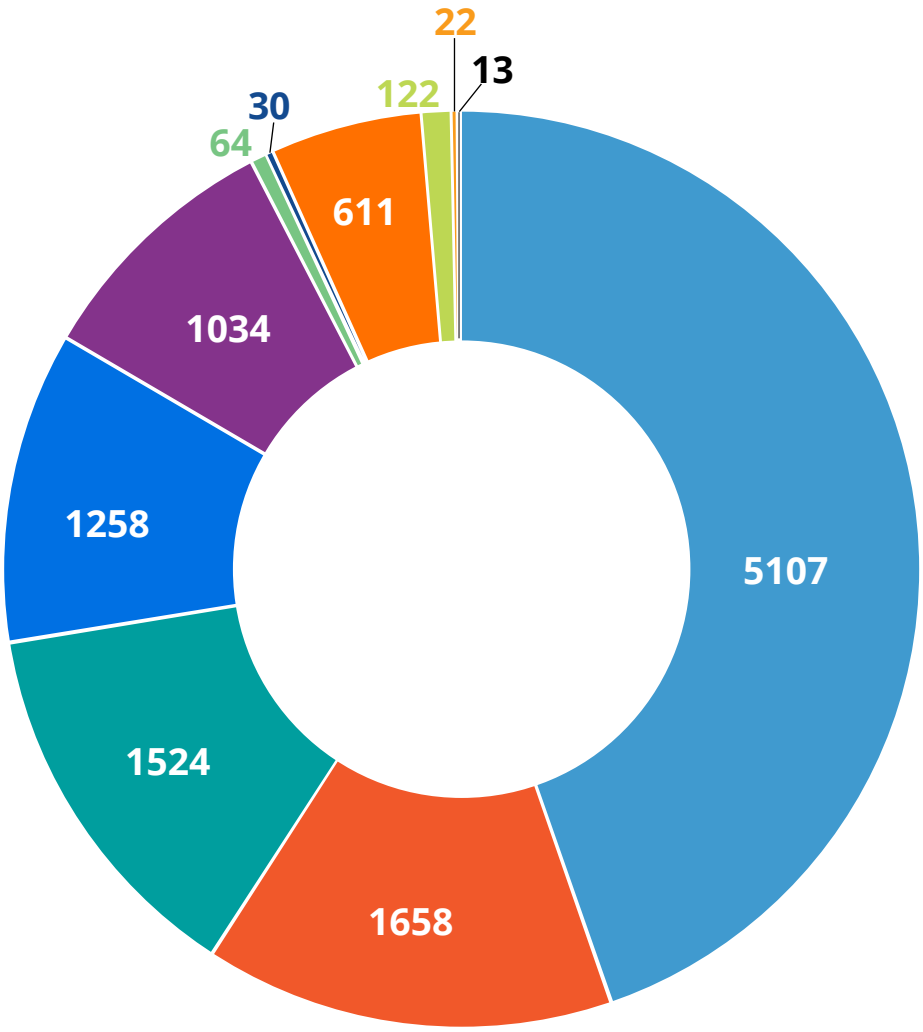
10558 Tweets were identified and analysed using sentiment analysis (coding/grouping Tweets into negative and positive posts) and a thematic analysis of key posts.

TWEETS BY MAJOR MENTAL HEALTH CONDITION

Tweets about various major MHCs revealed the complex ways in which these diagnostic terms were used. This was wide-ranging depending on a person's level of understanding, experience or exposure to a particular MHC. Interestingly, many of the diagnostic labels explored here are being used casually in everyday language, for example, to demean, criticise or judge others, things or situations. More positively, some Tweets provided a balanced and insightful understanding of what these conditions were about.

Figure 3 shows the number of Tweets by major mental health condition. The condition with the most Tweets (5000+) was PTSD followed by bipolar disorder (1658), BPD (1524) and schizophrenia (1258). There were relatively fewer Tweets regarding eating disorders (22) and specifically for binge eating disorders (13), but more for bulimia (122) and anorexia (611).

