






Finding help for OCD in Australia: development and evaluation of a clinician directory

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ABSTRACT

Objective: People tend to live with obsessive-compulsive disorder (OCD) for many years before receiving evidence-based treatment. This delay is partly due to a lack of access to information about which healthcare providers offer evidence-based treatment for OCD. This information was not easily accessible online for people in Australia.

Methods: In this study, we describe how an online directory of clinicians was developed and evaluated. We report on a needs analysis and survey of treatment-seeking histories among consumers and carers impacted by OCD. We describe the key features of the directory developed, and present survey feedback on its usability and utility.

Results: The results validated the need for a directory specific to clinicians who offer evidence-based treatment for OCD, and that it meets essential usability standards. Areas for improvement and further developments were identified.

Conclusion: This directory contributes to broader efforts invested to improve the treatment-seeking process for people living with OCD in Australia.

KEY POINTS

What is already known about this topic:

- (1) Globally, barriers to access delay appropriate treatment for OCD.
- (2) One barrier is not knowing who offers evidence-based treatment specific to OCD.
- (3) In Australia, there is no central source that provides such information.

What this topic adds:

- (1) The delays in treatment reported in Australia are comparable to other countries.
- (2) We developed a directory of clinicians with a special interest in treating OCD.
- (3) Consumer feedback suggests the directory will assist the treatment-seeking process.

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In any given year, approximately one in 50 people in Australia live with obsessive-compulsive disorder (OCD), according to the most recent prevalence data (Slade et al., 2009). Symptoms of OCD tend to cause substantive interference in day-to-day life. Indeed, data indicates that Australians who meet diagnostic criteria for OCD are unable to perform their normal duties, at home or work, for an average of 6.3 days per month (Slade et al., 2009). Evidence-based treatment guidelines for OCD have been clearly specified (American Psychiatric Association 2007; 2013; Australian Psychological Society, 2018; Katzman et al., 2014; National Institute for Health and Care Excellence,

2005; Skapinakis et al., 2016). These include cognitive-behavioural therapy, typically with exposure and response prevention, as a first-line psychological intervention, and selective-serotonin reuptake inhibitors as a first-line pharmacological intervention. However, people tend to live with OCD for years before they begin effective treatment.

Global research suggests that it takes approximately seven years for people to access effective pharmacological interventions (Dell'osso et al., 2019). Similarly, based on data from a recent meta-analysis of studies involving cognitive behaviour therapy with exposure and response prevention for OCD (Reid et al., 2021), we

calculated the average weighted duration of illness was 15 years prior to enrolling in the cognitive behaviour therapy trial. Research suggests that if people accessed adequate evidence-based treatment earlier, they might find treatment more effective, experience less psychosocial burden, and reduce the risk of comorbid disorders (Fineberg et al., 2019).

Barriers to seeking and receiving treatment

There are several reasons people live with OCD for so long before receiving adequate treatment. Regarding client factors, a literature review of studies investigating barriers to treatment-seeking reported that shame, a lack of knowledge about where to get help, and logistical constraints were consistent themes (García-Soriano et al., 2014). The authors noted that more education is needed to combat frequent underdiagnosis, and access to treatment should be improved. An Australian survey published the same year found similar themes (Gentle et al., 2014).

When people do overcome these barriers and seek treatment, they often face barriers in receiving appropriate assessment and treatment. There is a plausible risk of misdiagnosis by professionals, sometimes with significant adverse consequences (Stahnke, 2021). Such misdiagnoses can lead to missed opportunities to provide appropriate treatment during developmentally important years (Fineberg et al., 2019), prescriptions for medications that are known to exacerbate OCD symptoms (Abramovitch et al., 2013; Leung & Palmer, 2016), and inappropriate reports to authorities that may lead to legal complications (Bruce et al., 2018).

Following an accurate diagnosis, referrers or clients must then find a clinician with who offers evidence-based treatment, such as cognitive behaviour therapy with exposure and response prevention. Not all clinicians have an interest and competence in evidence-based treatments for OCD. This is an additional barrier to receiving effective treatment. Therapists are often hesitant to facilitate exposure-based exercises essential to exposure and response prevention (Jelinek et al., 2022; Moses et al., 2022; Pittig et al., 2019). There is also consensus that treatment for OCD is a specialised area (Pittenger et al., 2021; Sookman et al., 2021). Many postgraduate clinical psychology training programs in Australia however, tend to overlook disorder-specific cognitive behaviour therapy competencies, such as those required to address OCD (Impala et al., 2019). Anecdotally, the authors' experience is that many clients often see several health professionals over several

years before they receive an adequate course of an evidence-based treatment for OCD.

