The 'Missing Middle' Lived Experience Perspectives (Private Psychiatric Hospitals)

Identifying why people slip through the gaps or do not receive the mental health care they need - Focus on those accessing Private Psychiatric Hospitals

Lived Experience
AUSTRALIA

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Lived Experience Australia wishes to acknowledge and thank all the consumers, families and carers for speaking the truth of their experiences of engagement and disengagement associated with mental health services and supports. Having the courage to tell us about the barriers and how they found their own solutions has enabled us to gain a better understanding of their experiences with mental health services across Australia.

This detailed survey enabled us to have a better understanding of the ‘missing middle’ and what that means for people, beyond just a term. How consumers’, families’ and carers’ lives are affected has been captured in this ground-breaking national survey, a first of its kind in Australia.

This is the first robust data from a lived experience perspective that will be made available in a desire to inform policy and service reform, particularly service design, planning, implementation and evaluation.

Lived Experience Australia wishes to thank Ms Christine Kaine and Professor Sharon Lawn, who carefully and independently translated the data for this report.

And finally, we would also like to acknowledge the following people for their input into the development of this survey:

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Foreword

Lived Experience Australia (LEA) conducted a national survey covering a three-week period from 12 October 2020 – 2 November 2020 distributed through LEA's data base and social media as well as to other consumer and/or carer organisations with 535 people entering the survey. What makes these 'Missing Middle' collective reports different from others, is this is the first survey of its kind to seek and reflect the perspectives of both consumers AND carers about engagement and disengagement from mental health supports and falling through the gaps. Furthermore, it is the only survey which explicitly asked why people disengage and what it would take for them to re-engage with mental health services.

I am proud that LEA has been the vehicle through which people with lived experience have been able to contribute to this ground-breaking analysis of the 'Missing Middle', a term which is gaining popularity, but which in reading the many powerful comments within this and the companion document "the Missing Middle: Our Voices" Report, is both compelling and confronting.

Some respondents spoke of a broken system and how that system has broken them. Many talked about the GP as being their main support, how they want affordable choices and better communication and collaboration between practitioners and providers. Disengagement meant for some that the service didn't meet their needs or was not available, resulting in support being provided from their informal networks. Others talked about disengagement followed by deterioration in mental health resulting in a crisis, isolation, a decline in community participation and employment, and greater dependency on families and carers.

Others spoke of a system where they are listened to, are involved in decision-making, where practitioners are neither judgmental nor stigmatising toward them and they are receiving care for the time they need it. All crucial elements of person-centred recovery.

Our desire is to bring the perspectives, experience and needs of both consumers, families and carers, which must be recognised and acknowledged, into the forefront of policy and reform processes of service planning, design, implementation, and evaluation.

This is the research report focusing on private psychiatric hospitals, and when you read through it, please recognise that every statistic has a face behind it. We urge the reading of the full research report 'The Missing Middle' Lived Experience Perspectives' and the 'Our Voices' report which faithfully report the joint experiences of consumers, families and carers in a way that cannot be ignored.

We commend these Reports to you.

Janne McMahon

Janne McMahon OAM
Founder and Executive Director

Contents

1. Executive Summary 1

1.1 Key findings 1

2. Survey Results 3

2.1 Demographics 3

2.2 Main mental health services accessed 4

2.3 Accessibility of services 7

2.4 Disengagement from private mental health services 10

2.5 Communication and collaboration between health professionals/services 14

2.6 Contributing factors to deterioration in mental health and access to support 15

Appendix 1 – Survey Questions 17

1. Executive Summary

Lived Experience Australia (LEA) is the representative organisation for Australian mental health consumers, families and carers, formed in 2002. LEA is the only consumer and carer advocacy organisation with a focus on services provided within private sector settings as well as having over 2,000 individual consumer and carer members and a social media following of over 800. Our core business is to advocate for systemic change, empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system reform processes, design, planning, implementation, and evaluation. Most importantly, we advocate for consumer choice and family and carer inclusion. LEA encompasses advocacy for both consumers and carers across the healthcare system, not only within the private sector. This is because we know that people's experiences of help-seeking happen at many points and parts of the overall system and can include primary care/general practice, hospital services, psychological therapy services including private or office-based practice, and community mental health services.

This report utilises the data collected from the 'Missing Middle – Lived Experience Perspectives' research and has been analysed with a focus on those accessing private psychiatric hospitals. It provides a national collective voice of people with a lived experience seeking input from those who either have sought or accessed mental health services from private practitioners/private psychiatric hospitals. It provides a detailed account of their experiences of seeking, receiving and disengaging from mental health supports. We encourage you to access the full 'Missing Middle' research report covering all service types.

To enable analysis of consumers and carers accessing private mental health practitioner/private psychiatric hospital services, the original data was reviewed using two separate filters:

(1) Consumers who specifically identified as using private mental health services and hospitals and have private health insurance and the families and carers that support them. This filter was used as it was the most likely group of respondents who access private psychiatric hospitals in addition to other private mental health services.

(2) Consumers who specifically identified using private mental health services/hospitals as their primary mental health support over the past five years, and the families and carers that support them.

The questions within the survey and analysed within this private hospital report were asked as both 'health professional or service' and some consumers use a mix of both private and public mental health services, practitioners and hospitals. As a result, some of the responses related exclusive to practitioners whilst others relate to both practitioners and private hospitals. A further tracking analysis was undertaken to extract where possible the difference in responses and these are reflected within this report.

1.1 Key Findings:

The feedback from both consumers and carers regarding private psychiatric hospital services was generally positive with comments including the benefits of having a range of services available to them (both in-patient and out-patient), the ability to be self-directed in their own care, having a say in their discharge planning and timeline for discharge, having quality and trained staff, privacy and the ability to access care when it is needed. Some consumers commented on concerns regarding affordability of services (and the need for private health insurance more broadly), as well as a desire to be able to access after-hours support that was not currently available to them. Overwhelmingly, consumers who access private hospitals and the carers supporting them reported that they want affordable and accessible mental health services, with mental health professionals who they can trust, who will listen to them, involve them in decision-making, and collaborate with them about their care.

They want to be able to access support for the length of time it is needed and for it to be available when it's needed most, to prevent deterioration of their mental health resulting in crisis. They want services to follow up with them to support ongoing engagement and they want continuity of practitioners and hospital providers. They also want health practitioners and hospitals to coordinate and collaborate together in relation to their care.

The results from this survey tell us that people can 'fall through the gaps' when these needs cannot be met by practitioners and hospital providers.

Key findings are outlined on the following page.

[1.] Swerissen H. & Duckett S. (2020) A Primary Health Network redesign to address the 'missing middle' in mental health. https://www.croakey.org/a-phn-redesign-to-address-the-missing-middle-in-mental-health/#:~:text=The%20missing%20middle,to%20moderate%20mental%20health%20problems

What is most useful for consumers who access private psychiatric hospital services is having a welcoming environment, a range of services available (both in-patient and out-patient), the ability to be self-directed in their own care, quality staff, privacy and ability to access services when they are needed.

Consumers who access private psychiatric hospital care commented that what has been most useful to them includes: the hospital environment, such as aesthetics, amenities, calm, and supportive people around them; the range of services (in-patient and out-patient services such as day programs); the ability to have choice and make decisions about their own care; quality of services and facilities provided and well-trained staff (nurses, doctors, etc); privacy (such as having a private room); and that access is generally quick and easy when it's needed. Some consumers commented on the need for access to after-hours support services which were not currently available to them.

Affordability of private psychiatric hospitals and the required level of private health insurance is a concern for some consumers and carers.

A number of consumers and carers commented on the need for affordable private mental health services. Consumers who do not have private health insurance frequently commented on their desire to access private hospitals but were unable to due to costs and lack of affordability. Others commented on the difficulties in maintaining private health insurance, but how they did so despite the financial hardship it caused them, due to fear of having to access the public mental health system and a preference for private psychiatric hospital care.

