May 2026

Submission on the draft Mental Health and Wellbeing Strategy

Written by Marion Maw on behalf of Fixate - a Facebook-based community for people who live with OCD and their families

Obsessive-compulsive disorder (OCD) is a common and serious mental health condition that can become debilitating, disrupting the lives of many people and their families. An individual's mind gets stuck on unwanted thoughts –known as intrusive thoughts – that are distressing because they go against what the person truly wants, against their sense of who they are as a person. The persistent thoughts may concern anything the person cares about: health, contamination, harm, violence, sexuality, relationships, morality or religion, to name a few. These thoughts are called obsessions. The individual feels compelled to respond in some way, seeking certainty that the disturbing thoughts are not true and relief from associated anxiety. Unfortunately, responding to intrusive thoughts tends to promote additional thoughts of a similar nature, drawing the person further into the mental distress of an obsessive-compulsive spiral. People feel enormous fear, guilt, shame and embarrassment and often do not realise that they are experiencing a mental health issue instead worrying that they are a 'bad' person.

OCD is highly treatable, provided that people seek help and are able to access mental health professionals with adequate training in diagnosis and evidence-based treatment and, in particular, in the effective delivery of Exposure Response Prevention (ERP) therapy. At present, OCD is under-diagnosed and under-treated with only a small minority of people and their families being able to navigate the multiple barriers to the information, care and support that they need.

Fixate was founded in 2017 and now has ~2,800 members from throughout the country. Marion is one of the five Admins for Fixate and, in 2022, was organiser of the petition to Parliament *"Ensure access to ERP therapy for people living with OCD."*

This submission is informed by Marion's experiences as an Admin of Fixate, as a parent of a young adult who lived with the mental distress of unrecognised OCD throughout high school and as an OCD advocate. Fixate members have contributed to this submission via an online meeting and posts within our Facebook group.

Contents

Information about the person/organisation providing feedback

We encourage you to fill in this section. The information you provide will help us analyse your feedback. However, your submission will still be accepted if you do not fill in this section.

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Position *(if applicable):* An Admin of Fixate; OCD advocate

This submission *(tick one box only)*:

☐ is made by an individual or individuals (not on behalf of an organisation nor in their professional capacity)

☒ is made on behalf of a group or organisation(s)

What ethnic group/s do you belong to? (*you may tick more than one box)*

- Māori ☐
- NZ European/Pakeha ☐
- Samoan ☐
- Tongan ☐
- Niuean ☐
- Cook Islands Māori ☐
- Chinese ☐
- Indian ☐
- European ☐
- Middle Eastern, African, Latin American ☐
- Other (*(please specify)*

Please indicate which perspectives your submission represents (*you may tick more than one box)*:

Māori	☐	Family/whanau	☒
Pacific	☐	Lived experience/Tangata Whaiora	☒
Asian	☐	Local government	☐
Service provider	☐	Central government	☐
Gambling industry (levy payer)	☐	Researcher	☐

Children / Young people ☐ Disability ☐

Other *(please specify)* A Facebook-based community for people living with OCD and their families; currently about 2,800 members from throughout the country (for further information, please see our website https://www.ocd.org.nz/).

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Consultation questions

1. From your experience, what most gets in the way of people or whānau getting the mental health or wellbeing support they need, including support for addiction, substance harm and gambling?

Fixate is a Facebook-based community for individuals and families in Aotearoa New Zealand whose lives have been affected by OCD i.e. we are a population grouping based on lived experience with a particular mental health condition.

OCD is a common and serious mental health disorder. International studies have found that the twelve-month prevalence of OCD among working age adults is around 2%[1] i.e. about 100,000 people in New Zealand live with OCD.

In 2025, the International OCD Foundation issued a white paper *America's OCD Care Crisis: National Findings on the Failure of Effective OCD Treatment to Reach Patients*[2] which highlighted the key issues that prevent people from getting the mental health care that they need:

> *"Healthcare professionals are missing or misdiagnosing an overwhelming number of individuals with OCD, with a near total failure to provide gold standard treatment."*
>
> *"The needless suffering of millions of people continues because of a lack of both awareness about OCD and clinicians adequately trained to diagnose and treat it properly. Stigma, shame, lack of health insurance coverage, and high costs are also significant barriers to care."*

In the context of the draft Strategy, Fixate would like to highlight three main issues that get in the way of accessing support for OCD in Aotearoa New Zealand:

(i) Barriers to New Zealanders being able to navigate the help-seeking journey for OCD including lack of mental health literacy about OCD, health professionals not being adequately trained to recognise the possibility of OCD, and a shortage of clinicians with expertise in diagnosis and evidence-based condition-specific psychotherapy for OCD.

(ii) Lack of provision for families who support someone experiencing OCD including both general support and OCD-specific psychoeducation on how to constructively support someone rather than unintentionally feed the obsessive-compulsive cycle.

(iii) The absence of an obvious and reliable avenue by which our lived experience community can initiate engagement and have in-depth discussions with the mental health system about improved provision for OCD.

These three issues are discussed in more detail in the following five pages.

[1] Ringeisen et al. (2023). Mental and Substance Use Disorders Prevalence Study (MDPS): Findings Report. https://www.rti.org/publication/mental-substance-use-disorders-prevalence-study-findings-report

[2] America's OCD care crisis: National findings on the failure of effective OCD treatment to reach patients. https://iocdf.org/ocdcarecrisis/

(i) Barriers to NZers being able to navigate the help-seeking journey for OCD

Common themes of personal accounts from Fixate members shared in media interviews, as Supplemental information for our petition[3] and as conversations within our Facebook group are that:

- The individual and their family did not realise that the underlying cause of the mental distress was OCD and so were unintentionally 'feeding' the OCD.
- Both primary health professionals and mental health professionals such as counsellors and psychologists often did not recognise OCD instead offering support for anxiety, trauma, depression, self-harm and substance use etc.

The recent Adult Psychiatric Morbidity Survey 2023-2024 for England provided compelling evidence that OCD is a common mental health condition (CMHC) which is under-recognised:

- Chapter 1: Common Mental Health Conditions explains that the Clinical Interview Schedule-Revised (CIS-R) was used to assess six types of CMHCs: generalised anxiety disorder, depression, phobias, OCD, panic disorder and CMHC not otherwise specified.
- During the previous week, 2.2% of working age adults met the criteria for OCD. Of those people with more severe symptoms of distress (CIS-R score of 18 or more), 16.9% met the criteria for OCD (Tables 1 and 2, next page).
- OCD was particularly common upon young adults and had a similar prevalence to generalised anxiety disorder; 5.7% vs 7.6% of 16-24 year olds (Table 1, next page).
- Of those working age people who met the criteria for OCD in the past week, only 29.7% reported knowing that they had ever had OCD and a mere 9.6% of people reported that they had ever been diagnosed with OCD. By, contrast the corresponding figures for depression were 81.9% and 72.2% (Table 3, next page).
- It may be that professionals were misdiagnosing and/or overlooking OCD when there was a co-occurring CMHC: the majority of people who met the criteria for OCD in the past week reported that they had been diagnosed with various other CMHCs especially depression (51.1%) and panic attacks (39.2%).