These help-seeking journeys could be shortened if people in Australia had access to information about mental health professionals who offer evidence-based treatments which specifically address OCD. One solution is to develop an online directory of such professionals. Similar approaches have been used for other specialised treatment areas in Australia, such as eating disorders (<https://butterfly.org.au>), borderline personality disorder (<https://www.uow.edu.au/project-air/find-a-service/>), and trauma conditions (<https://www.traumasupport.com.au>). Such a directory might address client barriers regarding a lack of knowledge about where to get help and assist both clients and referrers in identifying appropriate treatment providers.

This study reports on the development and evaluation of an online directory of healthcare professionals in Australia who offer evidence-based treatments for OCD. Guided by participatory design principles (Schuler & Namioka, 1993), our first aim was to test the need for such a directory among consumers, by examining the treatment-seeking histories of respondents. We then describe the development of the directory, evaluate its usability and acceptability among consumers, and identify areas for improvement.

Methods

Website development

We first defined the core requirements for a clinician directory that could provide access to information about healthcare providers who offer evidence-based treatments for OCD in Australia. These are outlined in Table 1, along with proposed acceptance criteria. We then conducted a series of searches on Google.com.au using combinations of terms such as "OCD", "therapists", "directory", "psychologists", and "psychiatrists" to identify whether a directory exists which already meets these requirements.

Our online searches yielded seven quality online directories, listed in Table 2. All directories allowed consumers to search for providers who treat OCD, either as a search filter or a dedicated directory. However, most were limited to clinicians that belonged to a specific profession, a professional association (at a substantive cost), or were trained by a commercial organisation outside of Australia. Further, several directories made little effort to validate whether the clinicians knew which evidence-based

Table 1. Requirements for clinician directory.

Requirement	Proposed Acceptance Criteria
People seeking help for OCD should be able to quickly identify clinicians who provide treatment in this problem area.	The directory will give users the option to filter results so that they can view only clinicians who specifically offer evidence-based treatments for OCD.
People seeking help for OCD should be able to access information that represents the widest possible range of evidence-based providers.	The directory will allow any AHPRA-approved mental health clinician to be listed. There will be no pre-requisite that they belong to a specific profession or association. Membership or listing fees will not be a barrier to clinicians being listed.
People seeking help for OCD should be able to find providers who have a high likelihood of offering evidence-based treatment.	Before being publicly listed, there will be some form of specific validation that the clinician understands and will offer an evidence-based treatment specific to OCD, such as exposure and response prevention.

AHPRA = Australian Health Practitioner Regulation Agency.

Table 2. Existing clinician directories.

Publisher	Link
Australian Association of Psychologists	https://www.aapi.org.au/FindaPsychologist
Australian Clinical Psychology Association	https://acpa.org.au/Web/Web/Find-a-CP/FACP.aspx
Australian Psychological Society	https://psychology.org.au/find-a-psychologist
International OCD Foundation	https://iocdf.org/find-help/
NOCD	https://www.treatmyocd.com/therapists
Psychology Today	https://www.psychologytoday.com/au/counselling/
The Royal Australian & New Zealand College of Psychiatrists	https://www.yourhealthinmind.org/find-a-psychiatrist

treatments are appropriate for OCD, or had undertaken to offer them to clients.

As none of the directories met all three criteria, we developed a dedicated online directory to address this need. The directory was designed to allow listings from any healthcare professional registered with the Australian Health Practitioner Regulation Agency (AHPRA) who works in mental health, regardless of their profession or association membership. We did not impose a listing fee for the directory and invited clinicians in private-practice Facebook groups and our personal networks to register and encouraged them to invite others.

To enhance the quality of the listings and provide greater value than general search engine results, the directory was designed with a quasi-peer-endorsement process. This process involved requiring clinicians use a unique invitation code from a colleague already in the directory to submit a listing application. In their application, clinicians are also asked to describe their typical treatment process for OCD. Each listing is manually reviewed by a clinician with expertise in treating OCD to ensure the description reflects evidence-based practice, prior to being approved and publicly listed in the directory. Applications from psychologists must include a brief description of cognitive behavioural therapy with exposure and response prevention. Similarly, applications from psychiatrists must include appropriate assessment and first-line use of selective serotonin reuptake inhibitors. This manual review also includes a check that the services offered by the clinician are appropriate to their profession and that their AHPRA registration is valid at submission.

