Report of the Health Committee

Petition of Marion Maw: Ensure access to ERP therapy for people living with OCD

May 2023

Contents

Dr Tracey McLellan
Chairperson

Petition of Marion Maw

Recommendation

The Health Committee has considered the petition of Marion Maw—Ensure access to ERP therapy for people living with OCD—and recommends that the House take note of its report.

Request regarding access to exposure and response prevention therapy for people living with OCD

The petition was presented to the House on 3 August 2022. It requests:

> That the House of Representatives ensure that people living with Obsessive Compulsive Disorder have timely and equitable access to effective therapy by expanding the workforce trained in Exposure Response Prevention therapy (ERP) in primary and secondary health services; and note that 1,290 people have signed a petition in support.

Exposure and response prevention therapy involves a person being voluntarily exposed to the source of their fear without acting out any compulsions to neutralise or stop the fear. ERP is a form of cognitive behaviour therapy (CBT).

The petitioner, Marion Maw, submits that ERP is an evidence-based best practice therapy that provides skills to help people "break free" from OCD. In her view, ERP therapy is hard to access and many people are unable to receive the help that they need. People experiencing severe OCD may be referred to secondary services where staff with expertise in ERP are scarce. Others remain in primary care where staff are unlikely to have training in ERP.

Initial comments from the petitioner

The petitioner made her written submission on behalf of Fixate members. Fixate is a Facebook-based group for people in New Zealand who live with, or support someone living, with OCD. The group was started in 2017 by the parent of a child experiencing OCD.

Fixate provides an online forum for people to connect and share experiences, information, support, and encouragement. Five volunteer administrators (three with lived experience of OCD and two parents) manage the day-to-day operation of the Facebook group and a website. The group contains about 1,200 members.

The petitioner made an initial written submission in August 2022. We held an oral hearing with the petitioner and Louise Aitken in February 2023. Their experiences of OCD are as parents, and both are volunteers for Fixate. This section of our report focuses on the initial written submission and the oral hearing. The petitioner also made a further written submission in February 2023 in response to Te Whatu Ora's submission. We discuss that submission later in our report.

About obsessive compulsive disorder

The petitioner described OCD as a mental health disorder that can be debilitating. An individual's mind gets stuck on unwanted ideas, images, urges, and sensations (known as intrusive thoughts). The person finds the intrusive thoughts distressing because they go against what the person truly wants. They feel compelled to respond in some way, such as by seeking certainty that a disturbing thought is untrue. This tends to promote additional thoughts of a similar nature, drawing the person into an obsessive-compulsive spiral.

The petitioner explained that OCD is often first experienced as a child, adolescent, or young adult, or as a new parent during the perinatal period.[1] It may also be experienced following trauma. OCD is generally a chronic condition that "waxes and wanes" during an individual's life.

The petitioner said that about 1 percent of the population lives with OCD, equating to more than 50,000 New Zealanders, plus their family members who are affected. However, in its written submission, the NZ College of Clinical Psychologists highlighted data from the Dunedin longitudinal study. The data suggests that the figure is likely to be closer to 2 percent of the New Zealand population.

The petitioner noted that ERP therapy is well established as best practice treatment for OCD, and is firmly endorsed by international and national guidelines. For example, Whāraurau[2] describes a combination of selective serotonin reuptake inhibitor (SSRI) medication and CBT—ERP therapy as the gold standard.

The experiences of Fixate members

The petitioner said that Fixate members include young adults, parents who experienced perinatal OCD, and older adults, some of whom realised later in life that they have OCD. Its members may currently be experiencing considerable mental distress, be undergoing ERP therapy, or be in recovery. The members also include parents who support a child, adolescent, or young adult experiencing OCD and the partners of adults living with OCD. The petitioner told us that common themes have emerged as members have shared their stories. These experiences, which are set out below, have resulted in unnecessary suffering for individuals and their families.