International research has shown that assumptions, misconceptions and a lack of mental health literacy underlie the failure to recognise the possibility of OCD:

- Widespread societal stereotypes minimise, trivialise and misrepresent OCD.
- The assumption that 'serious' OCD is a rare mental health condition.
- The assumption that it would be obvious if someone had 'serious' OCD.
- There is little coverage of OCD during training and continuing education of health professionals[4]; existing beliefs and assumptions are not challenged.

[3] Links to media interviews and to material related to the petition can be found at https://www.ocd.org.nz/advocacy-in-nz/

[4] Lahey et. al (2024). Obsessive-compulsive disorder: a medical school curriculum and textbook review. https://journals.sagepub.com/doi/10.1177/23821205241242262

The research: Data about OCD from the Adult Psychiatric Morbidity Survey 2023-2024 in England.[5] [6]

Table 1. Prevalence of people who met the CIS-R* criteria for a common mental health condition in the past week.

CMHC* in past week	16-24 years	16-64 years
Generalised anxiety disorder	7.6%	7.5%
Depressive episode	3.8%	3.8%
Phobias	4.1%	2.6%
OCD	5.7%	2.2%
Panic disorder	0.8%	1.0%
CMHC – not otherwise specified	9.8%	8.6%
Any CMHC	25.8%	20.2%

Table 2. Relationship between symptom severity as assessed by CIS-R Score and frequency of meeting the CIS-R criteria for a common mental health condition for people aged 16-64 years.

	CIS-R score			
CMHC in past week	0-5	6-11	12-17	18+
Generalised anxiety disorder	0.2	6.8	16.0	48.4
Depressive episode	-	0.2	6.4	32.5
Phobias	0.0	0.5	3.9	22.0
OCD	0.0	1.0	4.0	16.9
Panic	0.1	1.4	3.4	4.8
CMHC – not otherwise specified	-	-	70.5	27.9
Any CMHC	0.3	9.6	100	100

Table 3. Comparison of whether people thought they had ever had each common mental health condition with diagnoses they had ever received.

Of those people identified by the CIS-R with OCD in the past week	
Reported ever having had OCD	29.7%
Reported ever diagnosed with OCD	9.6%
Reported ever diagnosed with depression	51.1%
Reported ever diagnosed with postnatal depression	4.7%
Reported ever diagnosed with 'nervous breakdown'	10.6%
Reported ever diagnosed with panic attacks	39.2%
Reported ever diagnosed with phobia	10.0%
Ever diagnosed with any other anxiety disorder	24.6%
Ever diagnosed with any CMHC	69.6%
Of those people identified by the CIS-R with depression in the past week	
Reported ever having had depression	81.9%
Reported ever diagnosed with depression	72.2%

Explanatory Notes:

- ** CMHC. Common Mental Health Condition; CIS-R, Clinical Interview Schedule-Revised; green, data mentioned in the text on the previous page.*
- *The figures in each column are not additive; an individual may have more than one CMHC.*
- *-A CIS-R score of 12 or more indicates a clinically significant level of symptoms such that primary care is warranted. A CIS-R score of 18 or more indicates more severe or pervasive symptoms likely to warrant intervention such as medication or psychological therapy. By definition, not otherwise specified requires a CIS-R score of at least 12 and not having met the criteria for a specific CMHC.*

[5] Morris, S., Hill, S., Brugha, T., McManus, S. (Eds.). (2025).*Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2023/4.*NHS England. DOI: 10.13140/RG.2.2.24367.39840

[6] Data sourced from Chapter 1, Tables 1.3, 1.5 and 1.12, Adult Psychiatric Morbidity Survey, NHS England. Data sets for each chapter can be found at: https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/survey-of-mental-health-and-wellbeing-england-2023-24/dataset

In a recent NZ study[7], interviews with ten New Zealanders who had yet to access a formal diagnosis of OCD revealed similar themes including:

- a societal wide inability to recognise OCD symptoms beyond stereotypes
- cost and invalidating experiences with health professionals
- uncertainty over the pathway to receiving a diagnosis or treatment for OCD

Once an individual and their family are aware that OCD is the issue, they often find it difficult to access mental health services that provide adequate care for OCD:

> *"When there is a limited understanding of the disorder, then the referral isn't going to be worded in a way that will actually get the help that is needed… It took around half a year for me to access help and would have taken much longer if I had not gone down the private route… It could have been a lot less stressful if the GP had known more about the disorder rather than just its stereotypes."*
> *-Fixate member[8]*

It is understandable that a primary health practitioner with little training in assessment of OCD may provide insufficient information in a referral:

> *"In primary care, a GP might have 15 minutes with someone. In that time, people rarely open up about the nature of their intrusive thoughts and just how debilitating their compulsions are. Understanding OCD takes rapport and the right questions. So a GP sees someone who looks okay, not at acute risk, and assumes they'll sit on a very long waitlist. And often my clients tell me they weren't even offered a referral, because the GP thought the wait would be pointless and suggested going private instead."*
> *-New Zealand private clinical psychologist with a particular interest in OCD*

- It takes financial capacity and considerable knowledge and effort to navigate accessing OCD therapy in the private sector. Many people cannot afford to pay for a course of treatment (one hour session per week for 12 to 20 weeks, perhaps $250 per session). There are a small number of therapists who have specialist training in OCD and it is usually up to the individual and their family to try to determine whether a therapist has the necessary expertise.

Why do people find it difficult to access effective OCD-specific psychotherapy in NZ?

- OCD is a highly treatable condition but there is a workforce issue.
- 'Not knowing what they don't know' – the basic training of clinical psychologists does NOT equip them to treat OCD effectively (just as the basic training for a surgeon would not equip them to carry out specialist cardiac or brain surgery). Ineffective treatment is not only a waste of resources; it is harmful as people come to believe that they are not capable of recovery.
- We need more clinicians with advanced training in OCD-specific therapy.
- Until recently, there haven't been opportunities for NZ clinicians to gain hands-on advanced training in the delivery of OCD treatment. A beacon of hope is a recent initiative by the charity Open Closed Doors and the international Bergen 4-Day Treatment team (See Question 6).

[7] Mia Cochrane (2025) Navigating the journey to help-seeking in Aotearoa's obsessive compulsive disorder community. BScHons dissertation, University of Otago (research manuscript in preparation)

[8] https://thespinoff.co.nz/society/02-05-2022/ocd-sufferers-want-better-support-for-a-misunderstood-disorder

(ii) Lack of provision for families who support someone experiencing OCD, including both general support and OCD-specific psychoeducation on how to constructively support someone rather than unintentionally feed the obsessive-compulsive cycle.

People often join Fixate because they are parents looking for information and encouragement as they learn how to support their child with diagnosed or suspected OCD. This is a common occurrence because OCD is usually first experienced as a child, adolescent or young adult. In addition, some people join Fixate because they are partners of an adult living with OCD.