The site has been designed so that neither the endorsing clinician's name nor the applicant's answers regarding the treatment process are made available to the public.

Consumer feedback

Participants

Participants who provided feedback included consumers, who identified as either living with a diagnosis of OCD, or caring for someone with OCD. To be included, participants were required to be 18 years or older and residing in Australia. Participants were recruited via study advertisements distributed on social media channels (on Twitter and an Australian OCD support group on Facebook) and by clinicians within the authors' professional networks. A total of 31 participants were enrolled in this study. Of these, 20 reported that they have a diagnosis of OCD ($M_{age} = 35.65$, $SD = 12.39$) and 11 reported that they are a carer for someone diagnosed with OCD ($M_{age} = 46.27$, $SD = 15.13$).

Materials

Consumer experience survey

Participants were asked to specify their age, type of consumer (patient/carer), treatments received to date, and the number of years since symptom onset, since diagnosis, and since treatment began, via an online survey. Participants were also asked "Have any of the following concerns influenced you to delay seeking treatment or avoid getting treatment for OCD

altogether?" and were presented with 17 potential barriers to access. This list was adapted for an Australian context from a previous study investigating barriers to OCD treatment in the United States (Marques et al., 2010). Participants were also invited to specify any other barriers not listed.

Usability testing task

Qualitative feedback was gathered using a procedure adapted from standard usability testing processes (18F, 2019; Hertzum, 2020). Participants were instructed: "Imagine you've had thoughts and urges that have been upsetting... Imagine that you have only recently been told that this is obsessive-compulsive disorder. You decide you want to find treatment. Please follow these two steps: (1) Using <https://ocd.org.au>, search for a mental health professional that could help; and (2) View their profile". Participants were invited to provide written feedback including their first impressions and experience searching the directory.

User Experience Questionnaire (UEQ)

The UEQ (Laugwitz et al., 2008) is a standardised measure of cognitive and emotional experiences when using software-based products or websites, with existing performance benchmarks derived by categorising scores from a large data set of previous user experience valuations (Schrepp et al., 2017). Participants were asked to rate their impressions on 7-point scales (scored -3 to 3) for 26 dichotomous items (e.g., "clear/confusing", "inefficient/efficient", "obstructive/supportive"). The items reflected six subscales that assessed both pragmatic (perspicuity, efficiency, dependability) and hedonic (stimulation, novelty, attractiveness) aspects of experience (α 's ranged from .91 to .94).

Procedure

Ethical approval for this study was obtained from the Human Ethics Research Committee at University of New South Wales (HC220039). After providing informed consent, participants completed the online Consumer Experience Survey at a time and place of

their choice. Participants were then presented with the homepage of the online clinician directory and asked to provide their initial impressions using an open-ended written question. Participants were then asked to complete the usability testing task, UEQ, and provide any final qualitative feedback.

Data analysis

Quantitative data were analysed in R (R Core Team, 2019) to calculate descriptive statistics. Answers to the UEQ were scored and compared to the most recent available benchmark data using a tool provided by one of the scale authors (Schrepp, n.d.). Qualitative data were processed using an inductive and latent theme analysis, guided by principles described in Braun and Clarke (2006). The first author coded answers to open-ended questions (initial impressions and final feedback), collapsed qualitative feedback from the two questions, extracted themes, and then checked these against the original data. Due to the brevity of the texts, this process was performed in Microsoft Excel (Robinson, 2022). The senior author reviewed the results and differences were resolved by discussion.

Results

Treatment journeys and barriers

A total of 31 participants began the survey and collectively provided data that indicated long durations of untreated illnesses and multiple barriers to treatment. The average treatment journey for participants who gave sufficient data is reported in Table 3. Two participants indicated that they received a diagnosis after starting treatment, which may reflect initial misdiagnosis and initially inappropriate treatment. Of the 29 participants who reported receiving a treatment, the majority reported accessing multiple modalities of care, the most common was medication ($n = 25$, 86%), followed by self-help ($n = 17$, 59%), other talk therapy ($n = 16$, 55%), cognitive behaviour therapy with exposure and response prevention ($n = 16$, 55%)

Table 3. Clinical history and treatment journeys in years.