Barriers to receiving a diagnosis

The petitioner submits that misconceptions and stereotypes about OCD are widespread. There is also a "harmful" lack of awareness and understanding about the condition in the wider community and among health professionals. The mental distress of OCD is often unrecognised by individuals, people around them, and health professionals, or may be wrongly attributed to other conditions. People may also find it difficult to disclose thoughts that are of a taboo nature.

According to the petitioner, international research shows that it takes an average of 10 years for an individual experiencing OCD to receive the correct diagnosis and access appropriate support. We heard that the petitioner's "parental alarm bells" began ringing when her

1 The period during pregnancy and up to a year after giving birth.

2 Whāraurau is the national centre for infant, child, and adolescent mental health workforce development.

daughter was in primary school. However, her daughter did not access the necessary information and support until her first year of university. The petitioner said she repeatedly hears of similar experiences as an administrator of Fixate.

The petitioner explained that a decade or more of unrecognised OCD can have enormous consequences. It can affect a person's wellbeing, impair relationships, and result in a reduced ability or inability to continue in school, study, or employment.

Barriers to accessing effective treatment

The petitioner told us that accessing effective OCD-specific treatment in the public health system is difficult. She noted that all clinical psychologists and psychiatrists are trained in CBT. However, this is not necessarily the case for non-clinical psychologists and other mental health practitioners.

Te Pou[3] provides a national centre for mental health workforce development in New Zealand. The petitioner referred to Te Pou's "stepped care approach" to talking therapies. The steps are: early presentation of problems or distress; mild to moderate presentations; moderate to severe presentations; severe presentations and disorders; and complex and long-term disorders. Under this approach, the primary level of care is intended for those with early, mild to moderate, and moderate to severe presentations. The secondary level of care is intended for severe presentations and disorders (specialist care) and complex and long-term needs (highly specialised care).

The petitioner submits that the initial diagnosis and subsequent management of OCD is often influenced by a GP's knowledge and beliefs about the disorder. GPs often refer an individual experiencing OCD to brief intervention counselling sessions in primary care. However, Fixate members have observed that these staff usually have little understanding of OCD and have no training in ERP therapy.

We were told that Fixate members have reported that the bar is high to access the secondary level of care. This is despite OCD being a mental health disorder and long-term condition that requires a specific therapy. Some members have also experienced long delays in having medication initiated or reviewed because of difficulties accessing a psychiatrist in the public health system. Fixate members have described secondary services in each region as providing "hit and miss" care for people with severe OCD and those with complex needs.

The petitioner said that people who can afford it may turn to the private sector, at considerable expense. However, they may struggle to find a psychologist or psychotherapist who has expertise in ERP and is accepting new clients. The petitioner believes socio-economic status should not determine whether a person can receive a diagnosis and access OCD-specific treatment.

The petitioner observed that expertise in OCD treatment is a specialty, which very few specialists have at present. We also heard that not enough people have the training to work with people experiencing OCD to meet the demand in both the public and private sector. The

[3] Te Pou is the national workforce centre for mental health, addiction and disability.

petitioner told us that some people are now turning to online therapists in the United States and Australia and are paying “quite a lot” of money to do so.

Effect on families of individuals experiencing OCD

The petitioner told us that the entire household is affected when a family member experiences OCD. We asked the petitioner what an earlier diagnosis would have meant for her family if appropriate knowledge, training, and expertise had been available. She said that there are costs “all over the place” associated with OCD. Children may not be able to cope with attending school, affecting their career development and ability to become productive in the workforce. Parents may also need to give up work to care for their child.

The petitioner described OCD as a spiral, which people get drawn further into. Spending 10 years developing habits, beliefs, and responses makes it difficult for a person to pull themselves out of the spiral. In the petitioner’s view, earlier diagnosis would result in a person needing less care.

The petitioner’s requests

Access to ERP therapy and medication

The petitioner pointed out that people with OCD do receive care. However, she said that the care is not particularly effective and is not an effective use of the health system’s resources. The petitioner recognises that the health system is strained. However, she believes that investing in more of the same will not help the OCD community. We heard that generic support for anxiety and depression is ineffective for OCD and merely acts as “Band-Aids”.