Families are often dismayed to realise that accommodating the demands of OCD is harmful (e.g. offering reassurance or helping their family member to avoid a feared situation) and need specific guidance on what is truly constructive support, something that contributes to the wellbeing of the entire family:

> *"We got turned away from CAMHS until our girl was in physical distress due to the OCD. We were given very helpful materials to read through when we entered services and she was diagnosed. We were also given YouTube clips, Ted talks as well. We learnt lots. I also got given a handout on how to validate your child's experience. We also got told about PDA and PANDA and that totally resonated. Both of these were super helpful and changed the way we responded to our darling. We related better. Our daughter has ASD traits but through screening didn't meet criteria but understanding her needs, how best to communicate was game changing. This was the major piece that worked as she would not engage with CAMHS."*
> *-Fixate member*[9]

The family above eventually received excellent support for their daughter's mental health and wellbeing. However, what of the people who do not (yet) 'tick enough boxes' to reach specialist services? At the primary level of the health system, individuals and families are unlikely to be offered OCD-specific psychoeducation and instead, hopefully, find and implement the advice of self-help resources for OCD.

Often a family needs support themselves and that isn't routinely offered:

> *"Our whole world was chaos and safety checks and hyper vigilance. The professionals were there, kinda, but there was no empathy or understanding to what it was like 24/7 at home to keep her safe and alive. There was no offer of what was there to help us process this, or how to support her link to education and her social networks. It took a hospitalisation in another town for a social worker to suggest a needs assessment to maybe get some supports at home. 5 months later we have this assessment booked in, but still no direct help for us as a family supporting her. Without putting our own money into finding private support to process our trauma and confusion we would have had nothing. I was off work for nearly 8 months to support her and this financial impact was never explored or given any assistance into options either.*
>
> *Our girl would not have been seen as quickly as she was without my knowledge of how to "work the system" to her benefit. Being able to advocate for her was only possible because of my professional skills and career, I know how hard it is for other families they are left with no knowledge, and therefore no ability to advocate for their child. We weren't informed of the themes of OCD or how it was presenting in our child. Only because I knew resources or had the knowledge to hunt through information was I able to provide this to the extended family to understand."*
> *-Fixate member*

[9] *Note: PDA, Pathological Demand Avoidance, PANDAS, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections; ASD Autism Spectrum Disorder*

(iii) The absence of an obvious and reliable mechanism by which our lived experience community can initiate engagement and have in-depth discussions with the mental health system about improved provision for OCD.

In recent years, advocates from Fixate have tried to engage with the public mental health system directly and via a petition to Parliament, a meeting with the Cross-Party Mental Health & Addiction Wellbeing Group; and a meeting with the Minister of Mental Health.

This advocacy has largely been an exercise in frustration and futility.

A key barrier to productive engagement has been no continuity of discussion. For example, with the new Parliament, the membership of the Health select committee changed significantly; and each time we have had contact with Health NZ, it has been with a different person.

It is as though we are stuck in 'Groundhog Day'.

- Each time we manage to make a connection, the conversation must begin anew with the basics.
- It is never possible to have in-depth discussion with counterparts who have developed a good understanding of OCD and the needs of our community.
- All too soon the time allocated for a rare and long-sought meeting is over; seemingly, it is sufficient that we have 'been heard'.

For example, in 2023, the report issued by the Health select committee on our petition made some suggestions for Te Whatu Ora:

- Consider whether the existing workforce could be trained in ERP therapy.
- Consider how it could involve people with personal experience of OCD or supporting a family member in the planning and provision of services.
- People with specific expertise in OCD and lived experience should be involved in reviewing the information about OCD on the Health Pathways platform.
- Explore how to make the information on the Health Pathways platform more consistent and accessible, including for families who care for an individual experiencing OCD.
- Investigate whether condition-specific planning at the national level could be used to create a guideline for OCD.
- Explore whether technology could be used to provide choice by creating a platform where people could digitally access therapists from around the country.
- The outcome? The time and energy of everyone involved in the petition and in subsequent meetings produced no tangible change. It seems that the petition report is simply gathering dust.

Lived experience communities should be able to initiate meaningful engagement with decision making in the public health system through an efficient and reliable mechanism. There should be 'a clearly marked front door to knock upon'.

2 From your experience, what most helps people or whānau to stay mentally well or get the support they need for their mental health and wellbeing, including gambling and substance-related harm?

From the experiences of Fixate's OCD community, an individual and their family currently need to be fortunate enough to have sufficient personal 'capital' to overcome multiple barriers to accessing the support they need:

The 'capital' of the individual experiencing OCD includes:

- Mental health literacy in general
- Confidence and persistence in help-seeking and in self-advocacy for access to the public health system and/or in navigating the private sector
- Ability to find and use self-help resources about OCD e.g. websites, podcasts, books and Just a Thought's online course.
- Connection with an OCD community such as Fixate (the first time someone talks about it may be within our Facebook group or via our website e-mail).
- Financial resources to pay for assessment, diagnosis of OCD and OCD-specific treatment in the private sector

The 'capital' of their family (or other support network) including:

- Parents who play an active role in help-seeking and in supporting their child, adolescent or young adult as they learn to manage OCD
- Similarly, for adults experiencing OCD, family and friends who have an open and accepting attitude to mental health challenges
- Family and friends who have accessed information about OCD including how to constructively support someone rather than unintentionally feed the obsessive-compulsive cycle

Also important is having a GP, counsellor, midwife or other professional who has a good understanding of mental health, is open to learning more about OCD and recognises the need for both general and OCD-specific support.

Often a piece of good luck that enables a 'lightbulb' moment – "I have OCD!"

> *"For a decade I lived in fear, not knowing why I was having these intrusive thoughts… Despite seeing various health professionals, it took another five years and a Netflix documentary for me to stumble on a clear explanation of what was going on."*[10]
> *-Fixate member*

Having enough of the 'basics' – family, friends, food, housing, financial security – to be able to commit the time and effort into navigating the journey to treatment and subsequently applying the skills necessary to live well with OCD; and also not having help-seeking experiences that are bad enough to prevent them reaching out again.

Only a minority of people experiencing OCD have sufficient personal 'capital' and luck that they are able to navigate the journey to adequate support. There is intersectionality to the barriers and hence inequity of access (see next page).

[10] Fixate's written submission on the petition *Ensure access to ERP therapy for people living with OCD*.

The research: Characteristics of working age adults with a diagnosis of OCD who accessed secondary health services in Aoteaora New Zealand

McLeod et al. (2024)[10] used de-identified data from Statistics NZ's Integrated Data Infrastructure to identify and characterise a cohort of 5,559 working age adults who had accessed public secondary health services and had a diagnosis of OCD recorded.

Given the twelve-month prevalence of OCD in adults is about 2%, ~200 individuals experiencing OCD per 10,000 people in the general population would be expected (see Figure 1).

However, the rate of people having had an OCD diagnosis recorded at some point in time over the entire period for which secondary health system data has been collected was only ~18 individuals per 10,000 people.

This finding means that the large majority of New Zealanders living with OCD could not be identified from secondary health system data i.e. it seems that most of the people experiencing OCD had not sought help, had not been diagnosed with OCD, had accessed only the primary level of public healthcare and/or had turned to the private sector for health care.