Figure 2: Number of Tweets by MHC



- Post traumatic stress disorder
- Borderline personality disorder
- Personality disorder
- EUPD
- Eating disorders
- Bulimia
- Bipolar disorder
- Schizophrenia
- Major depressive disorder
- Anorexia
- Binge eating disorder

POSITIVE, NEUTRAL AND NEGATIVE TWEETS (SENTIMENT ANALYSIS)

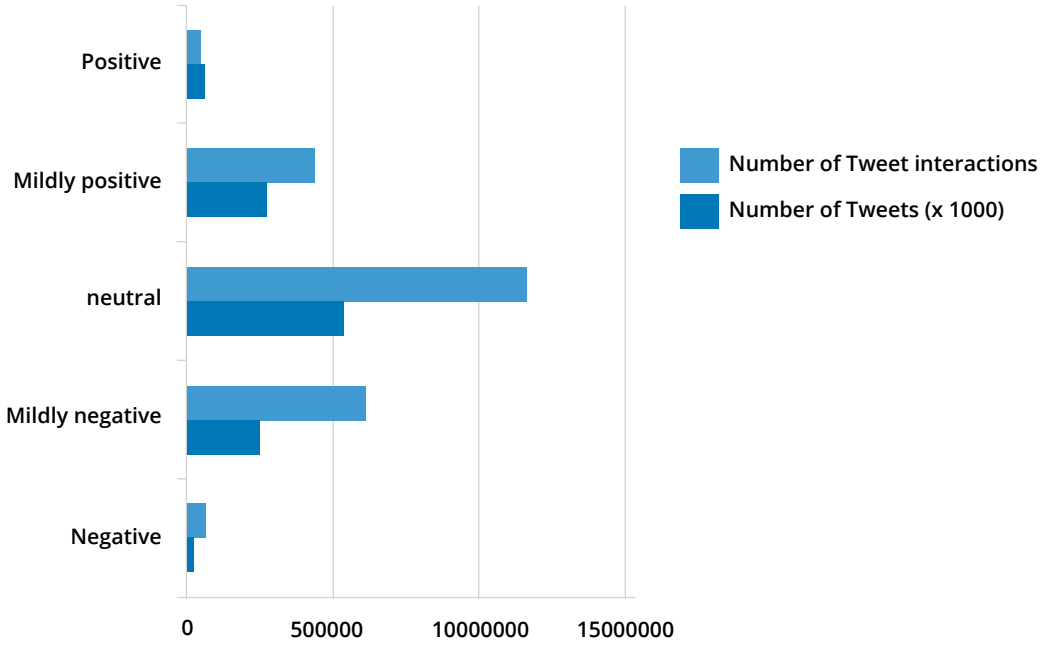
All Tweets were grouped according to their 'sentiment' whether positive, mildly positive, neutral, mildly negative or negative. Figure 3 shows that many Tweets were neutral about major MHCs, using less judgmental or emotive language.

Generally, many of the Tweets' discussions involve a mix of serious discussions of the negative effects of these conditions, reporting on cases and more matter-of-fact or casual usage of the terms. For example, bipolar was misused as a way to describe extreme ups and downs in a situation that has nothing to do with an MHC.

> *'This club is so bipolar'*

> *'... When the stock market stops acting bipolar.... then it's SHOWTIME*

Figure 3: Number of Tweets by interactions (e.g. likes, retweets, quotes and replies)



Negative Tweets were usually derogatory, using diagnostic labels to make judgements or to put people down even when the topic was not mental health. This indicates that major MHCs are so stigmatised that the labels can themselves become shorthand as an insult.

> *'@beneathhersoull is this what schizophrenia looks like.'*

> *'All these people claiming that God speaks to them? Should be evaluated for schizophrenia. I'm not even kidding.'*

Of the few positive Tweets, some were informative, supportive and encouraged help-seeking.

> *'If you believe someone you know may be suffering from schizophrenia and has not been diagnosed, it's crucial to approach the situation with empathy and support. Encouraging them to seek professional help can make a significant difference in their life.'*

> *'Remission from schizophrenia is possible. Millions of people need to hear this message of hope!'*

Some Tweets users even reprimanded others for the negative ways they talked about schizophrenia.