The petitioner considers that ERP therapy and SSRI medication should both be readily available. She said that ERP can provide the skills needed to manage OCD in the long term but is challenging to complete. For some people, SSRIs can decrease the intensity of obsessive thoughts but they can have side effects. A combination of ERP and SSRIs can help quieten the obsessive thoughts, making it easier to complete the exposure therapy.

The petitioner has a number of requests regarding ERP therapy, many of which relate to workforce development. They are:

- an acknowledgement that primary and secondary mental health services are not meeting the needs of people living with OCD
- a regional stocktake of the workforce that has expertise in providing OCD treatment, including in the context of associated conditions
- an evaluation of the “pipeline” for workforce development to produce enough mental health professionals who can capably and confidently provide OCD treatment
- mental health professionals working in primary care who have expertise in treating mild to moderate and moderate to severe OCD
- opportunities for mental health professionals working in primary and secondary care to upskill in OCD diagnosis and treatment
- a “realistic level” of support to navigate and finance OCD treatment in the private sector when treatment is not available in the public sector in a specific region

- a mechanism for people experiencing OCD, and health professionals making referrals, to know whether a therapist has specific expertise in OCD treatment.

Development of a national strategy for OCD

The petitioner believes a national strategy should be developed to support early diagnosis of OCD and to ensure timely and equitable access to OCD-specific treatment. She also requests a national health promotion strategy. Its purpose would be to improve recognition and understanding of OCD in the community and among health professionals. The petitioner is grateful for the efforts of a range of organisations that provide information about OCD. However, she maintains that "one-off piecemeal" initiatives do not replace the need for a national strategy.

The petitioner would like a working group to be established to create the national strategy, and to provide peer and clinical support for people who experience OCD and their families. The work should involve consultation and representation from a range of stakeholders, including the OCD community.

The petitioner also proposes several initiatives related to the national strategy. They include providing accessible resources for health professionals to help individuals and their families to access effective support, and routine screening for OCD when associated conditions are present. Examples include for new parents during the perinatal period, and when there is suicidal ideation, self-harm, or substance use. Other initiatives include introducing a national system to enable an individual and their GP to readily consult a child or adult psychiatrist with expertise in OCD and associated disorders.

The petitioner would like knowledgeable ongoing support provided for families who care for an individual experiencing OCD, including when the OCD is severe and untreated. We heard that the petitioner and Ms Aitken both learnt very quickly that the ways they thought would support a family member were actually "feeding" the OCD.

Collection of relevant data

The petitioner considers that data relevant to OCD is needed to assess the performance of the health system. She is concerned that it is not known how well New Zealand is performing in diagnosing and treating OCD. The petitioner would like data relevant to OCD to be collected and analysed at the primary and secondary level of healthcare. Relevant information includes the time from onset of symptoms to seeking help, receiving the correct diagnosis, and accessing OCD-specific treatment; and the socioeconomic consequences for individuals and their families.

Comments from Te Whatu Ora

OCD treatment options

Te Whatu Ora—Health New Zealand said it is important to note that there is no one solution to treating OCD. Treatment should be considered for each individual, based on a mental health practitioner's assessment of the individual's needs, preferences, values, and co-existing conditions.

Te Whatu Ora observed that the OCD treatment options with the strongest evidence include psychological and pharmacological therapy. It noted that ERP is the psychological therapy with the most substantial evidence base for OCD, with a cited response rate of 83 percent.[4]

Te Whatu Ora pointed out that mental health practitioners in New Zealand are guided by guidelines from two organisations: the Royal Australian and New Zealand College of Psychiatrists, and the National Institute for Health and Care Excellence (NICE).[5] The NICE guidelines recommend cognitive behaviour therapy, including ERP, for the treatment of obsessive compulsive disorder.

Te Whatu Ora explained that treatment options for children and young people vary depending on the degree of impairment experienced in an individual's daily life. For children and young people with mild symptoms, guided self-help combined with whānau support is recommended. CBT including ERP with whānau participation and support is recommended for children and young people experiencing moderate to severe functional impairment. An SSRI may also be considered for adolescents who are unable to participate in therapy, or who have declined it.