There were marked differences in the rates of OCD diagnosis according to demographic characteristics such as ethnicity and geographic location (see Table 4). For example, among the Asian population grouping the rate of OCD diagnosis was ~6 individuals per 10,000 people whereas among the European population grouping it was ~25 individuals per 10,000 people; and in the Te Manawa Taki region it was ~11 individuals per 10,000 people whereas in the Te Waipounamu region it was ~31 people per 10,000 people. The different rates of OCD diagnoses suggest inequity of access to secondary healthcare and merit further investigation.

[10]McLeod, K., Bowden, N., Thabrew, H., Truman, K. and Maw, M. (2025), Sociodemographic, mental health, education, employment and income characteristics of adults with obsessive–compulsive disorder who accessed secondary health services in Aotearoa | New Zealand. Journal of the Royal Society of New Zealand, 55: 1776-1795. https://doi.org/10.1080/03036758.2024.2406827

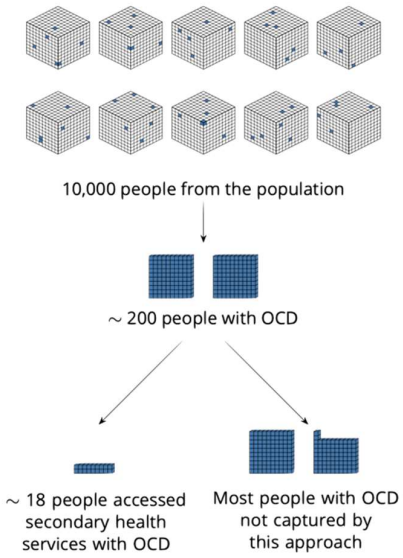

Figure 1: The Integrated Data Infrastructure-based method identifies only a subset of people in the population who live with OCD.

Table 4. Rate of OCD diagnoses partitioned by sociodemographic characteristics.

Rate of OCD diagnoses (per 10,000)	Sociodemographic characteristic
30.8	living in the Te Waipounamu region
24.7	European ethnicity
24.3	aged 18 – 24 years
22.9	born in New Zealand
22.8	living in medium urban areas
21.5	living in the Central region
21.5	women
20.6	aged 25 – 34 years
19.8	living in large urban areas
18.6	living in major urban areas
18.3	aged 35 – 44 years
18.1	**aged 18 – 64 years**
18.0	living in small urban areas
16.7	aged 45 – 54 years
14.7	men
13.4	Māori ethnicity
13.0	living in rural areas
12.3	living in the Northern region
11.7	aged 55 – 64 years
11.1	living in the Te Manawa Taki region
8.6	born overseas (migrants)
5.9	Asian ethnicity
5.6	Pacific Peoples ethnicity

3 What parts of the strategy feel the most right or important to you? Why?

Table 5. Parts of the strategy that are important for Fixate's OCD community.

The Strategy document	An OCD community perspective
A range of specific populations and people with specific conditions feel underserved.	Historically OCD was lumped in with anxiety disorders. It has been under-diagnosed and inappropriately and inadequately treated. Currently only a minority of people access the correct diagnosis and OCD-specific therapy.
The need to embed infrastructure to support lived experience leadership at all levels and to meaningfully involve people in service design and delivery.	The OCD community should be able to initiate meaningful engagement with decision making in the mental health system through an efficient and reliable mechanism. There should be 'a clearly marked front door to knock upon'. (Rather than it always being the mental health system that decides when and whether to initiate engagement with an already recognised population grouping or lived experience community.)
Tracking and evaluation of both access to and the effectiveness of care and support. The importance of evidence-based investment.	Access to evidence-based OCD-specific treatment should not be a hopeful aspiration; it should be a realistic expectation with clarity about the strategic actions required to achieve this. The rates of OCD diagnosis and access to OCD-specific treatment and the outcomes of treatment should be measured and monitored.
Early intervention especially for young people.	OCD is typically first experienced as a child, adolescent or young adult; currently it usually takes years to be diagnosed and access treatment.
Better support for families supporting someone with a mental health challenge.	Families need both general support and OCD-specific information and advice.
Filling gaps in the current data; there are people who experience poor mental health that are not seen.	In the past, people living with OCD and their families were seldom connected to others and were not perceived as a distinct community. Data for people with OCD has not been collected and/or evaluated separately; provision of services for OCD and access and outcomes of people with OCD have not been monitored separately.

4 What changes would make the strategy work better for people and whānau? Why?

Please note: Terms from the draft strategy are in blue.
Specific suggestions for changes are in red.

4.1 Overview of suggested changes to the strategy document

(i) Making the language used in the strategy easier to understand for 'ordinary' people. The draft Mental Health & Wellbeing Strategy builds upon previous strategy documents related to mental health. For those trying to understand the present document, it would be helpful to provide more context for some of the language (see sections 4.2 and 4.3).

(ii) We request that the needs and expertise of families be more strongly acknowledged. Various wording changes are suggested (see section 4.3).

(iii) We request that the need for provision of evidence-based condition-specific treatment for certain mental health conditions be explicitly acknowledged. Various wording changes are suggested (see section 4.3).

(iv) In addition, some editing changes are suggested that may improve the readability of the document (see section 4.3).

4.2 Making the language easier for everyone to understand

Please provide more context for the following language in the text, footnotes and/or a glossary.

(i) 'Models of care'. Please give a brief definition and perhaps provide a reference to the Commissioning Framework for Mental Health and Addiction: a New Zealand guide.[11]

(ii) 'Continuum'. It would be helpful if the context were always specified in the text e.g. 'a continuum of care', 'a continuum of severity of mental distress'.

(iii) 'Evidence'. It may be helpful to provide context in the text by elaborating on what kind of evidence e.g. data related to needs or system performance; international evidence of efficacy for specific kinds of intervention.

(iv) 'Lived experience'. Does this term never/sometimes/always encompass both 'people who have experienced mental health and addiction challenges' and 'families who support a family member? (Whereas 'tangata whaiora' always refers only to 'people who have experienced mental health and addiction challenges'?)

(v) 'Complex or enduring needs'. What is encompassed by this description? Does it include mental health disorders that require condition-specific treatment such as eating disorders and OCD?

[11] https://www.health.govt.nz/publications/commissioning-framework-for-mental-health-and-addiction-a-new-zealand-guide

(vi) Various population-related terms e.g. 'population groups', 'populations with specific needs', 'unique population needs', 'communities' and 'local needs'. On pg 4, a footnote explains 'population groups' in terms of demographic characteristics such as age, ethnicity, gender and orientation and rural vs urban location. Where do lived experience communities which have distinct needs such as the OCD community, the eating disorders community or neurodivergent communities fit within this language?

4.3 Suggested changes in wording through the draft document

(i) Pgs v and 14, Access, strategic action 3: "Deliver safe, trauma-informed, evidence-based… "

(ii) Pg v, Effectiveness, future state vision: "Lived experience and peer leadership will be present at every level with insights valued equally alongside clinical expertise to ensure responsive person-centred care including, when relevant, evidence-based condition-specific services.