Consumers who primarily access private mental health practitioners/hospitals and carers who support them stated that they chose the private providers due to feeling safe, trusting the provider, having a say or control in decision making, feeling listened to, are included in collaboration about their care or the person they care for and briefer waiting times compared with those who primarily access public mental health services/hospitals/ community teams.

Consumers primarily using private mental health practitioners/ hospitals rated briefer waiting times, the service meeting their needs, feeling listened to and collaborated with, having a say in decision-making, trust, safety and not feeling judged/ stigmatised more highly as reasons for using private mental health services compared with consumers who primarily use public mental health services/hospitals/communities teams who rated these areas as a lower contributing factor influencing their main reason of using public services.

Consumers are more likely to be supported for the length of time they need it in private hospitals compared with the public system.

Consumers who primarily access private mental health practitioners/hospitals were more frequently supported for the length of time they needed (65.27%, n=47) when compared with those who primarily access public mental health services/ hospitals/community teams (50%, n=50). Discharge notice from private hospitals was generally more positive than the public system, with consumers having more say in their discharge planning and timeline and not feeling rushed to leave.

Qualities that support engagement include being listened to, the knowledge and experience of the provider, feeling validated, having continuity of care and staff being non-judgemental.

Qualities of the private hospital that supported engagement, as rated by consumers and those that support them, included the private hospital helping them to feel more comfortable and engaged, kindness, respect, listening, knowledge and experience, validation, non-judgemental and continuity of care. Qualities of private mental health practitioners/hospitals that made consumers feel uncomfortable and more likely to dis-engage included disrespect, rudeness, disinterest or condescension by practitioners/staff.

Coordination and collaboration between health practitioners/hospital services for consumers accessing private mental health practitioners/hospitals is an issue of concern and can result in people falling through the gaps

Almost half of consumers accessing private mental health practitioners/hospitals and two thirds of carers supporting them said there was no coordination between health practitioners/services. In addition, 40% of consumers said they fell through the gaps and half of carers supporting someone with private health insurance said there was no referrals made to other services as part of discharge and follow-up care planning post-discharge.

Services that consumers who access private mental health practitioners/hospitals and have private health insurance would like to access but currently cannot included peer support and community groups/activities.

Consumers with private health insurance and carers supporting someone with private health insurance identified services they would like to access but currently cannot which include peer support, and more community groups/activities. Consumers also identified a desire to access in-person appointments, affordable psychiatrists (i.e. bulk-billing), support for prevention strategies, free psychiatry helplines and increased numbers of subsidised psychology sessions which they are currently unable to access.

2. Survey Results

2.1 Demographics:

Summary:

Seventy-five consumers respondents indicated that they use private mental health services and private hospitals and have private health insurance. Whilst the sample size is relatively small (n=75), and therefore responses by various demographic subgroup details are then also reduced in size, the data provides some interesting trends for consideration and further examination.

Seventeen carer respondents indicated that the person they care for uses private mental health services and private hospitals and has private health insurance providing a very small sample size (n=17), however data is included in this report for consideration.

Both consumer and carer respondents were largely from capital cities (72%, n=54), with some being from regional centres (25.33%, n=19) or a rural town (2.67%, n=2). There was no significant difference between people who mainly use private mental health practitioners/ hospitals and those who mainly use public mental health services/hospitals/community teams and their geographic location.

Respondents accessing private mental health practitioners and private hospitals across both categories were predominantly female (88%, n=66), with a smaller proportion of male respondents (10.67%, n=8) and other (1.33%, n=1).

The age range was largely between 20-59 years. There was a slightly higher number of consumers aged 20-39 years that use predominantly public mental health services/hospitals/community teams (37.62%, n=38), compared with those in the same age range that use predominantly private mental health practitioners/ hospitals (26.03%, n=19).

No consumers or carers who access private mental health practitioners and private hospitals indicated that they were of Aboriginal or Torres Strait Islander descent. Eleven consumer and carer respondents were born overseas including the UK, New Zealand, India, Singapore, Malaysia, and Egypt and most speaking only English at home.

Consumer responses:

Geographic Location

Greater numbers of consumers located in Victoria, Queensland and Western Australia who access private practitioners/ hospitals took part in the survey (see Figure 1, Table 1). This pattern is likely to reflect potential bias in the recruitment process and LEA membership by location rather than being reflective of national population trends in private health insurance required to access private psychiatric hospitals and the uptake of this cover by people with mental health conditions.

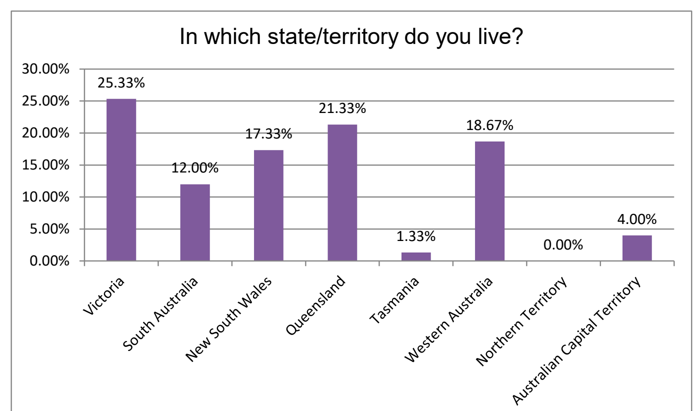


Figure 1: Consumers by state/territory

Table 1: Consumers by state/territory

Answer Choices	Responses	
Victoria	25.33%	19
South Australia	12.00%	9
New South Wales	17.33%	13
Queensland	21.33%	16
Tasmania	1.33%	1
Western Australia	18.67%	14
Northern Territory	0.00%	0
Australian Capital Territory	4.00%	3

Seventy-five consumer respondents provided information about their location: 72% (n=54) lived in a capital city, 25.3% (n=19) lived in a regional centre, and 2.7% (n=2) lived in a rural/ remote town.

Gender

Seventy-five consumer respondents provided information about their gender: 88% (n=66) identified as female, 11.7% (n=8) as male, and 1.3% (n=1) as other.

Age

Seventy-five consumer respondents provided information about their age. Those aged 40-49 years had the highest rate of private health insurance (36%, n=27), followed by those aged 20-39 and 50-59 years. Of note, for older age groups, with more likelihood of both mental and physical health conditions requiring health care services, fewer reported having private health insurance (see Figure 2, Table 2).

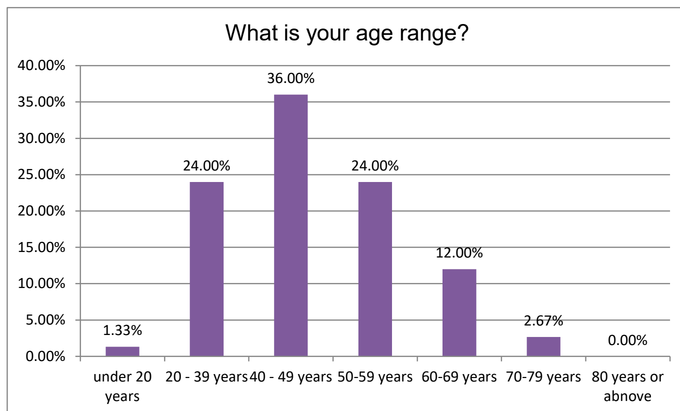


Figure 2: Consumers by Age

Table 2: Consumers by Age

Answer Choices	Responses	
under 20 years	1.33%	1
20- 39 years	24.00%	18
40- 49 years	36.00%	27
50-59 years	24.00%	18
60-69 years	12.00%	9
70-79 years	2.67%	2
80 years or above	0.00%	0

There were slightly more consumers aged 20-39 years that use predominantly public mental health services/hospitals/ community teams (37.62%, n=38), compared with those in the same age range that use predominantly private mental health services/hospitals (26.03%, n=19) (see Table 3).