> *'Schizophrenia is just as valid as any other disorder/disability and shouldn't be joked about.'*

> *'I hate the way you all talk about people with schizophrenia and other disorders that involve psychosis.'*

Some commented on mental health systems and the treatment of those with major mental health conditions.

> *'I find it crazy that illnesses like schizophrenia, bipolar, and major depressive disorder, are treated as if they are caused by thoughts and behaviours even though we have clear evidence of organic and genetic underpinnings. Some areas of psychiatry are outdated pseudoscience.'*

SENTIMENT SCORE BY MENTAL HEALTH CONDITION

When looking at the total number of Tweets by MHC and their average sentiment score most tended to lean towards more positive Tweets (see Figure 4).

BPD and emotional and unstable personality disorder (EUPD)

Borderline personality disorder appears to receive the most positive Tweets, often from those with experience of this.

> *'BPD is extremely painful; if someone is working hard to try and get better, it doesn't make them a villain to slip up every once in a while.'*

> *'BPD is not an excuse but it can be an explanation.'*

Comments on mental health services were sometimes included in Tweets regarding BPD.

> *'You might get treatment [for BDP] but you'll probably be speedily discharged first whilst being treated with contempt.'*

EUPD, used synonymously with BPD, however, often received negative Tweets reflecting a general discontent about the diagnosis, who have been misdiagnosed, confused about the diagnosis or demanding the right treatment for it.

> *'Since being diagnosed with EUPD I have never been told why it's been diagnosed, what symptoms I exhibit etc. I've also never been offered a single treatment for it, but according to my mental health team my lack of improvement is entirely my own fault.'*

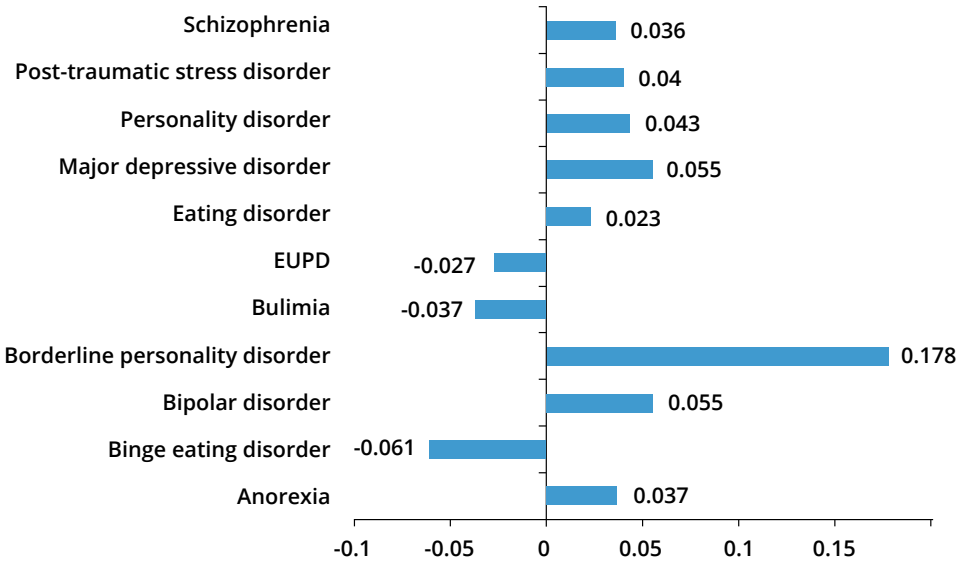
This reflects frustration over a lack of communication and treatment for a diagnosis of EUPD. This person feels unfairly blamed by their mental health team for not improving. This post highlights the importance of establishing a good relationship between mental health professionals and those receiving care.

Other similar posts from people with EUPD emphasise the difficulties they have when seeking help from a system that may be unwilling to support them.