For adults with a mild degree of functional impairment, treatment options include brief individual CBT, including ERP, using structured self-help materials. Adults experiencing moderate to severe functional impairment may be offered individual CBT, including ERP, and an SSRI.

Te Whatu Ora's response to the petitioner's requests

Te Whatu Ora recognises that good health outcomes and recovery from OCD are more likely when quick access to appropriate treatment is provided. It responded to the petitioner's requests and gave examples of the work under way to strengthen access to OCD diagnosis and treatment.

Provision of services in secondary care

Te Whatu Ora said its "absolute expectation" is that clinical psychologists are trained and have the skills to diagnose and treat people with OCD. People with moderate to severe OCD can access a clinical psychologist referral through the public system. It acknowledged that there can be long wait times to see clinical psychologists within specialist health services.

Te Whatu Ora recognises that this is not a direct measure of whether clinicians are providing ERP for people with OCD. However, it expects that clinicians will provide best practice treatment for individuals that aligns with clinical guidelines.

Te Whatu Ora considers that the health reforms are an opportunity to provide more uniform access to specialist advice and effective treatments across the country. It explained that it has several initiatives designed to help achieve this, which include developing clinical networks to ensure more consistent access to services. We heard that it sees the networks

[4] Foa, E B, & Kozak, M J (1996), Psychological treatment for obsessive-compulsive disorder, in M R Mavissakalian & R F Prien (Eds), Long-term treatments of anxiety disorders (pp 285–309), American Psychiatric Association.

[5] The NICE guidelines are evidence-based recommendations for health care in England and Wales.

as providing a formal channel for engaging with organisations like Fixate and other lived experience groups at a national level.

Te Whatu Ora is working with Te Aka Whai Ora—the Māori Health Authority to develop new operating models. These will integrate hospital and specialist services with the commissioning of primary, community, and te ao Māori mental health services. This work aims to help ensure that services around the country are cohesive and people can access appropriate care through primary care and specialist services.

The Ministry of Health—Manatū Hauora is also developing a mental health and addiction system and service framework. This will set guidance and expectations about the range of mental health and addiction services that will be available nationally, regionally, and locally.

Te Whatu Ora acknowledged the petitioner's request for support to navigate and finance OCD treatment in the private sector. However, it said it does not directly subsidise private mental health and addiction care nationally because the country has a public health system. Te Whatu Ora agreed that access to effective OCD treatment should not be limited to those who can afford to pay for a private psychologist. For this reason, it is investing in increasing the options and choice available in the public health system.

Provision of services in primary care

Te Whatu Ora noted that OCD is a relatively uncommon condition that often requires specialist care. It expects that people who are experiencing moderate to severe OCD would be referred to secondary services, which have appropriate specialist training. However, Te Whatu Ora considers that people should also be able to access care at a primary level for mild to moderate mental health distress.

Budget 2019 provided funding of $455 million to establish the Access and Choice programme, which provides mental health and addiction services in primary care settings. The aim of these services is to recognise and respond to mental health and addiction distress earlier. The programme is provided nationally through four workstreams:

- integrated primary mental health and addiction services
- youth-specific primary mental health and addiction services for 12- to 24-year-olds
- kaupapa Māori primary mental health and addiction services for people of all ages
- Pacific primary mental health and addiction services for people of all ages.

Integrated primary mental health and addiction services are based in general practice settings. They involve expanding the general practice team to include the roles of health improvement practitioner and health coach. We are interested in what percentage of mental health professionals in general practices are CBT-qualified. Te Whatu Ora said that they are all expected to have experience and training in talking therapies. However, it was unable to tell us how many are CBT-qualified.

We asked whether a person could choose what professional they saw through the Access and Choice programme. We heard that a person can for the youth-specific, kaupapa Māori, and Pacific services. However, for services in general practices, it would depend on whether the practice had more than one health improvement practitioner.