Table 3: Consumers by Age: private versus public

Responses	< 20 yrs		20 - 39 yrs		40 - 49 yrs		50-59 yrs		60-69 yrs		70-79 yrs		> 80 yrs		Total	
Public	1%	1	38%	38	24%	24	22%	22	13%	13	3%	3	0%	0	66%	101
Private	1%	1	26%	19	26%	19	25%	18	19%	14	3%	2	0%	0	47%	73
Total	1%	2	31%	47	27%	41	23%	35	16%	24	3%	5	0%	0	100%	154

Other Demographic Detail

No consumers accessing private mental health services or private hospitals indicated that they were of Aboriginal or Torres Strait Islander descent. Seven (9.33%) indicated that they were born overseas (2 from the UK, 2 from New Zealand, and 1 each from India, Singapore and Malaysia); all spoke mostly English at home.

2.2 Main Mental Health Services Accessed:

Summary:

Both consumer and carer respondents identified access to General Practitioners (GPs), private mental health practitioners/hospitals including psychologists as the primary source of mental health support over the past 5 years. The main reasons for using these services rated by both consumer and carer respondents was that they feel safe and trust the provider, they have some say or control in making decisions, they feel listened to and included in collaboration about their care or the person they are for.

Consumers who use private mental health practitioners/ hospitals as their primary support rated contributing factors such as briefer waiting times, service meeting their needs, trust, inclusion/collaboration, having a say in decision making, trust, feeling safe and not feeling judged/stigmatised more highly when compared with consumers who primarily use public mental health services/hospitals/community teams and their reasons for using the public system. Some consumers who access primarily public mental health services commented that they did so because they were unable to afford private services.

Several consumers also commented that they feel they have a wider range of support options available to them via private mental health practitioners/hospitals.

Consumer responses:

Consumers who access private mental health services and private hospitals and have private health insurance, predominantly used a GP to support their mental health (60%, n=45), with psychologists and private mental health services/ hospitals as the next most prevalent sources of mental health support (see Figure 3, Table 4).

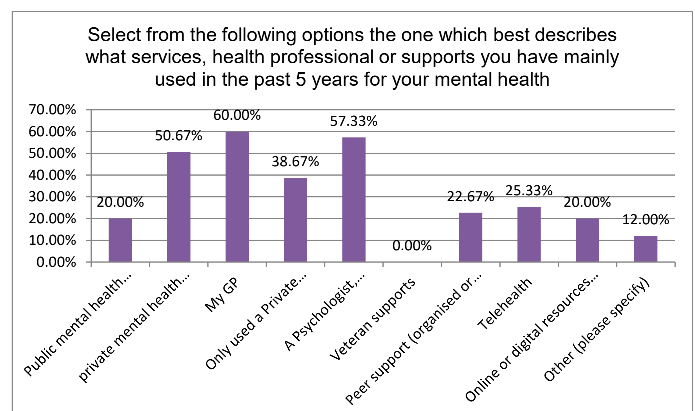


Figure 3: Consumers- Services, health professional or supports mainly used in the past 5 years by Consumers for their mental health

Table 4: Services, health professional or supports mainly used in the past 5 years by Consumers for their mental health

Answer Choices	Responses	
Public mental health services/ hospitals/community teams/ community teams	20.00%	15
Private mental health services/ hospitals	50.67%	38
My GP	60.00%	45
Only used a Private Psychiatrist	38.67%	29
A Psychologist, counsellor/therapist	57.33%	43
Veteran supports	0.00%	0
Peer support (organised or unorganised)	22.67%	17
Telehealth	25.33%	19
Online or digital resources or Apps	20.00%	15
Other (please specify)	12.00%	9

When asked the main reason why they use these services as their primary mental health support, most consumers accessing private mental health practitioners/hospitals identified that they feel safe and trust that practitioners/hospital, they feel they have some say or control in making decisions, they feel listened to and included in collaboration about their care (see Figure 4, Table 5).

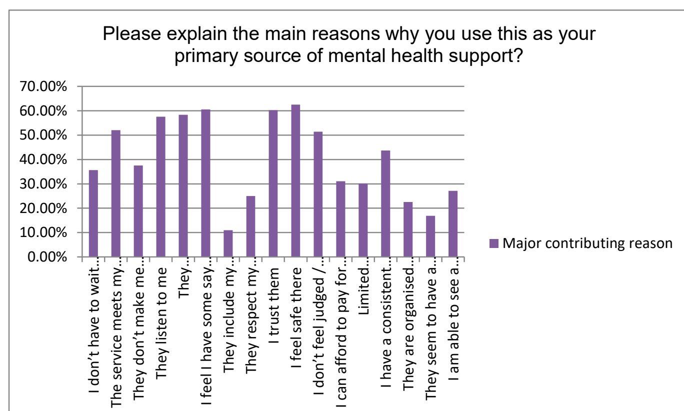


Figure 4: Consumers reasons for using primary source of mental health support

Seventeen consumers provided further comments which suggested a variety of reasons for using specific services and providers. Several comments indicated that consumers valued a coordinated approach and the ongoing relationships that they could have with private practitioners/hospitals, and also with a suite of care options that they felt were more available to them with private health insurance cover.

Comments specifically relating to private psychiatric hospital use from consumers included:

- *A safe environment. Having like-minded people around me. All levels of staff keeping me engaged while communication with one another to monitor my progress*
- *It takes one call to make a referral and you're in within 24 hours. The staff and services provided as an inpatient and outpatient*

Comments from consumers who use private mental health practitioners/hospitals as their primary source of mental health support included:

- *I was led to believe public mental health system would offer more, a better coordinated care. I was bitterly disappointed by poor level of care*
- *They respect my privacy and do not disclose without my permission.*
- *They have good contacts with private hospitals and associated doctors, so I can also get an admission if/when I require one.*

Table 5: Consumers reasons for using primary source of mental health support

	Major contributing reason		Contributing reason		Not a contributing reason		Not Applicable		Total
I don't have to wait too long to see someone	35.62%	26	38.36%	28	21.92%	16	4.11%	3	73
The service meets my needs	52.05%	38	31.51%	23	12.33%	9	4.11%	3	73
They don't make me repeat my story too much	37.50%	27	29.17%	21	26.39%	19	6.94%	5	72
They listen to me	57.53%	42	30.14%	22	8.22%	6	4.11%	3	73
They include/collaborate with me	58.33%	42	25.00%	18	11.11%	8	5.56%	4	72
I feel I have some say or control in making decisions	60.56%	43	32.39%	23	2.82%	2	4.23%	3	71
They include my family/carer	10.96%	8	15.07%	11	36.99%	27	36.99%	27	73
They respect my privacy if I don't want to include my family	25.00%	18	29.17%	21	13.89%	10	31.94%	23	72
I trust them	60.27%	44	26.03%	19	9.59%	7	4.11%	3	73
I feel safe there	62.50%	45	26.39%	19	8.33%	6	2.78%	2	72
I don't feel judged / stigmatised by them	51.39%	37	30.56%	22	11.11%	8	6.94%	5	72
I can afford to pay for this service	31.08%	23	27.03%	20	36.49%	27	5.41%	4	74
Limited options/choice of service providers in my area	30.14%	22	13.70%	10	30.14%	22	26.03%	19	73
I have a consistent worker	43.66%	31	19.72%	14	12.68%	9	23.94%	17	71
They are organised and coordinate the support services I need	22.54%	16	22.54%	16	33.80%	24	21.13%	15	71
They seem to have a clear plan/goals	16.90%	12	33.80%	24	33.80%	24	15.49%	11	71
I am able to see a worker whose gender is of my choosing	27.14%	19	12.86%	9	35.71%	25	24.29%	17	70

