

# Do patients with mental health and substance use conditions experience discrimination and diagnostic overshadowing in primary care in Aotearoa New Zealand? Results from a national online survey

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## ABSTRACT

**Introduction.** Quality of health care contributes to poor physical health outcomes for people with mental health and substance use conditions (MHSUC). **AIM.** This study investigated experiences of people with MHSUC who sought help for a physical health condition in primary healthcare services, examining quality of care attributes. **Methods.** An online survey of adults currently or recently accessing services for MHSUC was fielded in 2022. Respondents were recruited nationally through mental health, addiction and lived experience networks and social media. The attributes of service quality assessed were relationships (respect and being listened to), discrimination due to MHSUC, and diagnostic overshadowing (MHSUC diagnosis distracted from physical health care). **Results.** Respondents who had used primary care services were included ( $n = 335$ ). The majority of respondents reported both being treated with respect (81%) and being listened to (79%) always or most of the time. A minority of respondents reported diagnostic overshadowing (20%) or discrimination due to MHSUC (10%). People with four or more diagnoses or a diagnosis of bipolar disorder or schizophrenia had significantly worse experiences across all quality measures. Those with a diagnosis of substance use disorders had worse experiences for diagnostic overshadowing. Māori had worse experiences for respect and diagnostic overshadowing. **Conclusions.** Although many respondents reported good experiences in primary care, this was not the case for everyone. Quality of care was affected by type and number of diagnoses and the person's ethnicity. Interventions to reduce stigma and diagnostic overshadowing for people with MHSUC are needed in primary care services in New Zealand.

**Keywords:** bipolar disorder, diagnostic overshadowing, discrimination, mental disorders, patient experience, primary care health services, racism; schizophrenia, substance use disorders.

## Introduction

People with mental health and substance use conditions (MHSUC) are at high risk of chronic physical health conditions and premature mortality compared to the general population.<sup>1–3</sup> Those with multiple MHSUC diagnoses, especially a psychiatric and substance use disorder (dual diagnosis), have an even greater risk of premature mortality.<sup>4–6</sup> International evidence suggests that reduced quality of care is a modifiable cause of these poor physical health outcomes.<sup>7,8</sup>

Several aspects of quality of care may contribute to unequal health outcomes in people with MHSUC. Diagnostic overshadowing, where physical symptoms are overlooked or mis-attributed to MHSUC by clinicians, can lead to late or missed diagnoses and missed or inappropriate treatment.<sup>9</sup> Negative beliefs (stereotypes) or prejudice towards those with MHSUC, be they unconscious or overt, interpersonal or structural, can lead to unfair or discriminatory treatment, including lack of diagnosis and treatment, withholding the

## WHAT GAP THIS FILLS

**What is already known:** People with mental health and substance use conditions (MHSUC) are at higher risk of poor outcomes and mortality from physical health conditions. Quality of health care is a contributory factor.

**What this study adds:** Relationship quality and experiences of discrimination and diagnostic overshadowing were significantly worse for people with multiple MHSUC and more highly stigmatised conditions (bipolar disorder/schizophrenia and addiction). Reducing the levels of discrimination and diagnostic overshadowing in primary care has the potential to improve physical health outcomes for people with MHSUC.

best treatment options, lack of appropriate investigations and poor follow up.<sup>10,11</sup> Therapeutic pessimism, where the clinician does not believe the patient is capable of managing their condition or recovery, is a form of prejudice that contributes to these failures, especially for patients perceived as difficult, disruptive or hard to treat.<sup>9,12,13</sup>

The level of prejudice and discrimination experienced by people with MHSUC may vary depending on their diagnosis. A systematic review of stigmatising attitudes towards people with MHSUC in primary care found negative attitudes were higher towards patients with schizophrenia than those with depression and associated with therapeutic pessimism.<sup>14,15</sup> People with psychotic disorders such as schizophrenia experience high levels of stigma,<sup>16</sup> as do those with substance use disorders.<sup>17</sup> In general, people with substance use or psychosis diagnoses are more subject to stereotypical beliefs that they are dangerous and violent (as well as incompetent), which leads to discrimination, including lower-quality care.<sup>10</sup>