Information about the workforce with expertise in providing OCD treatment

Te Whatu Ora told us that a regional stocktake of the workforce with expertise in providing OCD treatment is not on its work programme at present. It explained that it implements funding in line with two directions. They are Te Pae Tata—the interim New Zealand Health Plan, and the Minister of Health's direction to ensure that public funding is applied efficiently and consistently.

Te Whatu Ora funds four national mental health and addiction workforce development centres, two of which collect information about the mental health and addiction workforce. Te Pou gathers and shares information about the health-funded mental health and addiction services workforce that provides services to adults.[6] The stocktakes were most recently published in early 2019 and April 2023. Whāraurau conducts a periodic stocktake of the health-funded mental health and addiction workforce working in infant, child, and adolescent services. Both stocktakes include information about the numbers of clinical psychologists, all of whom must be trained in CBT. They also collect information about other mental health practitioners, including nurses, occupational therapists, and social workers, who may have completed postgraduate courses in CBT.

Te Whatu Ora said it encourages people looking for OCD-specific treatment to contact health professionals before visiting them, to ask whether they have specific expertise. It suggested that registration bodies may also be able to provide contact details for health professionals specialising in OCD treatment.

Workforce development

We heard that the workforce shortages that the country is experiencing are a global issue. Te Whatu Ora explained that it is implementing a range of workforce initiatives to upskill and increase the current workforce, and develop new workforces. However, it said that there is no "instant solution" and this work will take time.

Te Whatu Ora noted that a significant focus of this work is on increasing and developing the clinical psychology workforce. It is increasing the number of clinical psychology internships it funds each year, from 12 in 2019 to 40 in 2024 and the years following. Te Whatu Ora has also increased the pay for interns to attract them to the public sector.

Te Whatu Ora has also funded 10 postgraduate courses for talking therapies and brief interventions. They include six papers that focus on CBT and best practice for treating OCD. It also provides funding for Te Pou to provide the Skills Matter initiative, which funds postgraduate training. The training is for new graduates and existing practitioners working in DHBs, NGOs, and primary care settings.

Requests regarding a national strategy

Te Whatu Ora explained that a working group to advise on OCD diagnosis and treatment, and a national health promotion strategy for OCD are not on its work programme. It reiterated that it implements its funding in line with Te Pae Tata and the Minister's direction to ensure that public funding is applied efficiently and consistently.

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6 The health-funded organisations are district health boards (DHBs) (now Te Whatu Ora) and non-governmental organisations (NGOs).

The petitioner also requests routine screening for OCD when certain conditions associated with it are present. Te Whatu Ora observed that people with OCD may also experience a range of other mental health conditions. It said that people may present to primary health services with anxiety-provoking thoughts that are seen as involuntary and intrusive. In these situations, health practitioners should assess and review the thoughts as possible OCD symptoms. Te Whatu Ora noted that health professionals in some districts use Health Pathways. This is an online platform that provides best-practice, condition-specific guidelines and associated information, including information about diagnosis.

The petitioner also requested a range of other information and resources. They include accessible resources for health professionals, a national system to consult a psychiatrist with expertise in OCD and associated disorders, and ongoing support for families. We were told that some Te Whatu Ora districts have implemented phone lines so GPs can consult a clinical psychologist or psychiatrist. Te Whatu Ora funds Yellow Brick Road, which offers free support, education, and information for families and whānau affected by mental health issues.

Collection of relevant data

Te Whatu Ora acknowledged that neither it, nor the ministry, collates data on the waiting times for OCD diagnosis. They also do not collate data about the prevalence of OCD or the rate of access to mental health services for people who receive an OCD diagnosis.

In its written submission dated October 2022, Te Whatu Ora noted that work was under way to build a national Primary Health Dataset. It said that it was too early to comment on whether this may provide more reliable data on OCD diagnosis and treatment.

Comments from the NZ College of Clinical Psychologists

The New Zealand College of Clinical Psychologists is a professional association that represents the interests of more than 1,800 clinical psychologists registered in New Zealand. Clinical psychologists are experts in mental wellbeing, behaviour, and neurodiversity. They work across a range of specialties and employers, including in the public sector and as private practitioners.