In comparing those who mainly use private mental health practitioners/hospitals versus those who mainly use public mental health services/hospitals/community teams, there were some differences in the above ratings. Consumers using private mental health practitioners/hospitals as their primary support rated the following reasons as major contributing factors more highly than those who use public mental health services/ hospitals/community teams as their primary support (see Table 6):

- I didn't need to wait long to see someone (46.38%, n=32) compared with those using public services (23.96%, n=23)
- the service met my needs (53.52%, n=38) compared with those using public services (29.59%, n=29)
- they listen to me (59.42%, n=41) compared with those using public services (40.82%, n=40),
- they include me/collaborate with me (60%, n=42) compared with those using public services (38.78%, n=38)
- I feel I have some say or control in making decisions (58.57%, n=41) compared with those using public services (38.78%, n=38)
- I trust them (56.34%, n=40), compared with those using public services (36.73%, n=36)
- I feel safe there (57.97%, n=40), compared with those using public services (36.73%, n=36)
- I don't feel judged/stigmatised by them (51.43%, n=36), compared with those using public services (33.67%, n=33)

However, those using predominantly public mental health services/hospitals/community teams rated affordability significantly higher (57.29%, n=55) compared with those who mainly use private mental health practitioners/hospitals (27.54%, n=19).

Table 6: Comparison on reasons for using primary mental health support – Private Versus Public

Please explain the main reasons why you use this as your primary source of mental health support?										
I don't have to wait too long to see someone	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	23.96%	23	36.46%	35	26.04%	25	13.54%	13	62.75%	96
Q9: Private	46.38%	32	31.88%	22	14.49%	10	7.25%	5	45.10%	69
The service meets my needs	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	29.59%	29	47.96%	47	15.31%	15	7.14%	7	64.05%	98
Q9: Private	53.52%	38	33.80%	24	7.04%	5	5.63%	4	46.41%	71
They listen to me	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	40.82%	40	37.76%	37	16.33%	16	5.10%	5	64.05%	98
Q9: Private	59.42%	41	31.88%	22	5.80%	4	2.90%	2	45.10%	69
They include/collaborate with me	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	38.78%	38	35.71%	35	17.35%	17	8.16%	8	64.05%	98
Q9: Private	60.00%	42	30.00%	21	7.14%	5	2.86%	2	45.75%	70
I feel I have some say or control in making decisions	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	38.78%	38	37.76%	37	14.29%	14	9.18%	9	64.05%	98
Q9: Private	58.57%	41	34.29%	24	2.86%	2	4.29%	3	45.75%	70
I trust them	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	36.73%	36	38.78%	38	14.29%	14	10.20%	10	64.05%	98
Q9: Private	56.34%	40	32.39%	23	5.63%	4	5.63%	4	46.41%	71
I feel safe there	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	36.73%	36	38.78%	38	16.33%	16	8.16%	8	64.05%	98
Q9: Private	57.97%	40	33.33%	23	4.35%	3	4.35%	3	45.10%	69
I don't feel judged / stigmatised by them	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	33.67%	33	40.82%	40	16.33%	16	9.18%	9	64.05%	98
Q9: Private	51.43%	36	32.86%	23	10.00%	7	5.71%	4	45.75%	70
I can afford to pay for this service	Major contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	57.29%	55	17.71%	17	12.50%	12	12.50%	12	62.75%	96
Q9: Private	27.54%	19	30.43%	21	28.99%	20	13.04%	9	45.10%	69
Limited options/choice of service providers in my area	Major Contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	39.18%	38	27.84%	27	22.68%	22	10.31%	10	63.40%	97
Q9: Private	28.99%	20	14.49%	10	30.43%	21	26.09%	18	45.10%	69
I have a consistent worker	Major Contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	34.69%	34	32.65%	32	16.33%	16	16.33%	16	64.05%	98
Q9: Private	44.93%	31	24.64%	17	10.14%	7	20.29%	14	45.10%	69
They are organised and coordinate the support services I need	Major Contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	24.49%	24	29.59%	29	28.57%	28	17.35%	17	64.05%	98
Q9: Private	23.19%	16	24.64%	17	26.09%	18	26.09%	18	45.10%	69
They seem to have a clear plan/goals	Major Contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	17.35%	17	36.73%	36	33.67%	33	12.24%	12	64.05%	98
Q9: Private	20.29%	14	37.68%	26	28.99%	20	13.04%	9	45.10%	69
I am able to see a worker whose gender is of my choosing	Major Contributing		Contributing		Not contributing		N/A		Total	
Q9: Public	16.49%	16	23.71%	23	38.14%	37	21.65%	21	63.40%	97
Q9: Private	17.39%	12	17.39%	12	34.78%	24	30.43%	21	45.10%	69

From the consumers who use public mental health services/ hospitals/community teams as their primary mental health support, many commented that they did so because they were unable to afford private services.

Carer responses:

Carers of someone who uses private mental health practitioners and hospitals, and have private health insurance cover, predominantly used a GP to support their mental health (70.59%, n=12), with psychologists, public mental health services and private mental health hospitals as the next most prevalent sources of mental health support (see Figure 5, Table 7).

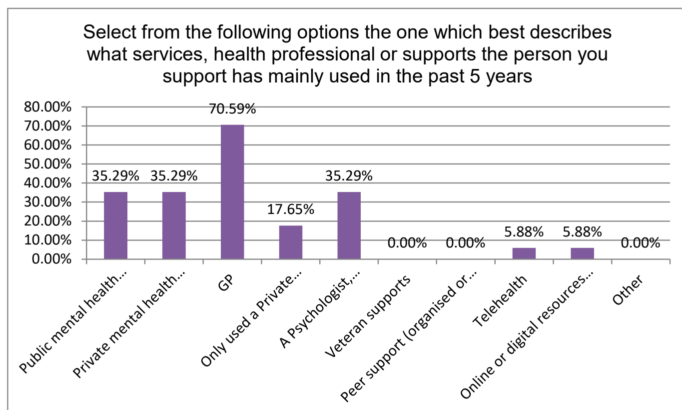


Figure 5: Carers- Services, health professional or supports mainly used in the past 5 years by Consumers for their mental health

Table 7: Carers – Services, health professional or supports mainly used in the past 5 years by Consumers for their mental health

Answer Choices	Responses	
Public mental health services/ hospitals/community teams/ community teams	35.29%	6
Private mental health services/ hospitals	35.29%	6
GP	70.59%	12
Only used a Private Psychiatrist	17.65%	3
A Psychologist, counsellor/therapist	35.29%	6
Veteran supports	0.00%	0
Peer support (organised or unorganised)	0.00%	0
Telehealth	5.88%	1
Online or digital resources or Apps	5.88%	1
Other	0.00%	0

When asked the main reason why the person they care for mainly uses private mental health practitioners/hospitals as their primary mental health support, most carers identified that the service listens to them, reduced wait times, the service meets their needs, they feel they have some control in making decisions, the service includes me as a family/ carer, the person trusts them, feels safe, and have a consistent worker (see Figure 6, Table 8).