Inequalities in the receipt of quality physical health care may be compounded among those with both MHSUC and other disadvantages.<sup>18</sup> The intersection of MHSUC and ethnicity within the health system is poorly understood, but in Aotearoa New Zealand (NZ), it is likely to unfairly impact Māori, who experience high levels of racism, which is a determinant of health.<sup>19,20</sup>

In primary healthcare services, the quality of the relationship between patient and clinician is fundamental to providing effective and appropriate care, particularly for people with long-term conditions and co-morbidities.<sup>21</sup> Interpersonal skills, demonstrated by respectful and empathetic attitudes, hearing and answering the patient's concerns and clear communication, are central for improved outcomes<sup>22–24</sup> and key predictors of patient satisfaction.<sup>25–27</sup> However, people with MHSUC often report lower satisfaction with primary care, on a range of quality measures.<sup>28–30</sup>

To design effective interventions to improve health outcomes for people with MHSUC, we need to understand where poor quality health care is occurring and who is most impacted. This study aimed to explore the role of

primary care in contributing to unequal physical health outcomes for people with MHSUC in NZ.

Our research questions were:

- Does the quality of respondents' relationships with primary care practitioners vary by demographics and type of MHSUC diagnosis?
- Do experiences of discrimination and diagnostic overshadowing vary by demographics and MHSUC diagnosis?

## Methods

Primary healthcare experiences were collected through a one-off cross-sectional online Qualtrics survey (Supplementary File S1).

## Content and development

The survey consisted of four main sections: mental health and addiction service use; physical health service use (including primary care and other health services); stigma and discrimination; and demographics (including MHSUC diagnoses).

Respondents were asked if they had used primary care services for physical health issues in the last 5 years. This timeframe was chosen to provide a sizeable period for which recall of experiences should still be robust. In addition, health practice has not changed considerably over this period.

In their interactions with primary care services, respondents were asked how often they experienced the following aspects of service quality:

- I was treated with respect (measure of relationship quality)
- I was listened to (measure of relationship quality)
- I was treated unfairly due to my mental health or addiction issues (measure of discrimination)
- My mental health or addiction issues distracted from my physical health care (measure of diagnostic overshadowing).

Responses were gathered through a five-point Likert scale – always, most of the time, sometimes, never, unsure.

Questions about relationship quality and discrimination were adapted from New Zealand's Adult Primary Care Patient Experience Survey,<sup>31</sup> a large national survey of patients attending primary care services, which has been extensively tested and reviewed.<sup>32</sup> The question on diagnostic overshadowing was developed in consultation with a study advisory group, as no existing validated questions were found.

Demographic questions included age, gender, ethnicity and sexual orientation. Respondents were asked to indicate MHSUC diagnoses they had received from a list (depression, anxiety, schizophrenia, bipolar disorder, personality disorder and addiction). Multiple responses were allowed, with an 'Other' option for diagnoses not listed. 'Other' options were manually coded into new or existing categories.

The survey questionnaire was reviewed by the advisory group, which included clinicians and people with lived experience of MHSUC, and pre-tested with a Māori male with lived experience of MHSUC.

## Recruitment and eligibility

The survey was fielded from 31 January to 1 April 2022. It was distributed through email, Facebook and Twitter by the researcher team, the research advisory group, Equally Well (a network of organisations and individuals working to improve physical health outcomes for people with experience of MHSUC),<sup>33</sup> and the University of Waikato student association. Paid advertising on Facebook was used from 17 to 31 March 2022. Information and invitations to participate were included in health sector newsletters, and sent to email distribution lists through Housing First, non-governmental addiction services and Māori health providers.