The College said it is “very much in support” of the principle of the petition—that is, to increase access to evidence-based treatments for people with significant mental health issues. In its view, the oral submissions of the petitioner and Te Whatu Ora reflected the tensions between generic mental health services and the conditions that have specific treatments associated with them.[7] The College observed that these conditions need very tailored interventions. Receiving the wrong treatment is, at best ineffective, and, at worst, damaging.

Benefits of evidence-based psychological therapies

The College explained that research suggests that psychological therapies provide the following benefits compared to medication:

[7] Examples of other conditions include bipolar disorder and ADHD (Attention Deficit Hyperactivity Disorder).

- They are generally more, or at least equally as, effective than medication in treating a range of mental health conditions.
- They can apply more widely, such as to relationship difficulties, grief, work-related stress, and burnout.
- They have fewer (if any) side effects.
- Generally, psychological therapies and medication cost the same to provide over the lifetime of treatment. Psychological treatment is usually provided over a shorter period but is more intense.

Guidelines for the treatment of OCD

According to the College, no agency in New Zealand has responsibility for evaluating and commissioning up-to-date psychological treatments. Therefore, New Zealand clinicians typically refer to overseas institutions like NICE, which has extensively reviewed the international evidence for treatments of mental health conditions.

The College highlighted the current NICE guidelines for the treatment of OCD.[8] The guidelines recommend CBT with ERP as the first-line treatment, which should be offered to everyone experiencing distress from OCD. The recommended number of individual hours with a therapist depends on a range of factors. Medication is only recommended where a person has moderate to severe difficulties in daily functioning and only in combination with CBT and ERP.

Access to evidence-based psychological therapies in New Zealand

The College noted that the Government has invested heavily in recent years in integrated primary mental health and addiction services. This is primarily through the Access and Choice programme. As part of the programme, health improvement practitioners are trained in brief interventions. The College referred to Te Pou guidance, which states that the practitioners receive four days of training, including in focused acceptance commitment therapy. According to the College, NICE guidelines do not recommend this therapy for any diagnosable condition. It added that health practitioners may have previous experience or may have completed further training on OCD. However, this is not a requirement of the role. As a result, skill and knowledge is likely to be extremely variable.

The College said that individuals with moderate to severe mental health conditions who cannot access suitable support in primary care are typically referred to secondary services. However, its members report that clients face significant barriers to accessing these services—treatment is prioritised to people at substantial risk of harming themselves or others. People who do access secondary care services may face a substantial wait time to meet with a psychologist.

We were told that many consumers and families seek to pay for private sessions from a clinical psychologist. However, a 2021 survey of the College's members found that many

[8] These recommendations do not include situations where a person may have other co-existing mental health difficulties, suicidal thoughts and behaviour, neurodiversity, or other challenges.

clinical psychologists in the private sector were overwhelmed with referrals and may not have been able to offer timely support.

Training and expertise required to provide ERP with CBT

The College explained that clinical psychologists are the main provider of psychological therapies to people with OCD in New Zealand. However, it noted that there is a shortage of this workforce within New Zealand. In 2017, the Psychology Workforce Task Group suggested that 1,000 more psychologists were needed to meet the demands within district health boards and primary care.[9]

The College acknowledged the recent increases in funded internships for clinical psychologists and for postgraduate training in CBT. It hopes that they will lead to corresponding increase in access to evidence-based psychological therapies. However, it pointed out that the initiatives are not specific to ERP and OCD, and increased access is likely to take several years.

The College pointed out that clinical psychologists are not the only professional group who can provide psychological therapies. However, non-psychologists typically require a lot more training and supervision. It noted that Te Pou funds more than 70 postgraduate training places in CBT for registered mental health practitioners. The programme offers a one-year postgraduate certificate, which is a prerequisite for a further one-year postgraduate diploma in CBT. The College said that ERP with CBT for obsessive compulsive disorder is considered an advanced skill and is usually addressed as a small part of the diploma after two years of study. Further, when a mental health professional has achieved the necessary foundational skills to provide ERP, the College recommends that they undertake specialised training in OCD. This enables them to maintain and maximise competence in working with this population.