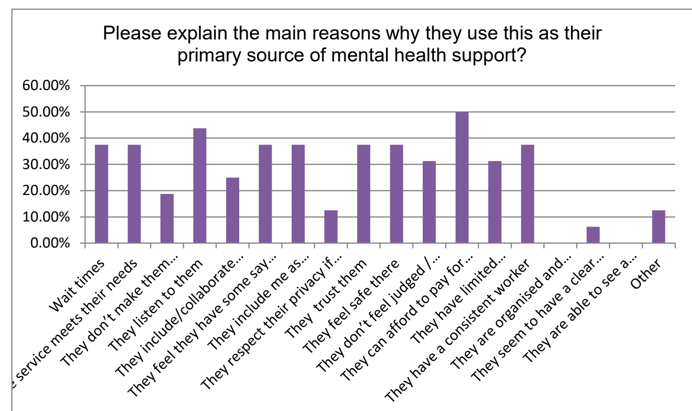


Figure 6: Carers- Reasons for using primary source of mental health support

Table 8: Carers- Reasons for using primary source of mental health support

Answer Choices	Responses	
Wait times	37.50%	6
The service meets their needs	37.50%	6
They don't make them repeat my story too much	18.75%	3
They listen to them	43.75%	7
They include/collaborate	25.00%	4
They feel they have some say or control in making decisions	37.50%	6
They include me as family/carer	37.50%	6
They respect their privacy if they don't want to inc family	12.50%	2
They trust them	37.50%	6
They feel safe there	37.50%	6
They don't feel judged / stigmatised	31.25%	5
They can afford to pay	50.00%	8
They have limited options/choice of service providers in their area	31.25%	5
They have a consistent worker	37.50%	6
They are organised and coordinate the support services they need	0.00%	0
They seem to have a clear plan/goals	6.25%	1
They are able to see a worker whose gender is of their choosing	0.00%	0
Other	12.50%	2

Living with MH issues is tough, and many consumers do not have the courage or the resources to stand up and say "hey, this is not working for me".

- Consumer Comment

2.3 Accessibility of Services:

Summary:

Almost two thirds of consumers who use private hospital services were able to access them when they needed to (62.8%, n=49).

Almost two-thirds of consumers who primarily access private mental health practitioners/hospitals rated that they were helped for the length of time they needed (65.27%, n=47), compared with those who primarily use public mental health services/hospitals/community teams as their primary support where only 50% (n=50) said the health practitioner/service helped them for the length of time they needed.

Consumers who access public mental health services/hospitals/community teams stated that it was more frequently the service that ended the support (33.3%, n=21) compared with those who primarily use private mental health services/hospitals (11.1%, n=4) where it was more frequently the consumer who chose to end the support.

Both consumer and carer respondents who access private mental health practitioners/hospitals identified particular qualities of the private mental health practitioner/hospital that helped them to feel more comfortable and engaged. Both groups identified qualities such as respect, kindness, listening, knowledge and experience, validation, non-judgemental and continuity of care that supported engagement. Consumers identified qualities that made them feel uncomfortable including disrespect, rudeness, disinterest or condescension by the health practitioner. Carers highlighted a lack of goals or progress, the health practitioner not appearing engaged and a loss of control.

Consumers who access private psychiatric hospital care commented on the welcoming environment, the range of services (both in-patient and out-patient), ability to be self-directed and make decisions about their care, the quality of staff and having privacy.

A number of consumers and carers commented on difficulties with affordability and having the 'right' level of private health insurance to access private psychiatric hospitals was a concern.

Consumer responses:

Almost two thirds of consumers who use private hospital services were able to access them when they needed to (62.8%, n=49).

Two-thirds of consumers (66.22%, n=49 of 74) who access private mental health practitioners/hospitals said that particular qualities of the services helped them feel comfortable to engage with them. Of the 41 further comments, consumers noted personal recovery-oriented qualities of the health practitioners/hospitals they saw, and also geographic features of the services (e.g. their waiting rooms and locations) that made them feel more comfortable. They also valued an approach to care that seemed engaged, personalised, organised and coordinated as part of the initial assessment and from one visit to the next.

- *They were friendly, helpful, believed me and gave hope.*
- *Good listener, patient, informed, knowledgeable.*
- *Being seen, heard, viewed as a person and not a diagnosis.*
- *They were kind on the phone, the waiting room and therapy room were comfortable to be in.*

More than three-quarters of consumers (78.67%, n=59 of 75) with private health insurance said that particular qualities of health practitioners/hospitals helped them feel comfortable to engage with them. Of the 49 further comments, consumers predominantly described a range of qualities as important, including respect, kindness, listening, knowledge and experience, validation and a non-judgmental approach, declared commitment to continuity of care, and being a good personality match.

- *Respect for my intelligence, the research I do, my self-motivation and actions I take to manage my illness. Kindness. Acceptance, no stigma. No judgements, no assumptions.*
- *Empathy, compassion. Engaging with me as a human rather than an illness/object. Validating my perspectives.*

Almost half of consumers (43.24%, n=32 of 74) who access private mental health practitioners/hospitals said that particular things about the practitioner or hospitals that made them uncomfortable. Of the 32 further comments, consumers highlighted a range of concerns, including disrespect, rudeness, disinterest and condescension by the health practitioner. Some consumers also mentioned the location and pressures associated with the cost of services.

- *With my first psychiatrist who I disengaged from; she was rude to me. Often treated me like I was an annoyance. Often invalidated me. And told me I wasn't sick enough for further support.*
- *Emotional distancing, boundaries and the professional 'poker face' along with power dynamics.*
- *Not person-centred and didn't include me in the decisions.*

A larger proportion of consumers who use private mental health practitioners/hospitals as their primary support rated the private mental health practitioner/hospital as helping them for the length of time they needed (65.27%, n=47) compared with those who use primarily public mental health services/hospitals/community teams as their primary support, where only 50% (n=50) rated the health practitioner supporting them for the length of time they needed.

Of the consumers who were not supported for the length of time they needed, those who use public mental health services/hospitals/community teams more frequently rated the service as ending the support (33.3%, n=21) compared with those who primarily use private mental health services/hospitals (11.1%, n=4) (Table 9). For those primarily accessing private mental health practitioners/hospitals, it was more frequently the consumer who made the decision to end the support (50%,n=18).

Table 9: Who made the decision to end support – private versus public mental health services as primary support.

	Myself		Service		Other		Unsure		Total	
Q9: Public	33.33%	21	33.33%	21	26.98%	17	6.35%	4	75.00%	63
Q9: Private	50.00%	18	11.11%	4	19.44%	7	19.44%	7	42.86%	36

Consumers who access private psychiatric hospital care, commented that what has been most useful to them includes the hospital environment (aesthetics, amenities, calm, supportive), the range of services (in and out-patient services), ability to be self-directed in their own care, quality and training of staff (nurses, doctors, etc), privacy, and that access is generally quick and easy when you need it.

When asked what private mental health services and private hospital services they currently rely on, 59 consumers provided comments which included (in order of most frequently identified):

- Private Psychiatrist n=40
- Private Psychologist n=32
- In-patient services/admissions n=21
- Day programs n=20
- Out-patient programs (DBT, CBT, etc) n=5

Consumers commented on affordability being a barrier to accessing private psychiatric hospitals due to costs associated with private health insurance cover and the need for a 'top level' of cover for private psychiatric hospital care.

Comments included:

- *At the moment I am not using any of the private mental health services, but if I need to go into hospital for mental health issues I will not be covered as I am not in the top cover which I think is not fair. For the amount of money that we pay for health, I should be able to go first class into a private hospital*
- *I did have private health insurance until I turned 25 and was removed from my parents' policy and because I couldn't justify paying for private health insurance with no real existing medical conditions I have only being using the free services. In saying that, now that Headspace is no longer available to me, I have looked into getting private health insurance to afford ore mental health services outside of the 6-10 free sessions*
- *My last hospital admission was in 2017 for 5.5 weeks. Only after being admitted was I informed my private*

health hospital cover level wasn't high enough to cover my admission therefore had to pay the whole cost upfront.

- *I guess because the cost bearing factor has risen enormously....I would be inclined going to the Public Hospital...and that's only if need be.*
- *At the time [health insurance] covered inpatient and outpatient services. But in recent years health fund has stopped outpatient support. Fund only covers a little of my psychologist and exercise physical appointments. I'm really at the point where I can't afford health fund, don't really get much back after (even with top hospital quality extras cover) but I'm at the point of diminishing returns and FEAR. If I stop coverage, I also lose 30-year history and what if I do need it in future again.*

Carer responses:

When asked if the person they care for was able to receive support from a private mental health practitioner/hospital in a reasonable time, 58.8% (n=10) were able to and 41.2% (n=7) were not able to. Nine carer respondents provided further comments highlighting affordability of private practitioners, difficulties with long waiting times (both with public and private mental health practitioners, however noting that access to private mental health practitioners/hospitals appeared to be quicker than public).