Duration	Mean (SD)	Median	Min	Max
Since symptom onset	14.39 (13.29)	8.0	1.0	55.0
Since diagnosis	5.73 (7.32)	2.5	1.0	32.0
Since treatment begun	5.38 (7.16)	2.5	0.5	32.0
Between symptoms and diagnosis	8.66 (12.02)	4.0	0.0	48.0
Between diagnosis and treatment	0.36 (1.68)	0.0	-5.0	5.0
Duration of untreated illness ^a	9.02 (12.14)	5.0	0.0	50.0

Based on full data provided by $N = 28$ participants. One participant was omitted from this table as they indicated they were yet to receive a professional diagnosis. ^aFidelity of treatment was not assessed and may not have been in line with evidence-based treatment for OCD.

Table 4. Barriers to seeking or receiving treatment.

Barrier	N	Percent ^a
I was unsure about who to see or where to go.	16	59%
I felt ashamed of my problems.	15	56%
I wanted to handle it on my own.	14	52%
I worried about what people would think if they knew I was in treatment.	12	44%
I was not comfortable discussing my problems with a mental health professional.	11	41%
I was worried about how much it would cost.	10	37%
I received treatment before and it didn't work.	10	37%
I could not get an appointment.	9	33%
I was not comfortable telling my GP about my symptoms.	9	33%
I felt ashamed of needing help for my problem.	8	30%
I didn't think treatment would work.	8	30%
I was not satisfied with the treatments that were available.	6	22%
I thought it would be too inconvenient or take too much time.	4	15%
I was afraid of being criticised by my family if I sought professional help.	4	15%
I was scared about being put in a hospital against my will.	4	15%
I was scared about problems with the law or police.	2	7%

Items adapted from (Marques et al., 2010). Five participants (18.5%) also disclosed experiences with clinicians who either did not identify OCD or provide appropriate treatment. ^aPercentage of total respondents to this question ($n = 27$) who endorsed each barrier.

and cognitive behaviour therapy without exposure and response prevention ($n = 13$, 45%). Answers to open-ended questions regarding pathways to receiving treatment indicated that most participants found treatment via primary care ($n = 10$, 45%), followed by their own research ($n = 8$, 36%), and then secondary/tertiary care ($n = 4$, 18%). Two participants reported only receiving help for their OCD following suicide interventions. The barriers to seeking or receiving treatment are given in Table 4, the most common of which is a lack of clarity of where to get help.

Evaluation of directory

Mean user experience scores, gathered after participants reviewed the website, were compared to benchmarks given in the associated data analysis tool (Schrepp, n.d.) and described in the methods. These are presented in Table 5. Scores for all three pragmatic areas of user experience were above average, compared to the benchmarks. Participants rated the attractiveness and hedonic aspects of their experience as below average or bad, compared to updated benchmarks embedded in the data analysis tool. Nineteen

participants provided qualitative feedback, summarised in Table 6, which validated the need for the directory and highlighted specific areas to improve visual and written communication.

Discussion

This study aimed to report on the needs analysis, development, and evaluation of an online directory of healthcare professionals who offer evidence-based treatments specific to OCD. Participants reported treatment histories and barriers that validate the need for this directory. Usability data compared favourably to benchmarks in themes that affect access to information. Qualitative feedback highlighted areas for improvement, some of which have already been addressed, consistent with an iterative development process.

The treatment journeys reported by participants highlighted the need to improve pathways to adequate care in Australia. Participants reported an average of 9 years (median: 5) between symptom onset and access to treatment. Data were positively skewed, owing to floor effects. However, these estimates are similar to results from a recent review of international literature (Dell'osso et al., 2019). Unlike studies specifically investigating duration of untreated illness, we did not evaluate the adequacy of the treatments received. As such, the actual duration to *adequate* evidence-based treatment may in fact be higher.

Eighty-six percent of participants reported receiving medication and only 55% of participants reported receiving cognitive behaviour therapy with exposure and response prevention. Although these figures may be slightly higher than international averages (Brakoulias et al., 2019), our sample may have had a

Table 5. Benchmarked user experience scores.

Scale (theme)	Mean	Comparison to benchmarks
Attractiveness (overall impression)	0.82	Below average ^a
Perspicuity (ease of use)	1.38	Above Average ^b
Efficiency (effort and speed)	1.19	Above Average ^b
Dependability (security and predictability)	1.26	Above Average ^b
Stimulation (fun and excitement)	0.90	Below Average ^a
Novelty (creativity and interest)	-0.13	Bad ^c

^a50% of results better, 25% of results worse; ^b25% of results better, 50% of results worse; ^cWithin the range of the 25% worst results. $N = 18$ respondents.