> *'I've spent 15 years stuck in a system that hates people with EUPD. I've been told to ask for help but when I do, I am met with remarks that I am selfish, dramatic, a liar, a drain on the system and not worth medical treatment.'*

> *'EUPD has become a dustbin diagnosis for those who "inconvenience" services, and experience trauma, and suicidality...'*

Figure 4: Average Tweets' sentiment score by major MHC
(higher average scores indicate more positive posts)



Bipolar disorder

Bipolar disorder also scored highly in terms of positive Tweets in this analysis. Typical Tweets regarding bipolar disorder ranged from descriptions of what it is, the experience and how those with this diagnosis managed it.

> *'Bipolar disorder is actually a sickness in the brain, their brain works differently from the normal usual way. They experience mood swings, they can be very happy, energetic and very angry this minute and suddenly feel sad, depressed and withdrawn the next minute.'*

On a more personal level, some Tweets described the challenges and experience of bipolar disorder more negatively.

> *I'm clingy, I'm bipolar, I'm petty, I'm a cry-baby, I'm sweet, I'm mean, I'm crazy, I'm sensitive. At the moment, I'm just a handful.'*

Other tweets described a personal process of recognising the signs of relapse and how they manage the symptoms.

> *'...I learned to see the signs of manic episodes coming on. I let my family know when I am getting that way, and I distance myself in a way that does not impact my family. I stay medication-compliant and keep my appointments. I do all of this because I am a grown woman and not a child who needs someone to tell me when to do the things I know I have to do.'*

Eating disorders

The few Tweets about eating disorders, bulimia and binge eating disorders received the most negative comments and included some of the typical challenges of living with these conditions.

> *'Binge eating disorder logic is, "the sooner I finish this entire jar of peanut butter, the sooner it is gone and unable to tempt me".'*

Tweets on anorexia were more frequent, some commenting on the way it is discussed on social media.

> *'Can we please stop comparing eating disorders? I don't think you can argue that bulimia is so much easier than anorexia...when it's just not necessary. It's like comparing siblings, they're all related and are terrible disorders.'*

Being the disorder or having it were common discussions, although one Tweet commented on how bulimia is portrayed.

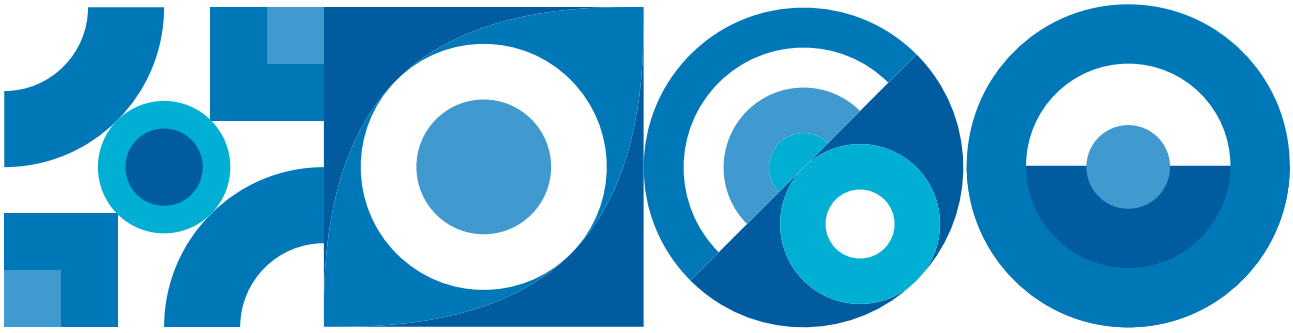
> *'I hate when bulimia representation is just "bulimia is failed anorexia" despite the fact that my bulimia is 100% failed anorexia.'*

At times Twitter users personified their eating disorders giving them names like 'Mia' for bulimia and 'Ana' for anorexia, etc.

> *'anorexia = ana*
>
> *bulimia = mia*
>
> *eating disorder not otherwise specified (ednos) = eddy/eddie…'*

Others commented on their difficulties around eating and potentially struggling with the term anorexia.