- *Only privately. Public services were essentially non-existent either as result of wait times which were estimated to be between 8-12 months. Public hospitals and CAT teams were singularly inexperienced; didn't appear wanting to engage and when discovered had accessed private services used this as an opportunity to hand ball to those services without regard for capacity to financially maintain those private services.*

When asked what particular qualities of the private mental health practitioner/hospital helped the person they care for feel comfortable to engage with them, seven carers provided comment. The qualities identified included continuity, being treated with respect, listening, and not being rushed and able to take their time. Two of the comments received specifically regarding private psychiatric hospitals included:

- *This was after the first private hospital admission - our daughter had limited insight prior to that and did not want to be admitted. It took me to say "I can't do this anymore" and then a firm discussion by her doctor that admission was necessary for the admission to happen for her to agree to go voluntarily. All the way in, there were protests that "my life is over, I'll be drugged and not able to do anything ever again". Once recovered, she said she would not be afraid to go back to hospital if she needed to in the future.*
- *Private inpatient facility provided quality psychological group support programs and outpatient groups*

Eleven carers provided comments regarding the particular things about the private mental health practitioners/hospitals that made them uncomfortable which included not being engaged, loss of control, and a lack of goals or progress.

2.4 Disengagement from private mental health services:

Summary:

Over 87% of both consumers and families/carers overwhelmingly agreed that disengagement (stopping) use of mental health services as an issue of concern. Comments were primarily focused on disengagement with private mental health practitioners rather than private psychiatric hospitals.

When asked why they rated in this way, consumers who access private mental health practitioners/ hospitals reported that judgement, stigma and a lack of a personalised recovery-orientation by mental health practitioners was an issue of concern. Consumers also commented that affordability, feeling shame, fear and a lack of confidence to be assertive about what they need to support their mental health also contributed to disengagement. Consumers most frequently identified mental health practitioners not listening to them, feeling stigmatised or judged, lack of collaboration and feeling excluded with little say or control in decision making as primary reasons for disengagement.

A number of consumers who access private mental health practitioners/hospitals commented on previous disengagement from mental health services in general, which included a lack of rapport with the provider, lack of continuity (provider leaving or retiring from the practice), and feeling worse or triggered by the contact and feeling that the provider was dismissive.

For consumers and those that support them who access private psychiatric hospitals, discharge notice was generally more positive than the public system, with consumers having more say in their discharge planning and timeline.

Consumers who use private mental health services/ hospitals as their primary support, identified that if they needed support in future, they would access a psychiatrist (73.68%, n=42) or private psychiatric hospital (52.63%, n=30) compared with those who use public mental health services/hospitals/community teams who rated higher against public community mental health services (30.77%, n=12), or a counsellor/therapist (39.56%, n=36) (table 16).

Those who access private mental health services/hospitals as their primary support were less likely to rate lack of options/choice of service providers in their area as the reason for disengagement (29.41%, n=15) compared with those who access public mental health services/ hospitals/community teams as their primary support who rated more highly that disengagement was due to lack of options/choice of providers in their area (46.99%, n=39).

Consumer Responses:

Consumers who access private mental health practitioners/ hospitals overwhelmingly held the view that disengagement from mental health services is an issue for many people, with 87.84% (n=65 of 74) saying yes (Figure 7). Of the 50 further comments, several consumers felt that judgment, stigma and lack of a personalised recovery-orientation by many health practitioners/hospitals was a major issue of concern. They also indicated that there were problems with overall affordability of services.

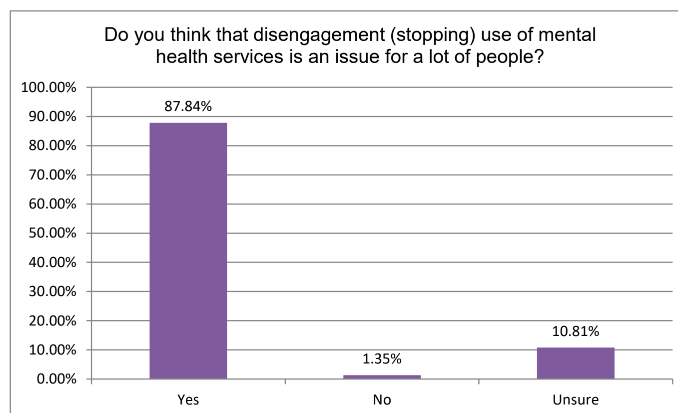


Figure 7 : Consumers – Is disengagement an issue for a lot of people?

Example of comments received from consumers who access private mental health practitioners/hospitals included:

- *I guess it must be if people can't afford it but need it. That's what I'm scared of, luckily and nicely my parents are still paying for mine as I'm still yet to get a job of my own. But when I do get my own income, I'm scared I may struggle to continue to afford my psychologist I've seen for the last 5 years and still need fortnightly.*
- *Yes, because many people disengage due to not having their views, beliefs and holistic needs understood or catered to and can't bear to continue service use. However, they still need mental health support and often end up needing it more after disengagement but are too disillusioned to return to mental health services. Our metal health system cannot possibly provide personal recovery as the national framework guides because it doesn't understand true personal recovery.*

Several consumers also thought that people disengage due to shame, fear and lack of confidence to be assertive about what they need to support their mental health.

- *Overcoming the personal sense of 'failure' that you need help is one thing but then the constant reminder that you are still needing help is a major factor in people walking away from help. Low self-esteem leads you away from help. Those seeking help need to feel less shame and mental health problems need to be seen alongside physical health issues.*
- *Living with MH issues is tough, and many consumers do not have the courage or the resources to stand up and say "hey, this is not working for me".*

Less than half of consumers who access private mental health practitioners/hospitals (42.421%, n=28 of 66) said that the health practitioner/hospital gave them and their family and carer sufficient notice of their impending discharge from the service (see Table 10). However, based on comments received by consumers, discharge notice from private psychiatric hospitals appeared to be more positive, with consumers having time to prepare for discharge, being supported during the process and having more say in their discharge planning and timelines. Comments regarding discharge from private psychiatric hospitals specifically included:

- *You do not feel pushed to discharge in a hurry, or too early, because you are paying them for the care you need.*
- *Discharge planning commenced 2 weeks prior to my discharge date. Planning included identifying what supports I would have at home and what supports would be arranged for at home*
- *We made the discharge from the hospital a goal to work towards. Instead of just turfing you out without notice. I was given a discharge date but was never once pressured into sticking to it.*
- *The private hospital had a well implemented practice of reviewing the goals of admission every week and discussing what would help prepare for discharge.*
- *Private psychiatric hospital makes discharge planning part of the treatment.*
- *When I was in hospital discharge was talked about from the beginning*
- *Not getting shoved out after 24/48 hours dosed up on meds (I've heard horror stories from friends), instead I was able to stay for several weeks and get intensive help, 24/7 support, but also be in a safe and calm environment with like-minded patients, access to specifically trained nurses and doctors, where the focus was on sustainable recovery and not sedation/discharge as soon as possible.*

Table 10: Consumers – Notice of impending discharge from the service

Answer Choices	Responses	
Yes	42.42%	28
No	30.30%	20
Unsure	27.27%	18

Consumers who access private mental health practitioners/hospitals reported the primary reasons why they disengaged with health practitioners/hospitals in the past. The most common reasons were that the service didn't meet their needs, lack of a clear plan or goals meant they didn't seem to be making any progress, and the service didn't offer the right type of support (see Figure 8, Table 11).