Respondents were eligible if they had accessed primary or secondary health care services for a MHSUC in the past 5 years, had engaged with any healthcare service for a physical issue in the past 5 years and were >18 years. From 488 visitors to the online survey, 408 agreed to participate. People who only partially completed the survey and did not answer any questions about provision of physical health services were excluded, as was one duplicate response. The final dataset comprised 354 eligible individuals. The analysis sample for this paper included only those who had used primary care services for physical health ( $n = 335$ ).

Survey responses were anonymous unless respondents provided contact details for a follow-up interview. This personal information was stored separately from the survey data, in secure folders protected by the University of Otago digital system, which only researchers could access.

## Data analysis

As data were from a convenience, self-selected sample, only descriptive and unweighted statistics (sample proportions) were calculated using Microsoft Excel version 2205 (Microsoft Corporation, Redmond, WA, USA). Relationships between variables were analysed using chi-squared tests because of the categorical nature of the data. Respondents were not forced to answer any question so there were variables with missing data due to incomplete or partial responses.

For demographic questions, chi-squared tests were performed for the demographic and service quality questions answered. For diagnosis and discrimination questions, comparison groups were those not reporting that diagnosis or that type of discrimination. Only groups with at least 20 people were tested for differences. The significance threshold was  $P < 0.05$ . Questions about demographic characteristics and MHSUC diagnoses were asked at the end of the survey, and around 12% of respondents did not complete these sections, although they contributed to earlier survey questions.

**Table 1.** Survey sample characteristics.

Characteristic	<i>n</i> (%) for total sample
Age (years)	
18–25	55 (19)
26–35	87 (29)
36–45	61 (21)
46–54	51 (17)
55+	42 (14)
Missing	39 (12)
Gender	
Female	221 (66)
Gender diverse	14 (4)
Male	57 (17)
Prefer not to answer	4 (1)
Missing	39 (12)
Ethnicity	
Māori	56 (17)
Non-Māori	239 (71)
Missing	40 (12)
Sexual orientation	
Heterosexual	191 (57)
LGBQA+ <sup>A</sup>	103 (31)
Missing	41 (12)
Number of diagnoses	
1–3	230 (69)
4+	52 (16)
Diagnosis not given by a healthcare professional	15 (4) <sup>B</sup>
Missing	38 (11)
Diagnosis	
Addiction	56 (17)
Anxiety	220 (66)
Bipolar disorder or schizophrenia	58 (17)
Depression	235 (70)
Personality disorder	40 (12)
Post-traumatic stress disorder (PTSD)	53 (16)
Use of secondary care services	
Seen psychiatrist in last 12 months	129 (39)
Total	335

<sup>A</sup>Lesbian, gay, bisexual, queer, asexual and other.

<sup>B</sup>Includes one unsure response.

For service quality questions, the ‘always’ and ‘most of the time’ responses were combined into one category, as were the ‘sometimes’ and ‘never’ responses. ‘Unsure’ responses were excluded from analyses. Number of diagnoses was created by a count of all indicated diagnoses from each respondent. Schizophrenia ( $n = 15$ ) was combined with bipolar disorder ( $n = 51$ ) and reported diagnoses of  $n < 20$  in total were not included (eg obsessivecompulsive disorder, Asperger’s syndrome, autism, attention deficit hyperactivity disorder, eating disorder, dissociative disorder).

Ethics approval was granted by the Southern Health and Disability Ethics Committee (reference: 21/STH/216). Consent was assumed by engagement with the online survey; information about the survey, details about privacy and

confidentiality and contact details for support was provided in the introduction to the survey.

## Results

There was a preponderance of female respondents, and a lower representation from older adults (Table 1), which is typical for online surveys.<sup>34</sup> Māori respondents comprised 17% of the sample, 31% identified as LGBQA+ and 4% as gender diverse.