> *'Does anyone else with anorexia find it so hard to use that actual word…I have trouble with food or 'eating disorder' but 'anorexia' feels like a whole other thing to say out loud.'*



DISCUSSION AND CONCLUSION

This report drew on three sources of information to help raise awareness and educate the public and other key stakeholders about major MHCs, to reduce the stigma and discrimination associated with these conditions.

STIGMA AND DISCRIMINATION – KEY EVIDENCE

The literature review provided much evidence concerning the negative attitudes, misconceptions and discriminatory behaviour towards people with major MHCs. Previous mental health awareness campaigns have shown some effectiveness in reducing public stigma, dispelling some of the many myths and stereotypes associated with MHCs.

However, stigma and discrimination persist where major MHCs are concerned. Some authors call for campaigns that address specific major MHCs, rather than use generic terms such as 'mental health' or 'mental illness', which gloss over the heterogeneity of these conditions.

It is becoming increasingly important to understand the difference between mild to moderate MHCs and major MHCs which are more chronic and enduring. Depression and anxiety have become more accepted in the public sphere since the COVID-19 pandemic and various general mental health awareness campaigns. However, misconceptions about major MHCs, such as schizophrenia, eating disorders, and major depressive disorder still fuel negative attitudes and behaviour among the general public. Interestingly, different major MHCs attract different levels of stigma and discrimination which suggests the need for more targeted awareness-raising campaigns.

EXPERIENCES OF STIGMA AND DISCRIMINATION – THE WORKSHOP

Asking participants who they told about their MHCs was revealing. Many were rightly cautious, to avoid experiencing or exposing themselves to negative attitudes or behaviours in a variety of different situations. Stigma and discrimination could come from unexpected places, such as from relatives or mental health professionals, and many participants had developed strategies to either share or withhold information about their MHCs depending on the situation or circumstance. Self-stigma was evident and participants discussed their awareness of it.

Participants were clear about the need to be listened to and heard, and for their experiences to be validated and acknowledged by others. Similarly, to be seen as a person and not just their diagnosis.

CONVERSATIONS ON X (FORMERLY TWITTER) – THE SOCIAL LISTENING EXERCISE

Social media is an important platform for many, with chatting being a key feature of social media. Social media has become much more widely used since many of the published mental health campaigns carried out in the 2000s. This is not always an easy or beneficial platform for certain vulnerable groups, but it is used by many with an MHC.

The 10000+ Tweets analysed revealed the complexity of discussions about major MHCs. Certain conditions attract more attention than others, particularly PTSD. It is difficult to know why given the lack of information about the context of discussions/posts and where they came from.

Interestingly, the sentiment analysis revealed many posts were 'neutral' or 'mildly negative'. References to MHCs were used in several ways:

- By those without MHCs as an insult or to describe someone/or a situation
- By people with MHCs to comment on their diagnoses and treatment
- To explain what MHCs are and their challenges
- To provide hope to people with MHCs
- To rebuff negative discussions about MHCs

While there were fewer negative Tweets some were challenging to read indicating the deep struggle many people with major MHCs have, not just with their conditions but in terms of seeking help, support and navigating a system that at times is hostile, stigmatising and discriminatory. Reaching wider towards community and social safety nets and support (e.g. via charities and non-governmental organisations) provides alternative solutions that can be more accessible, person-centred and user-friendly.

However, this social listening analysis has many limitations given it is a small and selective sample from one social media platform and therefore should be treated with caution.

The three sources of information provide important key messages in which to develop targeted campaigns to increase awareness about each of the major MHCs, so people with these conditions are given the opportunities to lead a full and prosperous life, free of stigma and discrimination.

It is important to know that people with any mental health conditions have the right to be accepted, to receive empathy, and support and treated with compassion and love to aid their healing and recovery.