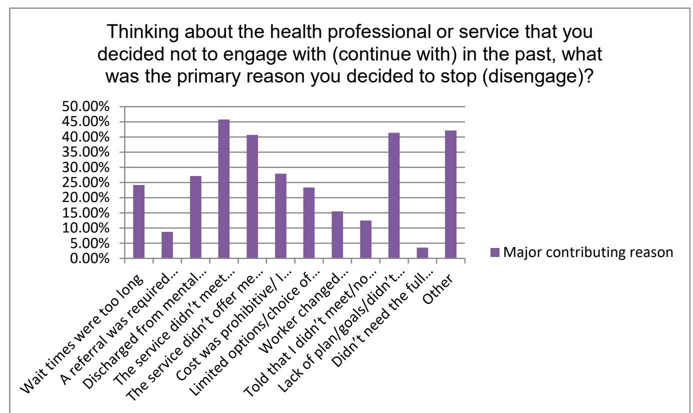


Figure 8: Consumers' reasons for disengagement with health practitioners and services in the past

Table 11: Consumers' reasons for disengagement with health practitioners and services in the past

Thinking about the health professional or service that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?	Major contributing reason		Somewhat contributing reason		Not a contributing reason		Unsure		Total
Wait times were too long	24.14%	14	10.34%	6	62.07%	36	3.45%	2	58
A referral was required but I didn't get one when I asked	8.77%	5	7.02%	4	84.21%	48	0.00%	0	57
Discharged from mental health professional/mental health service with no follow-up	27.12%	16	20.34%	12	50.85%	30	1.69%	1	59
The service didn't meet my needs (wrong care)	45.76%	27	20.34%	12	30.51%	18	3.39%	2	59
The service didn't offer me the right type of support that I needed	40.68%	24	30.51%	18	27.12%	16	1.69%	1	59
Cost was prohibitive/ I couldn't afford to pay for it	27.87%	17	26.23%	16	44.26%	27	1.64%	1	61
Limited options/choice of service providers in my area	23.33%	14	20.00%	12	55.00%	33	1.67%	1	60
Worker changed frequently/ no consistent worker	15.52%	9	10.34%	6	68.97%	40	5.17%	3	58
Told that I didn't meet/no longer met criteria of the service	12.50%	7	12.50%	7	71.43%	40	3.57%	2	56
Lack of plan/goals/didn't seem to be progressing/going anywhere	41.38%	24	25.86%	15	29.31%	17	3.45%	2	58
Didn't need the full number of appointments as I felt better quickly	3.57%	2	7.14%	4	85.71%	48	3.57%	2	56
Other	42.11%	8	5.26%	1	42.11%	8	10.53%	2	19

Twenty-two consumers provided further comments about additional reasons for disengagement which appeared to predominantly reflect past experiences with private mental health practitioners rather than psychiatric hospitals specifically. These included lack of rapport with the practitioner, the practitioner retiring/ceasing private practice, not feeling listened to, feeling worse/being 'triggered' by the contact, and feeling that providers were dismissive or focused more on their business model rather that providing quality support. Comments appeared to reflect experiences with private practitioners (i.e. psychologists and psychiatrists) rather than private psychiatric hospitals.

The most common reasons were that they felt practitioners didn't listen to them, they felt stigmatised and judged by services, services didn't collaborate and they felt excluded, with little say or control in making decisions (see Figure 9, Table 12).

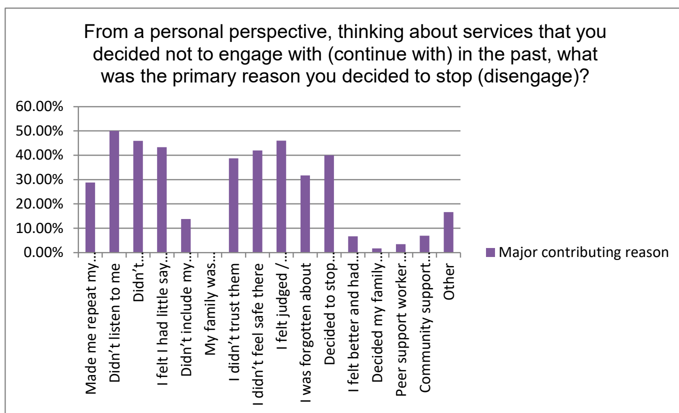


Figure 9: Consumers- Primary reasons for not engaging and disengaging with services in the past, from a personal consumer perspective.

Table 12: Consumers – Primary reasons for not engaging and disengaging with services in the past, from a personal consumer perspective.

From a personal perspective, thinking about services that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?	Major contributing reason		Somewhat contributing reason		Not a contributing reason		Unsure		Total
Made me repeat my story too much	28.81%	17	22.03%	13	49.15%	29	0.00%	0	59
Didn't listen to me	50.00%	31	25.81%	16	24.19%	15	0.00%	0	62
Didn't include/collaborate with me	45.90%	28	14.75%	9	39.34%	24	0.00%	0	61
I felt I had little say or control in making decisions	43.33%	26	25.00%	15	31.67%	19	0.00%	0	60
Didn't include my family/carer	13.79%	8	10.34%	6	74.14%	43	1.72%	1	58
My family was included and I didn't like that	0.00%	0	7.14%	4	91.07%	51	1.79%	1	56
I didn't trust them	38.71%	24	20.97%	13	38.71%	24	1.61%	1	62
I didn't feel safe there	41.94%	26	12.90%	8	43.55%	27	1.61%	1	62
I felt judged / stigmatised by them	46.03%	29	20.63%	13	33.33%	21	0.00%	0	63
I was forgotten about	31.67%	19	13.33%	8	55.00%	33	0.00%	0	60
Decided to stop because another service was better for me	40.00%	24	21.67%	13	36.67%	22	1.67%	1	60
I felt better and had recovered	6.67%	4	10.00%	6	78.33%	47	5.00%	3	60
Decided my family or close friends supported me better	1.72%	1	10.34%	6	82.76%	48	5.17%	3	58
Peer support worker was best suited to my needs	3.45%	2	6.90%	4	82.76%	48	6.90%	4	58
Community support groups were best for me	6.90%	4	8.62%	5	75.86%	44	8.62%	5	58
Other	16.67%	3	0.00%	0	55.56%	10	27.78%	5	18

Consumers who access private mental health practitioners/ hospitals as their primary support were less likely to rate lack of options/choice of service providers in their area as the reason for disengagement (29.41%, n=15) compared with those who access public mental health services/hospitals/ community teams as their primary support who rated more highly that disengagement was due to lack of options/choice of providers in their area (46.99%, n=39). Some consumers highlighted the range of services available through private psychiatric hospitals specifically and two commented that there is no private psychiatric hospital available in their area.

Sixteen consumers provided further comments to explain the reasons for their responses, with trust, determination to avoid the public mental health system, and desire for a collaborative approach being prominent reasons for re-engaging with certain private practitioners and hospitals. Of note, some consumers stated that they had given up trying to re-engage with practitioners.

Consumers who use private mental health practitioners/ hospitals as their primary support, were more likely to access a psychiatrist (73.68%, n=42) or private psychiatric hospital (52.63%, n=30) which was statistically significant compared with those who primarily use public mental health services/ hospitals/community teams that rated higher against public community mental health services (30.77%, n=12), or a counsellor/therapist (39.56%, n=36) (see Table 13).

Table 13: Who consumers would re-engage with in the future – public versus private mental health services as primary support

	Psychiatrist		Public community mental health		Counsellor/ therapist	
Q9: Public mental health services / hospitals / community teams	34.07%	31	30.77%	28	39.56%	36
Q9: private mental health services / hospitals	73.68%	42	14.04%	8	19.30%	11

Carer Responses:

Carers who support someone that uses private mental health practitioners/hospitals held the view that disengagement from mental health practitioners is an issue for many people, with 88.24% (n=15 of 17) saying yes (see Figure 10). Of the 11 further comments, several carers felt that the quality of services was problematic and also noted problems with continuity of practitioner.