The College observed that a clinical psychologist would be expected to be able to diagnose OCD and offer some type of treatment. However, it emphasised how complex people with OCD can be, and that people rarely present with OCD symptoms and “nothing else”. We heard that the United Kingdom has specialist centres that provide purely OCD treatment. In New Zealand, services tend to be more generic because the population is smaller. Consequently, a person may work in a community mental health team and never see someone with OCD. Although they would have background training, they would not have specialist exposure or training.

We asked whether the College believes any other professions can provide support in this area. We suggested nurse practitioners or mental health nurses as examples. The College believes there is not much of a workforce in the “middle ground” at present. It ranges from specialists like psychiatrists and psychologists to generalists who work in primary care, but there is not much in between. The College considers that the solution is having more psychologists or finding a way to train existing staff. It gave nurses as an example, but recognises the workforce shortages.

[9] The group was a cross-agency group convened by the Ministry of Health.

We asked what one area the College would focus on if it could change the situation. We heard that the College would consider how psychological therapies could be provided more effectively and efficiently. It highlighted the *improving access to psychological therapies programme* in the United Kingdom. It described the programme as a targeted way of providing evidence-based psychological therapies to people, which evidence shows works very well. A person presenting at a GP receives an assessment about their key issue. If they have OCD, they receive CBT and ERP provided by people with specialist training. We heard that the programme involved huge investment in training non-psychologists, particularly psychology graduates.

Further comments from the petitioner

In February 2023, the petitioner made a further written submission. She thanked Te Whatu Ora and the NZ College of Clinical Psychologists for their submissions, noting that it was helpful to understand their perspectives.

However, the petitioner was disappointed by Te Whatu Ora's response. She said that Te Whatu Ora appeared to be describing what should be happening rather than what actually happens. The petitioner also pointed out that CBT is a "very broad umbrella" term that covers many areas, and OCD-specific treatment fits under that umbrella. However, even if a person has broad or specific knowledge of CBT, it does not mean that they know about OCD or how to apply OCD-specific CBT.

The petitioner understood the "practical point" on why the actions requested in the submission are not on its work programme. However, she is "dismayed" about its reference to the Minister's direction to ensure that public funding is applied efficiently and consistently for all New Zealanders. The petitioner considered that a statement about equity in Te Pae Tata is more relevant. It is that "equality treats everyone the same regardless of need, while equity treats people differently acknowledging their different needs."[10] The petitioner requests that her petition be considered from an equity viewpoint, rather than a one-size-fits-all approach, which is not serving the OCD community.

The petitioner's concerns

The petitioner's other concerns in response to Te Whatu Ora's submission are summarised below.

The petitioner remains concerned about the lack of a national strategy for OCD. Although she believes guidelines for OCD are worthy, they achieve very little on their own. The petitioner noted that international focus has shifted to ensuring that guidelines are implemented. She highlighted two NICE guidelines that are particularly relevant: system-wide leadership from specialist teams and the need for leadership throughout the health system and related services. The petitioner submits that there is precedent for condition-specific planning at a national level with representation from a range of stakeholders. Autism spectrum disorder is one such example.

[10] Te Pae Tata | Interim New Zealand Health Plan, 2022, page 15.

The petitioner referred to Te Whatu Ora's comments that assessment for the diagnosis of OCD should already be routine when there is a possibility of OCD. She provided several testimonies of Fixate members who have sought support for OCD and had their symptoms overlooked, misunderstood, minimised, or misdiagnosed.

Te Whatu Ora's submission set out its expectations for clinical treatment for OCD using the terms mild, moderate, and severe. However, the petitioner is concerned that it does not define these terms. Fixate members report being told that their condition is not "bad enough" to access treatment from secondary health services. The petitioner therefore requests more clarity about how decisions are made on whether a referral for OCD will be accepted. She would also like people who do not meet the threshold for secondary services to be given OCD-specific guidance. This would be in the form of an information booklet for New Zealanders diagnosed with OCD and their families, with Fixate consulted on its content.