(i) Pg v and pg 23, Effectiveness, strategic action 4: "Improve availability of robust population- and community-level data to inform alignment of investment to ~~population~~ needs."

(ii) Pg v and pg 23, Effectiveness, strategic action 6: "Shift commissioning approaches to a partnership approach and support providers to identify and respond to the needs of individual communities and monitor outcomes."

(iii) Pg vi-vii, Contents: The Strategic Framework on pg v. and the illustration on pg 28 should be listed.

(iv) Pgs 2 and 3, the sections on 'Giving effect to mental health and addiction targets' and 'Relationship to other strategies and plans'. These two sections may be better placed after the current pg 19. This order would be consistent with the order of the introductory material on pg 1. For this reader, it would be preferable to first cover material related to the present strategy and so become familiar with it before looking at the strategy's relationship to other documents. Being immediately presented with the other documents evoked a sense of 'overwhelm' – Oh, no… do I need to read those other documents before even getting started on this one?

(v) Pgs 4 and 5, Paragraph one on pg 4 mentions the 'burdens' associated with mental ill health and addiction and on pg 5 goes on to acknowledge in more detail the nature of 'inequitable physical health outcomes'. We suggest that there be a paragraph that elaborates on the nature of current mental ill health and addiction outcomes for people and their families and communities. Outcomes are key. How should we judge whether mental health interventions are effective? Not by monitoring targets related to service delivery (though that is important), but by monitoring outcomes for people and their families and communities.

(vi) Pg 5, paragraph two: "These ~~measures~~ findings point to a critical challenge."

(vii) Pg 5, paragraph 3: "… can only provide insights about people who interact with the system." Even among those people who do interact with the system, it is an 'overclaim" to suggest that the data can tell their stories.

(viii) Pg 5, final paragraph: " and thus more people are relying upon alternative sources of support…"

(ix) Pg 6, Variation in investment and fragmention across services: Please elaborate a little on what is meant by disparities in outcomes e.g. outcomes such as …

(x) Pg 6, Limits on access to services: "… some parts of the continuum of care…"

This may be an appropriate place to mention that the relative availability of access to appropriate psychotherapy vs medication means that people often do not have a real choice between evidence-based treatment options.

It may also be an appropriate place to acknowledge the need for adequate provision for both 'generic' and condition-specific services.

(xi) Pg 8, Direction of travel, paragraph one: "…from a limited focus on specialist treatment to a continuum of care approach…" Both population wellbeing AND specialist treatment are important, not a choice of one OR the other.

(xii) Pg 9, Figure 5, Prevention & Early Intervention: "… a particular focus on strengthening both prevention and intervention early in the life course is needed."

(xiii) Pg 10, Measuring and monitoring progress, paragraph two: "This will include analysis of quantitative measures to track access, outcomes and equity at district levels for specific population groups and separately for mental health and addiction services; and also quantitative or qualitative measures to track access, outcomes and equity for people with specific mental health conditions such as psychosis, eating disorders and obsessive-compulsive disorder. Achieving targets at the national level is not sufficient if it still means that people in specific places, or who are part of specific population groups, or who have specific mental health challenges do not experience the same improvements."

(xiv) Pg 10, Measuring and monitoring progress, paragraph three: Please elaborate a little on what is meant by "progress and outcomes" and by "measure the experiences of people interacting with the system: Meeting or exceeding access targets? Improvements in people's mental health and wellbeing as measured by assessment tools used before and after an intervention? Service users considering that interactions were respectful and safe?

(xv) Pg 11, paragraphs three and four: This may be an appropriate place to mention the intersectionality of neurobiology/neurodifference, being neurodivergent and social environments that enable people 'wired differently' to thrive.

(xvi) Pg 12, paragraph one: "… and to support those around them and feel confident about accessing help if they need it…"

(xvii) Pg 13, Why this matters, paragraph four: Please elaborate a little on "Inconsistent models of care"; to this reader it is jargon and I am not sure that I understand the meaning.

(xviii) Pg 13, What the future will look like, paragraph one: "Support will be responsive, age-appropriate, evidence-based and accessible for all."

(xix) Pgs v and 14, Access, strategic action 3: see (i).

(xx) Pg 15, paragraph two: "… ensuring the care meets the needs of ~~local~~ individual communities and delivers inclusive, person-centred and evidence-based support."

(xxi) Pg 15, paragraph three: "… ensuring people and their families receive the care and support they need."

(xxii) Pg 15, paragraph four: "This workforce will be equipped to deliver care that is inclusive, age appropriate, evidence-based, culturally responsive and person-centred."

(xxiii) Pg 15, final paragraph: "People who access mental health, addiction, physical health, and social support and their families will interact with workforces that have the skills to support their mental health alongside their physical health and social needs."

(xxiv) Pg 16, Strategic action 3: "… and offer responsive, ~~and~~ safe and evidence-based support.

(xxv) Pg 16 and 23, Strategic action 5: "Further develop the Consumer, Peer Support and Lived Experience workforce with intentional planning, coordination and support mechanisms to enable this workforce to play a ~~significant~~ substantial role in the design and delivery of supports and services."

(xxvi) Pg 16 and 23, Strategic action 5: One leadership role of community groups is advocating for appropriate models of care. Some community organisations will have or be developing the capacity to contract to provide their own supports and services; other community groups may remain reliant on the public system to mediate service provision. To be effective partners with the mental health and addiction system in the design and delivery of care, some communities may benefit from support in building their capacity to meaningfully engage.

Does strategic action 5 include action to develop and support the capacity of individual communities to engage with the mental health and addiction system? We would like to this point to be specifically addressed.

(xxvii) Pg 17, paragraph two: "People with lived experience, their families and communities hold valuable knowledge…"

(xxviii) Pg 17, paragraph three: "At the same time, assumptions, prejudice and discrimination related to mental health and addiction challenges persist across health and social systems."

(xxix) Pg 17, paragraph four: "To be effective, care must be accessed in a safe and positive environment. ~~a~~ The system needs to be supported by the right settings and enablers…"

(xxx) Pg 17, final paragraph: "This inclusive approach will strengthen accountability and ensure services ~~remain~~ are responsive to the needs of individuals, families and communities."

(xxxi) Pg 18, paragraph one: "Services will be sustainably resourced, with flexible commissioning models that enable tailored responses to the priorities of local and lived experience communities ~~to local priorities~~ and of diverse populations."

(xxxii) Pg 18, paragraph three: "Through continuous improvement and innovation, the mental health and addition system will ~~remain~~ be resilient, equitable, and focused on protecting and enhancing the wellbeing of all people."

(xxxiii) Pg 18, Effectiveness, action 2: "Implement targeted strategies to combat assumptions, prejudice and discrimination … "

(xxxiv) Pg 18, Effectiveness, action 4: "Improve availability of robust population- and community-level data, including prevalence and wellbeing data to inform continuous alignment of investment to ~~population~~ needs."

(xxxv) Pg 19, Effectiveness, action 6: "Shift commissioning approaches to a partnership approach and support providers to identify and respond to ~~local needs~~ the needs of individual communities and monitor outcomes."