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APPENDIX

Glossary of major mental health conditions referred to in this report

CONDITION	DESCRIPTION
Bipolar I disorder*	At least one manic episode (abnormally elevated mood, increased energy) lasting at least a week. May also include major depressive episodes.
Bipolar II disorder*	At least one hypomanic episode (less severe than mania) and at least one major depressive episode, with no history of manic episodes.
Dissociative Identity Disorder (DID	A condition where a person has two or more distinct identities or personality states, each with its own way of thinking and behaving. This fragmentation often leads to gaps in memory beyond ordinary forgetfulness. DID typically arises from severe adverse life events, serving as a coping mechanism for the individual.
Generalized anxiety disorder (GAD)	Persistent and excessive worry about various aspects of life which is difficult to control and causes significant distress or impairment in daily living.
Major depressive disorder (MDD)*	Persistent feelings of deep sadness, hopelessness, and loss of interest in once enjoyable activities. These persist for weeks or longer and can affect daily living.
Obsessive-compulsive disorder (OCD)**	Obsessions are characterised by repetitive and persistent thoughts, images, or impulses/urges that are intrusive, unwanted, and usually associated with anxiety or distress. Compulsions are repetitive behaviours or mental acts that a person feels driven to perform.

CONDITION	DESCRIPTION
Personality disorders	These are characterised by persistent disturbances in how a person experiences and interprets themselves, others, and the world. Impairments include issues with self-worth and identity, difficulties in forming close bonds with others and managing emotional experiences.
Dissocial (antisocial) personality disorder	May experience difficulties regulating strong emotions, forming meaningful relationships, understanding the perspectives and rights of others, and having a fragile sense of self.
Emotionally Unstable Personality Disorder - *Borderline* (BPD)*	May experience extreme mood swings disturbed self-image and intense unstable relationships, fear of abandonment, chronic feelings of emptiness, and recurrent suicidal behaviour or self-harm.
Emotionally Unstable Personality Disorder. EUPD -*Impulsive*	Having very intense unstable emotions, and marked impulsive and potentially self-damaging behaviours.
Post-traumatic stress disorder (PTSD)**	Persistent mental and emotional stress (PTSD) as a result of injury or severe psychological shock.
Complex post-traumatic stress disorder (Complex PTSD)**	A form of PTSD that develops after prolonged and repeated adverse events, often where escape isn't possible, such as childhood abuse, domestic violence, or captivity.
Schizoaffective disorder**	Combines symptoms of schizophrenia with major mood episodes (depression or mania) for a large proportion of the duration.
Schizophrenia	A chronic condition involving hallucinations, delusions, disorganised speech, and reduced emotional expression. It typically begins in young adulthood.
Acute and transient (Brief) psychotic disorder**	Short episodes where a person experiences symptoms like delusions, hallucinations, or disorganised thinking. These episodes come on suddenly but usually resolve fairly quickly.

EATING DISORDERS[51]	
CONDITION	**DESCRIPTION**
Anorexia nervosa*	A condition where a persistent restriction of food leads a person to become significantly underweight (for their age, gender, developmental stage and physical health), where they experience an intense fear of gaining weight and a disturbance of their perceived weight and body shape.
Binge eating disorder	Characterised by repeated episodes of regularly eating large amounts of food quickly but without a sense of control during the episode (e.g. not being able to stop eating or control how much has been eaten).
Bulimia nervosa*	Involves eating large amounts of food quickly and then trying to prevent weight gain through vomiting, using laxatives, or excessive exercise.

NEURODEVELOPMENTAL DISORDERS	
CONDITION	**DESCRIPTION**
Attention-Deficit/Hyperactivity Disorder (ADHD)	Characterised by persistent issues with paying attention, staying focused, disorganisation and or being overly active or impulsive hasty actions without forethought.
Autism Spectrum Disorder (ASD)	This begins in childhood and affects social interactions, communication, and behaviour, often with repetitive actions or focused interests. It impacts daily life differently for each person who can vary in intellectual and language abilities.

Content adapted from ICD11[18] and ICD10[52] and for eating disorders from BodyWhys[51]

*Conditions where suicidal ideation and behaviours are more central or frequently observed and are defining aspects of them.

**Conditions where suicidal thoughts and behaviours are associated but are not core features.

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