One in seven respondents specified four or more MHSUC diagnoses and 85% reported more than one. Depression and anxiety, the most common mental health disorders in New

**Table 2.** Respondents treated with respect, by characteristics.

Treated with respect	Always/Most of the time		Sometimes/Never		Total	P value
	N	%	N	%	N	
Gender						
Female	201	91	20	9	221	0.6262
Male	53	93	4	7	57	
Age (years)						
18–25	48	87	7	13	55	0.6188
26–35	79	91	8	9	87	
36–45	56	92	5	8	61	
46–54	49	96	2	4	51	
55+	38	90	4	10	42	
Ethnicity						
Māori	47	84	9	16	56	0.0333*
Non-Māori	222	93	17	7	239	
Sexual orientation						
Heterosexual	177	93	14	7	191	0.2132
LGBQA+ <sup>A</sup>	91	88	12	12	103	
Number of diagnoses						
1–3	219	94	15	6	234	0.0003*
4+	35	76	11	24	46	
Diagnosis						
Addiction	48	80	8	20	56	0.1039
Anxiety	199	90	21	10	220	0.4148
Bipolar disorder or schizophrenia	46	79	12	21	58	0.0003*
Depression	213	91	22	9	235	0.4708
Personality disorder	35	88	5	13	40	0.3675
PTSD	44	83	9	17	53	0.0194*
Overall total	303	91	30	9	333 <sup>B</sup>	

<sup>A</sup>Lesbian, gay, bisexual, queer, asexual and other.

<sup>B</sup>Excludes one missing and one unsure response.

\* $p < 0.05$

Zealand,<sup>35</sup> were around four-fold more frequent than the next most commonly reported diagnoses (PTSD and combined bipolar disorder/schizophrenia). Co-occurring depression and anxiety were common, with 85% of people reporting depression also reporting anxiety. Almost everyone with an addiction diagnosis (93%) endorsed another diagnosis. Eighty-three percent of those with bipolar/schizophrenia diagnoses had another diagnosis. People with addiction or bipolar/schizophrenia diagnoses were those most likely to have four or more MHSUC diagnoses (43 and 47% respectively).

Nine percent of respondents reported sometimes or never being treated with respect (Table 2) and 21% reported never or sometimes being listened to (Table 3). Ten percent

experienced discrimination due to MHSUC always or most of the time (Table 4) and 20% experienced diagnostic overshadowing always or most of the time (Table 5).

People with four or more MHSUC diagnoses or with a diagnosis of bipolar/schizophrenia reported worse experiences across all service quality measures. People with addiction fared worse for the measure of diagnostic overshadowing; people with post-traumatic stress disorder (PTSD) reported lower levels of respect and being listened to.

Māori experienced less respect and more diagnostic overshadowing. For LGBQA+ people, measures of discrimination were higher (borderline significance for the measure of being listened to) and female respondents were less likely to feel listened to.

**Table 3.** Respondents listened to, by characteristics.

Listened to	Always/Most of the time		Sometimes/Never		Total N	P value
	N	%	N	%		
Gender						
Female	167	76	54	24	221	0.0114*
Male	51	91	5	9	56	
Age (years)						
18–25	42	76	13	24	55	0.4329
26–35	64	74	23	26	87	
36–45	46	77	14	23	60	
46–54	41	80	10	20	51	
55+	37	88	5	12	42	
Ethnicity						
Māori	40	71	16	29	56	0.1952
Non-Māori	189	79	49	21	238	
Sexual orientation						
Heterosexual	155	82	35	18	190	0.0541
LGBQA+ <sup>A</sup>	74	72	29	28	103	
Number of diagnoses						
1–3	188	81	45	19	233	0.0040*
4+	28	61	18	39	46	
Diagnosis						
Addiction	44	73	12	27	56	0.9151
Anxiety	173	79	46	21	219	0.5033
Bipolar disorder or schizophrenia	35	61	22	39	57	0.0007*
Depression	182	78	52	22	234	0.8320
Personality disorder	31	78	9	23	40	0.9292
PTSD	36	68	17	32	53	0.0496*
Overall total	262	79	70	21	332 <sup>B</sup>	

<sup>A</sup>Lesbian, gay, bisexual, queer, asexual and other.

<sup>B</sup>Excludes two missing and one unsure response.