(xxxvi) Pg 22, Strengthen the focus, Why this matters: "Families, friends and communities are often the first line of support for people experiencing distress or harms and need tools, knowledge and assistance to maintain their own mental health and wellbeing and provide support to others."

(xxxvii) Pg 22, Increase access, Why this matters: "Discrepancies and barriers… in health outcomes for population groups and communities experiencing multiple and/or complex challenges or with specific needs."

(xxxviii) Pg 22, Effectiveness, Why this matters: "Assumptions, prejudice and discrimination…"

(xxxix) Pg 22, Increase access, What the future will look like: "People have timely access to safe, trauma-informed, evidence-based …"

(xl) Pg 22, Increase access, What the future will look like: "Population groups and communities with specific needs…"

(xli) Pg 22, Increase access, What the future will look like: "Mental health and addiction services are more connected across the continuum of care… "

(xlii) Pg 22, Effectiveness, What the future will look like: "… free from assumptions, prejudice and discrimination…"

(xliii) Pg 23, Increase access, What the future will look like: "… without unwarranted geographic variation and tailored to the needs of individual communities."

(xliv) Pg 23, Effectiveness, What the future will look like: "Mental health and addiction services have sustainable resourcing and flexibility in commissioning to effectively respond to the unique needs of individual communities."

(xlv) Pg 23, Increase access, strategic action 3: "Deliver safe, trauma-informed, evidence-based, accessible and age and culturally appropriate services for populations with specific needs.

(xlvi) Pg 23, Grow the workforce, strategic action 3: "Upskill the workforce… and offer responsive, safe and evidence-based care."

(xlvii) Pg 16 and 23, Grow the workforce, strategic action 5: See (xxv) and (xxvi).

(xlviii) Pg 23, Effectiveness, strategic action 2: "… to combat assumptions, prejudice and discrimination…"

(xlix) Pg 23, Effectiveness, strategic action 4: "Improve availability of robust population- and community-level data, including prevalence, access, outcome and wellbeing data, to inform continuous alignment of investment to needs."

(l) Pg 23, Effectiveness, strategic action 6: "… to identify and respond to the needs of individual communities and monitor outcomes."

(li) Pg v and pg 23, Effectiveness, strategic action 6: See (ii).

(lii) Pg 24, Prevention and early intervention, Quantitative measures: In addition, certain communities may warrant monitoring of community-specific measures. For example, international studies have repeatedly found a large diagnosis gap and a large treatment gap for people who experience OCD, with it taking on average around a decade from symptom onset to accessing the correct diagnosis and then evidence-based OCD-specific treatment. Specific monitoring is needed to determine the current size of these gaps and whether they are closing.

(liii) Pg 24, Increase access, Quantitative measures. In addition, people with specific mental health conditions may warrant monitoring of access. For example, comparison of the community prevalence of OCD to the rates of access to specialist mental health services (as assessed by the rates of diagnoses recorded in the Programme for the Integration of Mental Health Data (PRIMHD).

(liv) Pg 24, Effectiveness, Quantitative measures: In addition, Tailored monitoring may be needed to evaluate the effectiveness of specific interventions e.g. routine use of the Yale-Brown Obsessive-Compulsive Scale to assess the severity of symptoms prior to and after treatment for OCD would enable data to be gathered and evaluated on the effectiveness of treatment delivery (and benchmarking to international expectations of effectiveness).

(lv) Pg 28, illustration: The illustration should have a legend added. The illustration shows a continuum of the severity of mental distress on the x-axis and a

continuum of wellbeing on the y-axis. A suitable figure legend might be "Figure ? Levels of wellbeing and mental distress are inter-related." Because an individual's position on the grid may change over time, I would also suggest changing the word 'people' to 'someone' on the labels on the illustration. For example, someone living with a mental health condition such as OCD may currently be experiencing minimal mental distress and good wellbeing (e.g. the person has accessed OCD-specific treatment and gained the skills necessary to manage the condition); that same person may formerly have experienced severe mental distress and poor wellbeing (e.g. the condition has not yet been diagnosed and they have not accessed OCD-specific treatment); in the future, the person may be experiencing minimal mental distress and yet have poor wellbeing (e.g. have the skills to manage OCD but have other stresses in their life).

(lvi) A sentence on pg 28, paragraph four says "Mental health challenges occurring across a continuum from mental distress to complex conditions." This sentence is confusing because a continuum suggests a single dimension i.e. a line or axis on a graph. By analogy with the language used to discuss autism, I suggest that 'spectrum' is a better word choice and that paragraphs four and five be rearranged as follows.

"The spectrum of mental health challenges encompasses mild and everyday experiences through to severe and/or complex difficulties. Levels of mental health and wellbeing can fluctuate and vary; it is possible to thrive and live well in the context of ongoing mental health challenges (see Figure ?).

Similarly, substance use and gambling harm encompass a spectrum including no or low harm, problematic use and addiction. Serious harm, such as overdose, can still occur for those who are not in distress or addicted."

(lvii) Pg 28, the final sentence of "The impact on a person's autonomy, ability to function, belonging and contribution to society can be minimal to severe, and people's experiences may be temporary or enduring." should be followed by a sentence acknowledging the impact on and support needs of family members including the social, mental health and financial impact on carers and the need for psychoeducation on how to better support their family member.

(lviii) Pg 29, paragraph one: Help the reader by specifying 'psychological' in "levels of psychological distress and harms from illicit substance use and gambling are increasing."

(lix) On pg 29, regarding the bullet points such as "4.7% of people will experience a serious mental disorder": At different points in time, an individual living with the mental health disorder OCD may experience mild, moderate or serious distress as the severity of symptoms tends to wax and wane throughout life i.e. the nature of the disorder and the severity of present distress are not one and the same.

The findings of the survey would therefore be better expressed as "4.7% of people experienced serious distress from a mental health disorder; 9.4% of people experienced moderate distress from a mental health disorder; and 6.6% of people experienced mild distress from a mental health disorder."

(lx) Pg 29, final paragraph: The findings of the survey would be clearer as follows, "While prevalence data on diagnosable disorders is outdated, annual surveys have shown a trend of worsening mental health and wellbeing. Over the past decade, the percentage of people aged 15 years and over who reported high or very high psychological distress[13] in the previous four weeks has been increasing. This trend has had greater impact on specific groups; for instance, for people aged 15-24 years, an already higher rate of psychological distress has nearly doubled."

(lxi) Pg 30, paragraph two: This paragraph canvasses the distinct needs and poorer outcomes of various population groups. The groupings are mostly according to various demographic characteristics (e.g. ethnicity, age, income…). In addition, there is a catchall phrase 'those who have other conditions'. Which people are those 'who have other conditions' intended to encompass? Those people who have physical health conditions, those people who have long-term mental health conditions and also those people who are neurodivergent?

(lxii) Pages 30-31, There is a section headed "Some population groups experience poorer mental health and addiction outcomes". Is it meant that 'There are poorer outcomes from mental health and addiction challenges for people in these population groups'? or is it meant that 'The higher rates of mental health and addiction challenges are themselves an outcome for these population groups'? i.e. Would this section more clearly be headed "Some population groups experience higher rates of mental health and addiction challenges"?