The petitioner agrees that the Health Pathways platform has the potential to be a useful tool to improve care for OCD but she has some concerns about it. They include that the platform is usually only accessible to health professionals and the content may vary between regions. The platform's structure also makes it difficult for advocates to easily see what information is being presented to health professionals. The petitioner would like a national review of the information about OCD on Health Pathways. The review should include consultation with a psychologist and psychiatrist who have specific expertise in OCD. Fixate would also like to be involved in the consultation as it is aware of the knowledge gaps that most often cause problems for individuals and their families.

The petitioner observed that the importance of lived experience is now recognised in New Zealand when planning and providing mental health care. In her view, people with personal experience of OCD or supporting a family member could be more involved in this work. The petitioner also suggests that OCD-specific peer support groups could be established. The groups, which would need to be appropriately resourced, would be for individuals living with OCD and for those who support someone living with OCD.

Our response to the petition

We thank the petitioner for highlighting this important matter. We commend her and other Fixate volunteers for their advocacy on behalf of people experiencing OCD and their families. We would particularly like to acknowledge its work to provide an online community and website to enable experiences and information to be shared.

We note the College's comments that the petition highlights the tensions between generic mental health services and conditions like OCD that need tailored interventions. We acknowledge the investment in recent years to provide mental health and addiction services in primary care. However, we understand that it is not a prerequisite for health improvement practitioners to have CBT training, and they are unlikely to have specific OCD and ERP expertise.

We recognise that work is under way to increase the clinical psychologist workforce and to provide postgraduate training in CBT. However, increased access will take some time and the initiatives are not specific to ERP and OCD. In the meantime, we urge Te Whatu Ora to consider whether the existing workforce could be trained in ERP.

We note that Te Whatu Ora has several initiatives under way to provide more uniform access to specialist advice and effective treatments across the country. We were interested to hear that Te Whatu Ora intends to engage with organisations with lived experience through its clinical networks. We encourage Te Whatu Ora to consider how it can involve people with personal experience of OCD or supporting a family member in the planning and provision of services.

We consider that the health reforms also provide an opportunity for more consistent use of tools such as the Health Pathways platform. We agree that people with specific expertise in OCD and lived experience should be involved in reviewing the information about OCD. We suggest that Te Whatu Ora explores how to make the information on the platform more consistent and more accessible, including for families who care for an individual experiencing OCD.

We acknowledge that a working group to advise on OCD diagnosis and treatment and a national health promotion strategy are not on Te Whatu Ora's programme. However, we note that there is precedent for having condition-specific planning at a national level. We encourage Te Whatu Ora to investigate whether this approach could be used to create a guideline for OCD.

We note the petitioner's comments that people are now using online therapists in the United States and Australia. We encourage Te Whatu Ora to explore whether technology could be used to provide choice. This could involve creating a platform where people could digitally access therapists from around the country.

We urge the Health Committee of the 54th Parliament to follow up on this matter within 6 to 12 months.

Appendix

Committee procedure

The petition was referred to us on 25 October 2022. We met between 9 November 2022 and 31 May 2023 to consider it. We received written submissions and heard oral evidence from the petitioner, Te Whatu Ora, and the NZ College of Clinical Psychologists.

Committee members

Dr Tracey McLellan (Chairperson from 15 February 2023)
Tangi Utikere (Chairperson and member until 8 February 2023)
Matt Doocey
Dr Elizabeth Kerekere
Dr Anae Neru Leavasa
Marja Lubeck (from 8 February 2023)
Debbie Ngarewa-Packer
Sarah Pallett
Soraya Peke-Mason (from 3 May 2023)
Dr Shane Reti
Toni Severin
Lemauga Lydia Sosene (until 3 May 2023)

Evidence received

The documents we received as evidence in relation to this petition are available on the Parliament website.

Recordings of our hearings can be accessed online at the following links:

- Hearing of evidence with the petitioner and Te Whatu Ora (15 February 2023).
- Hearing of evidence with the NZ College of Clinical Psychologists (22 February 2023).