Table 6. Themes from qualitative feedback.

Theme	Example	N
Aesthetics divided opinion	<i>"Eye-catching ... great to see diversity"</i> <i>"[collage of faces] makes me feel a bit uncomfortable"</i> <i>"bland and medical looking"</i>	11
Reduce clinical jargon	<i>"I didn't understand many of the [search options]"</i> <i>"Not sure of the various types of qualifications"</i> <i>"text heavy ... [communicate via] audio, video, imagery"</i>	7
Continue adding providers	<i>"not enough people specializing in OCD near me"</i> <i>"No providers in [city] but telehealth is ... great."</i>	6
Directory provided hope	<i>"I feel hopeful of finding help (and wish this existed sooner)"</i> <i>"I have just been waiting for OCD experts, but this site provides a number of names... Thank you".</i>	4
Clarify added value	<i>"Really similar to other [directories], but could be useful to have an OCD specific one"</i> <i>"Better than trying to [use a search engine]"</i>	4

higher proportion of well-informed participants given its recruitment sources. These data suggest that many participants have not received the first-line psychological treatment recommended for OCD. This may be addressed in part through access to a directory that lists providers who specifically offer this treatment.

Overall, the reported barriers to seeking or receiving treatment highlighted a systemic need to increase access to information and reduce stigma, which is consistent with international literature (García-Soriano et al., 2014). It is notable that one of the most common barriers was "not knowing who to see or where to go". Together, these findings validate the need that this directory is designed to address. However, much larger advocacy work and education within the public and health domains is also required.

The user experience ratings for pragmatic aspects of the directory were above average, compared to software and website benchmarks (Schrepp, n.d.; Schrepp et al., 2017). Users were able to search the directory and access information with little effort. However, ratings were below average for attractiveness and stimulation, and bad for novelty. Two themes from the qualitative data also highlighted that users perceived the site as clinical. Although plain and conventional aesthetics may be adequate, or even suitable given the context, refinements were clearly required. In response, we have improved visual aspects and reduced jargon. This is an area requiring further improvement as we consider the advocacy and education work also needed in Australia.

Limitations and future directions

Although data describing participants' treatment journeys are consistent with international research, it is acknowledged that the sample is relatively small. A larger study that involves stratified random sampling and evaluations of the interventions received would provide a stronger population view of how people

experience treatment-seeking for OCD. In addition, the sample size prevented us from analysing whether demographic factors or treatment-seeking histories influenced their evaluations of the directory. Fewer participants provided data regarding their user experience, although benchmarking data indicates that almost half of all user experience samples are approximately this size (Schrepp et al., 2017). Although the sample was also adequate to identify problems from qualitative data (Hertzum, 2020), further insights may have been gained from in-person testing.

More broadly, this study and the online directory emphasise appropriate medication and exposure and response prevention as first-line treatments of choice for OCD. However, evidence-based treatment also requires that clinicians consider a person's characteristics, culture, preferences, and the their own expertise in delivering treatment (American Psychological Association, 2006). There are other therapeutic approaches that do not necessarily include exposure and response prevention, such as cognitive therapy (McKay et al., 2015; Öst et al., 2015), acceptance and commitment therapy (Bluett et al., 2014; Philip & Cherian, 2021) and inference-based cognitive behaviour therapy (Aardema et al., 2022; Julien et al., 2016). These approaches were not captured in our study data and are not yet acknowledged in the online directory, but may be more appropriate for clients who do not find medication or exposure and response prevention acceptable. Further research exploring the broader scope of evidence-based treatment for OCD, with clinicians in Australia, may help to inform opportunities for better skill development and dissemination.

This study validates that consumers seeking help for OCD need access to information about clinicians who can provide appropriate evidence-based treatment in Australia. It also illustrates that co-design with consumers and clinicians is needed to improve usability and acceptability. Importantly, clinicians do not need to develop a

niche practice or work in a specialised public health service to competently treat OCD. All mental health care professionals registered in Australia can develop skills required to effectively treat OCD through ongoing professional development activities, including keeping up to date with the literature on evidence-based treatment, engaging in professional training workshops, and seeking supervision from practitioners with specialised practice. Additional initiatives are required to support ongoing improvements to workforce capacity in delivering evidence-based treatment within health and public domains. Together, we hope that this directory and future initiatives improve the treatment journey for people living with OCD in Australia.

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Data availability statement

Data are available from the authors upon reasonable request.

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