\**p* < 0.05

**Table 4.** Respondents treated unfairly due to mental health or addiction issues, by characteristics.

Treated unfairly	Always/Most of the time		Sometimes/Never		Total N	P value
	N	%	N	%		
Gender						
Female	23	11	193	89	216	0.4141
Male	4	7	53	93	57	
Age (years)						
18–25	7	13	46	87	53	0.1801
26–35	5	6	79	94	84	
36–45	9	15	50	85	59	
46–54	2	4	49	96	51	
55+	4	10	37	90	41	
Ethnicity						
Māori	8	16	43	84	51	0.0903
Non-Māori	19	8	217	92	236	
Sexual orientation						
Heterosexual	12	6	175	94	187	0.0306*
LGBQA+ <sup>A</sup>	14	14	85	86	99	
Number of diagnoses						
1–3	18	8	210	92	228	0.0097*
4+	9	20	35	80	44	
Diagnosis						
Addiction	7	18	46	82	53	0.2847
Anxiety	22	9	191	91	213	0.3349
Bipolar disorder or schizophrenia	10	18	46	82	56	0.0148*
Depression	24	11	204	89	228	0.1813
Personality disorder	3	8	34	92	37	0.7823
PTSD	8	16	42	84	50	0.0753
Overall total	31	10	289	90	320 <sup>B</sup>	

<sup>A</sup>Lesbian, gay, bisexual, queer, asexual and other.<sup>B</sup>Excludes one missing and 14 unsure responses.\**p* < 0.05

## Discussion

A majority of people with MHSUC reported positive experiences of primary care services. However, experiences differed by diagnosis, number of diagnoses and some demographic characteristics. Within the range of MHSUC diagnoses, people with anxiety and depression, the most common mental disorders, consistently reported better experiences on all quality measures. By contrast, addiction and bipolar/schizophrenia were diagnoses associated with poorer experiences, possibly because they are more stigmatised. Negative stereotypes about people with substance use disorder and schizophrenia are extremely common in the general population and amongst clinicians, but not so for depression, probably because

depression is more widespread.<sup>13,14,16,36</sup> In New Zealand, campaigns such as ‘Like Minds, Like Mine’ (now ‘Nōku te Ao’) have raised the profile of depression and improved attitudes, although this may be a short-term effect.<sup>37,38</sup>

## Comparison with other literature

Māori respondents comprised 17% of the sample, comparable to 2018 Census data (16.5%).<sup>39</sup> The proportions of respondents identifying as LGBQA+ and gender diverse were higher than in population-based surveys,<sup>40,41</sup> which could be due to significantly higher rates of MHSUC in these groups.<sup>42,43</sup>

From New Zealand’s Adult Primary Care Patient Experience Survey (APCPES) in February 2022,<sup>31</sup> 95% of patients

**Table 5.** Respondents' mental health or addiction issues distracted from physical health care, by characteristics.

Distracted from physical health care	Always/Most of the time		Sometimes/Never		Total N	P value
	N	%	N	%		
Gender						
Female	41	19	172	81	213	0.8525
Male	11	20	43	80	54	
Age (years)						
18–25	15	28	39	72	54	0.4214
26–35	16	19	67	81	83	
36–45	12	21	45	79	57	
46–54	8	16	42	84	50	
55+	5	13	34	87	39	
Ethnicity						
Māori	21	42	29	58	50	0.0000*
Non-Māori	35	15	197	85	232	
Sexual orientation						
Heterosexual	33	18	149	82	182	0.5313
LGBQA+ <sup>A</sup>	21	21	78	79	99	
Number of diagnoses						
1–3	39	17	186	83	225	0.0034*
4+	16	37	27	63	43	
Diagnosis						
Addiction	18	35	33	65	51	0.0020*
Anxiety	45	21	166	79	211	0.2467
Bipolar disorder or schizophrenia	17	31	38	69	55	0.0202*
Depression	44	20	180	80	224	0.9508
Personality disorder	11	31	25	69	36	0.0803
PTSD	14	27	37	73	51	0.1254
Overall total	63	20	255	80	318 <sup>B</sup>	