The final paragraph in this section is definitely about the poorer outcomes of people with mental health and addiction challenges, with the example of poorer physical health. As noted earlier in (v), pages 4-5 make similar brief references to poorer physical outcomes. There are many way in which people with mental health and addiction challenges have poor outcomes e.g. income, housing, social connection. In this regard, it is highly relevant that certain mental health conditions such obsessive-compulsive disorder, bipolar disorder and schizophrenia are often chronic and usually first experienced by early adulthood. Would this topic be better placed in a separate section or transferred to pages 4-5?

(lxiii) Pg 32-33, Landscape of supports and services: There is little mention of responsibility for raising literacy about mental health conditions and for addressing misconceptions, stigma and discrimination.

(lxiv) Pg 33, the bullet point concerning whole-of-population and tailored services: In addition to services for eating disorders, there is condition-specific provision for an Early Intervention in Psychosis Service and, in Canterbury, for the Anxiety Disorder Service. Rather than focus on eating disorders, this bullet point would more inclusively be "… conditions that require specific interventions."

(lxv) Pg 33, paragraph 3: Not only are people reaching out to their families, often there is a reliance on a substantial degree of family support. What then is meant by 'resources for families and others' – simply a brochure or something more substantial?

(lxvi) Pg 34-36, Current System Performance: Somewhere in this section, it may be helpful to explain: What criteria/decision pathways have been used to prioritise actions for inclusion in government work programmes and will be used to prioritise which actions will be included in the implementation plan?

(lxvii) Pg 35, second point within the bullet point on Variation in investment: "-investment per capita…" meaning 'per head".

(lxviii) Pg 36, Limits on access to services: "… access to mental health and addiction services in some parts of the continuum of care…"

(lxix) Pg 36, Limits on access to services: Somewhere in the draft strategy should be mention of the unmet demand for access to psychological therapies e.g "– growing complexity of needs requiring more extensive or extended time in care and unmet demand for access to psychological therapies."

(lxx) Pg 36, System enablers, bullet point on Lived experience leadership: This bullet point seemingly encompasses only lived experience roles within the public health system. What about the enabler role of leadership from lived experience organisations? For example, an important role of lived experience groups is to provide insight into the needs of their particular communities and of the barriers that are encountered. In addition, some lived experience organisations have the capacity to contract to provide services.

(lxxi) Pg 36, bullet point on Data and information: Data is currently gathered via PRIMHD that enables monitoring of targets for access to specialist services and national data will be gathered in the forthcoming prevalence study for young people. There should also be recognition of the need to support research into areas other than system performance and prevalence and demographically-defined population groups. In particular, there should be mention of the experiences, needs and outcomes of people who are affected by specific challenges such as OCD and of the families who support them.

For example, "In particular, key to target efforts and investment will be data on needs, service use and outcomes of demographically-defined population groups and also research on the experiences, needs and outcomes of people who are affected by specific mental health and addiction challenges and of the families who support them."

(lxxii) Pg 39, paragraph two: "Overall, there is concern that people are not receiving the type and degree of support that they need across all levels from mild distress to complex needs."

(lxxiii) Pg 39, paragraph three: "Workforce capacity is widely seen as the primary factor in service shortages."

(lxxiv) Pg 39, paragraph four, "People and their families want their needs to be viewed holistically, and for primary and ~~for~~ specialist mental health supports and services that are well resourced and connected."

(lxxv) Pg 39, paragraph six, "People with lived and living experience of mental wellbeing challenges and their families…"

(lxxvi) Pg 39, final paragraph, "People and their families want improved linking with other government services…"

(lxxvii) Pg 40, Public Consultation, Common Themes: The bullet point about tailoring support may be better expressed as "Tailor support for those population groups with distinct needs and/or higher levels of need."

(lxxviii) Pg 41, a consultation summary point: For various reasons, neurodivergent people have a higher rate of mental health conditions. At present, this point seems to be the only mention of neurodiversity in the entire strategy. The point needs to be re-worded as 'neurodiversity' is not a condition; ADHD and autism are examples of neurodivergence or of neurodevelopmental conditions.

For example, "Enhance support for people with a range of specific conditions (e.g. people who are neurodivergent)."

5 This strategy will come with a plan that sets out what needs to happen to bring it to life. The first plan will have a three-year focus. What are the most important steps we should take in the next three years to make the biggest difference to people's mental health and wellbeing, including reducing substance and gambling related harm? Please tell us why.

Table 6. The most important steps in the next three years for Fixate's OCD community.

Aspect of the Strategy	Why this is important to Fixate
Substantive engagement with the leadership of lived experience communities should not be an aspirational goal for the mental health and addiction system; it should be an expectation, a requirement that must be met. There should be 'a clearly marked front door to knock on' for communities that want to initiate engagement with the health system about their needs and concerns.	We request that the health system recognise that Fixate provides a voice for people and families affected by OCD -a common and serious mental health condition - and that the OCD community has condition-specific needs. We strongly desire to establish meaningful and long-term engagement between the leadership of Fixate and decision-makers and clinicians in the health system about provision for care and support for the OCD community.
Investment in the capacity of the specialist mental health workforce to deliver evidence-based psychotherapy including condition-specific treatment.	OCD is a highly treatable condition provided people are able to access evidence-based condition-specific therapy. The limiting factor at present is a shortage of NZ clinicians with the necessary expertise. Establishing a NZ community of practice and model of service delivery for OCD (see Question 6) should be a high priority for investment.
A continuum of care that enables people to access evidence-based condition-specific care and support, without being required to wait until symptoms and functional impairment are "severe enough'.	In the case of the OCD community, this means that people with mild-moderate severity of OCD symptoms and functional impairment have a clear pathway to access OCD-specific psychoeducation and treatment e.g. one avenue could be a sufficient number of therapists with expertise in OCD on the Gumboot Friday platform and a search filter option for 'OCD'.
A continuum of care that ensures families are routinely offered both general and needs-specific psychoeducation and support.	In the case of the OCD community, this means that there will be OCD-specific provision e.g. investment in delivery of Supportive Parenting for Anxious Childhood Emotions (SPACE) courses.

6 If you could choose just one thing for us to do to make the biggest difference in the next three years, what would it be?

When Fixate's petition was heard by the Health select committee, the New Zealand College of Clinical Psychologists commented on the tensions between generic mental health services and conditions like OCD that need tailored interventions.

The Fixate community strongly endorses the need for tailored interventions for mental health conditions. There is existing provision for Early Intervention for People with First Time Psychosis, the Eating Disorders service and, in Canterbury, the Anxiety Disorders Service.

We call for equitable provision for tailored interventions for OCD, a highly treatable mental health condition that is common and is responsible for substantial disability.