<sup>A</sup>Lesbian, gay, bisexual, queer, asexual and other.<sup>B</sup>Excludes two missing and 15 unsure responses.\**p* < 0.05

reported that their primary care professional (Yes, definitely) treated them with respect (94% for Māori, 95% for female) and 92% reported being listened to (Yes, definitely) (91% for Māori, 91% for female).<sup>44</sup> Although we cannot test for significant differences between the APCPES and our survey, people with MHSUC reported worse experiences and sizeable differences for some diagnoses. For example, in our survey, only 61% of those with bipolar/schizophrenia felt listened to. From other surveys, 17–31% of people with MHSUC have reported discrimination in physical health settings, which is comparable to our study.<sup>45</sup>

The importance of relationships for people with MHSUC attending primary care has been explored in other research. In qualitative interviews with people with MHSUC, lack of

knowledge and stigma from providers were identified as barriers to accessing care, whereas positive relationships, characterised as empathetic, non-judgmental and person-centred, enabled access.<sup>46</sup> Having a regular GP, with the associated benefits of continuity of care and building a trusted relationship, leads to greater satisfaction with primary care services.<sup>47</sup>

### Strengths and limitations

This survey fills a gap in experiences of physical health care in general practice settings from the perspective of people with MHSUC in NZ. However, as for most web-based surveys, we were unable to define our target population and calculate a response rate. The sample size was relatively small, meaning



that sub-group comparisons for Pacific, Asian and gender-diverse people were not feasible. Respondents reported a range of MHSUC diagnoses, but were not necessarily a representative sample and those without internet access would be excluded. Self-selection bias, where people interested in the topic are more likely to participate, could have affected results, particularly if those with negative experiences of primary care responded at a higher rate. We were unable to distinguish the impact of other types of discrimination, such as racism, sexism, bias against LGBQA+ people, on experiences of care.

## Implications for practice

Experiences of discrimination from clinicians, being ignored and disrespected and having physical symptoms overlooked deter people with MHSUC from seeking health care and thus contribute both directly and indirectly to poorer health outcomes.<sup>10,48</sup> Interventions to improve health outcomes in people with MHSUC often focus on patient factors, such as lifestyle interventions and optimised management of both mental and physical health. However, such strategies need to be multi-pronged and incorporate health service delivery, workforce development and training, national and local policies and social support.<sup>10,49</sup>

In primary care, ensuring that all practitioners are trained, skilled and comfortable with interacting and supporting people with MHSUC is not only foundational for improving health outcomes, but also for reducing stigma and discrimination towards people with MHSUC.<sup>11,14,45</sup> For clinicians (including trainees), implicit bias tests can be useful in raising awareness, but concrete actions are needed to effect changes in discriminatory practice.<sup>11,50</sup> Programmes are more likely to be successful if they cater to specific workforce groups, and include features such as social contact with people living well with MHSUC and an emphasis on recovery, to counter therapeutic pessimism.<sup>11,51</sup>

The APCPES provides an opportunity for ongoing measurement of the experiences of people with MHSUC, although it currently does not report on quality measures separately for people with MHSUC. At a practice level, systematically gathering both quantitative and qualitative patient feedback can be used to drive service improvement, but requires leadership, active engagement of patients and commitment by staff to enacting change.<sup>52</sup>

The high level of diagnostic overshadowing reported in this survey requires more research into how to best quantify this experience and how it can be reduced. A future publication will analyse qualitative data collected in this survey, to further understand how people with MHSUC experience diagnostic overshadowing and discrimination.

## Conclusion

This survey was the first in NZ to investigate how people with MHSUC experience primary care services when seeking

help for a physical condition. Worse experiences for people with more stigmatised diagnoses (schizophrenia/bipolar disorder and addiction) point to an ongoing need to address bias in health professionals and to implement data monitoring and quality improvement measures to ensure that people with MHSUC are consistently taken seriously, treated fairly and with respect.

## Supplementary material

Supplementary material is available [online](#).

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