In particular, we request that the public health system builds upon an exciting and promising development regarding effective evidence-based OCD treatment in NZ:

> In 2025, the charity Open Closed Doors[12] was setup with the aim of promoting better provision for people experiencing OCD and their families. In particular, Open Closed Doors has established a partnership with the international Bergen 4-Day Treatment team to introduce their well-established and highly effective method for delivery of ERP therapy – the internationally recommended first-line treatment for OCD - into New Zealand. To get off the ground, the venture has relied upon charitable funds.
>
> The basic concepts of ERP therapy can be readily understood by attending a workshop. However, the nuances are critical if therapists are to achieve consistently effective outcomes. The training programme for delivery of the Bergen 4-Day Treatment is hands on – a small group of clients and therapists, with a 1:1 therapist to client ratio, work both as a group and one-to-one. The hands on training and ongoing monitoring of implementation ensure strong adherence to the proven methodology.
>
> In the most recent publication of outcomes using the Bergen 4-Day approach[13], the 12-month follow up results for a group of 86 patients in Iceland were: all participants completed the treatment (which is unusual for ERP therapy); treatment gains by patients were maintained over time, with 84% showing improvement and 67% recovered; and functional impairment along with symptoms of anxiety and depression also decreased significantly.
>
> Charitable funding has enabled pilot treatment groups to be held recently in Auckland and Christchurch including the training of some clinicians from the public health services for Auckland, Waitemata, Waikato and Canterbury.

The Open Closed Doors initiative to introduce the Bergen 4-Day Treatment is a beacon of hope. We call for the public health system to capitalise on this opportunity, firmly establishing the capacity to provide effective evidence-based treatment for OCD as recommended by international guidelines.

[12] https://ocdhope.org

[13] Davidsdottir SD, Ludvigsdottir SJ, Kvale G, et al. The Bergen 4-day treatment for OCD in Iceland: 12-month follow-up. *The Cognitive Behaviour Therapist*. 2026;19:e17. doi:10.1017/S1754470X26100555.

7 To make space for new or better ways of doing things we might need to stop doing other things. What do you think we should stop doing, or do less of, so we can focus on what would work better? Please tell us why.

Investment in the early diagnosis and effective treatment of OCD would mean better outcomes for service users; we would also stop wasting resources on ineffective care.

People who are experiencing OCD tend to have a 'revolving door' experience with the mental health system; without the correct diagnosis and effective condition-specific treatment that is entirely predictable.

Consistent with a 'revolving door' of ineffective care, the Adult Psychiatric Morbidity Survey 2023-2024 in England found that people who met the CIS-R criteria for OCD in the past week were more frequent users of both primary and specialist services for mental health reasons (see Table 7).

Table 7. Health care service use self-reported by people who met the diagnostic criteria for a common mental health condition (CMHC) in the past week, Adult Psychiatric Morbidity Survey 2023-2024 in England.[14]

Service used for a mental health reason	OCD	Any CMHC	Population
Inpatient stay in past quarter	1.6%	0.5%	0.1%
Outpatient visit in past quarter	3.3%	2.3%	0.6%
Spoken with GP in past 2 weeks	21.6%	7.1%	1.7%
Spoken with GP in past year	58.2%	39.2%	13.2%

Similarly, an Australian study[15] found that OCD diagnoses are a significant grouping among children and adolescents who require inpatient mental health care and that the costs for admissions associated with OCD were substantial:

- Hospital admission for children and adolescents at two mental health inpatient units in Sydney were evaluated.
- Patients with any OCD diagnosis accounted for ~9% of admission and a disproportionate ~15% of hospital bed days.
- When compared to the other primary diagnoses such as anxiety, depression, eating disorders and psychosis, the patients with a primary diagnosis of OCD (~3% of admissions) had the second longest length of stay (~23 days) and hence the second highest cost per admission (~AUD 64,000).
- The patients with a primary diagnosis of OCD also had the highest rate of readmission within 28 days (about 1 in 6 patients).

Providing clinicians with advanced training in OCD treatment and enabling a service structure that achieves excellent outcomes for patients within a supportive community of practice would not only improve the productivity of the health system, it would also enhance workforce satisfaction.

[14] Data sourced from Chapter 2, Table 2.8, Adult Psychiatric Morbidity Survey, NHS England. Data sets for each chapter can be found at: https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/survey-of-mental-health-and-wellbeing-england-2023-24/dataset

[15] Dyason KM et al. Gen Hosp Psychiatry. https://www.sciencedirect.com/science/article/pii/S0163834323001536?via%3Dihub

8 We want to make sure that the things we do are making a difference to people. What should we be checking, measuring or keeping an eye on to know if the strategy is making a difference?

From the perspective of Fixate's OCD community, it is essential that the health system engage with the leadership of lived experience communities and that monitoring includes evaluations tailored to the needs of those communities.

Monitoring of the current five targets from the Government Policy Statement on Health provides 'top-level' information about the time taken to access mental health services and about workforce numbers for professional categories such as clinical psychology interns or psychiatry trainees.

Similarly, monitoring of mental health outcomes using data gathered with the Health of the Nation Outcome (HoNOS) family of measuring tools provides 'top level' monitoring of the effectiveness of mental health services. Even so, as yet, the collection of HoNOS data is incomplete, particularly so for community services. Outcomes are evaluated by comparing HoNOS scores from the group admitted and the group discharged from the service in the same time period; rather than by comparing HoNOS scores gathered from individuals at the time of their admission and at the time of their subsequent re-assessment or discharge.

These mandated ways of monitoring outcomes for users of mental health services do not 'drill down' enough to monitor the issues that Fixate's OCD community is concerned about such as:

- *Access to treatment*. What criteria are used to decide whether or not someone experiencing OCD meets the threshold for referral to specialist services? At present, people with OCD often fall into "the missing middle".
- *Effectiveness of treatment provided for OCD*. Are current response and recovery rates consistent with treatment delivery from well-trained and supported clinicians? If the HoNOS data for admission and discharge were compared for each person treated for OCD, would people with OCD typically show strong responses to treatment? Could the Yale-Brown Obsessive Compulsive Scale - an internationally recognised and validated tool used to assess the range and severity of OCD symptoms - always be used on admission and discharge for OCD treatment?
- *The diagnosis- and treatment- gap for OCD*. How many years does it take, on average, for an individual to access the correct diagnosis and then OCD-specific treatment in NZ? Are these gaps closing?
- *Basic training of NZ health professionals and allied professionals such as GPs, nurse practitioners, midwives, counsellors, social workers and teachers.* What information is being provided about OCD?
- *The experiences and needs of families who support someone experiencing OCD.* No research has been done on this issue in NZ.

In conclusion, we request that there be provision for targeted monitoring and for carrying out targeted studies to enable "drilling down" to check on whether the Strategy is making a difference for individual lived experience communities.

9 Are there any other thoughts, concerns or ideas you want to share?

This submission has focused on the condition-specific needs of the OCD community.

We attempted to balance the competing factors of (i) writing a clear, concise document and (ii) providing enough background information about OCD to give a context to the comments being made about the draft strategy and priorities for the implementation plan.

We have not covered more general needs such as timely access to psychiatric expertise for differential diagnosis and the optimisation of medication; and provision during the perinatal period for mental health literacy, diagnosis and care and support for parents experiencing mental distress including perinatal OCD.

If any further information would be helpful, please do not hesitate to contact us.