- *It takes a lot for people to seek help. It's a confusing and anxiety provoking experience to do so. So, I suspect a lot of people retreat and just try to manage and solve mental health problems themselves*

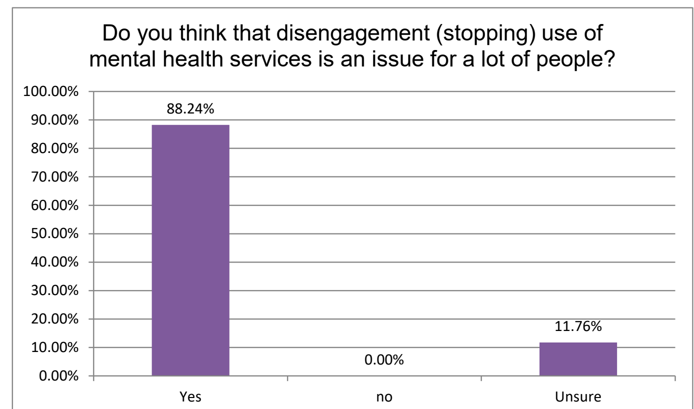


Figure 10 : Carers – Is disengagement an issue for a lot of people?

Less than one third of carers of someone who accesses private mental health practitioners/hospitals (29.41%, n=5 of 17) said that the health practitioner/hospital gave them and the person they care for sufficient notice of their impending discharge from the service, with 35.29% (n=6) saying no and 35.29% (n=6) who were unsure (see Table 14).

Table 14: Carers- Notice of impending discharge from the service

Answer Choices	Responses	
Yes	29.41%	5
No	35.29%	6
Unsure	35.29%	6

Carers of someone who accesses private mental health practitioners/hospitals reported the primary reasons why the person disengaged with health practitioners in the past. Over 80% (n=12+) reported that major or contributing factors were the service not offering them the right type of support, lack of plan/goals/didn't seem to be progressing/going anywhere and discharged from the mental health professional with no follow-up (see Figure 16, Table 15). Two carers commented on barriers to affordability of private services.

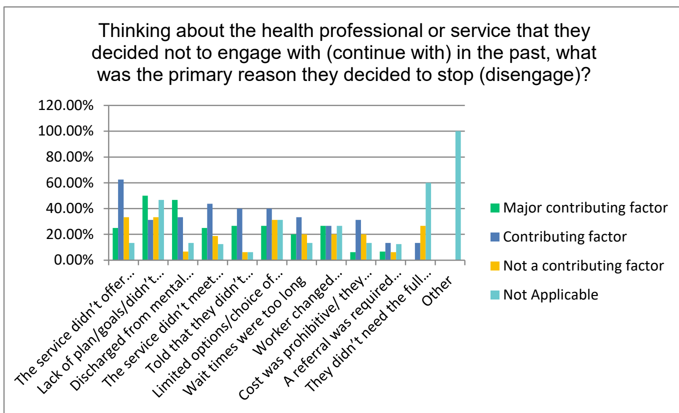


Figure 11: Carers- reasons for disengagement with health professionals in the past.

Table 15: Carers- reasons for disengagement with health professionals in the past.

Answer Choices	Major contributing factor		Contributing factor		Not a contributing factor		Not Applicable		Total
The service didn't offer them the right type of support that they needed	25.00%	4	62.50%	10	33.33%	5	13.33%	2	15
Lack of plan/goals/didn't seem to be progressing/going anywhere	50.00%	8	31.25%	5	33.33%	5	46.67%	7	15
Discharged from mental health professional/mental health service with no follow-up	46.67%	7	33.33%	5	6.67%	1	13.33%	2	15
The service didn't meet their needs (wrong care)	25.00%	4	43.75%	7	18.75%	3	12.50%	2	16
Told that they didn't meet/no longer met criteria of the service	26.67%	4	40.00%	6	6.25%	1	6.25%	1	16
Limited options/choice of service providers in their area	26.67%	4	40.00%	6	31.25%	5	31.25%	5	16
Wait times were too long	20.00%	3	33.33%	5	20.00%	3	13.33%	2	15
Worker changed frequently/ no consistent worker	26.67%	4	26.67%	4	20.00%	3	26.67%	4	15
Cost was prohibitive/ they couldn't afford to pay for it	6.25%	1	31.25%	5	20.00%	3	13.33%	2	15
A referral was required but they didn't get one when they asked	6.67%	1	13.33%	2	6.25%	1	12.50%	2	16
They didn't need the full number of appointments as they felt better quickly	0.00%	0	13.33%	2	26.67%	4	60.00%	9	15
Other	0.00%	0	0.00%	0	0.00%	0	100.00%	5	5

The most common reasons for disengagement were that they had little say or control in decision making, the service didn't listen to them, they made them repeat their story too much, they didn't include them, and the consumer didn't trust the services (see Figure 12, Table 16).

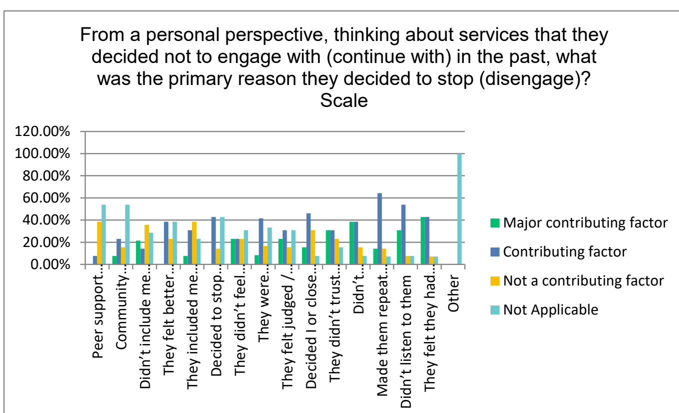


Figure 12: Carers- Primary reasons for not engaging and disengaging with services in the past, from a personal carer perspective.

Table 16: Carers- Primary reasons for not engaging and disengaging with services in the past, from a personal carer perspective.

Answer Choices	Major contributing factor		Contributing factor		Not a contributing factor		Not Applicable		Total
Peer support worker was best suited to their needs	0.00%	0	7.69%	1	38.46%	5	53.85%	7	13
Community support groups were best for them	7.69%	1	23.08%	3	15.38%	2	53.85%	7	13
Didn't include me as their family/carer	21.43%	3	14.29%	2	35.71%	5	28.57%	4	14
They felt better and had recovered	0.00%	0	38.46%	5	23.08%	3	38.46%	5	13
They included me but they didn't like that	7.69%	1	30.77%	4	38.46%	5	23.08%	3	13
Decided to stop because another service was better for them	0.00%	0	42.86%	6	14.29%	2	42.86%	6	14
They didn't feel safe there	23.08%	3	23.08%	3	23.08%	3	30.77%	4	13
They were forgotten about	8.33%	1	41.67%	5	16.67%	2	33.33%	4	12
They felt judged / stigmatised	23.08%	3	30.77%	4	15.38%	2	30.77%	4	13
Decided I or close friends supported them better	15.38%	2	46.15%	6	30.77%	4	7.69%	1	13
They didn't trust them	30.77%	4	30.77%	4	23.08%	3	15.38%	2	13
Didn't include/collaborate with them	38.46%	5	38.46%	5	15.38%	2	7.69%	1	13
Made them repeat their story too much	14.29%	2	64.29%	9	14.29%	2	7.14%	1	14
Didn't listen to them	30.77%	4	53.85%	7	7.69%	1	7.69%	1	13
They felt they had little say or control in making decisions	42.86%	6	42.86%	6	7.14%	1	7.14%	1	14
Other	0.00%	0	0.00%	0	0.00%	0	100.00%	4	4

It takes a lot for people to seek help. It's a confusing and anxiety provoking experience to do so. So, I suspect a lot of people retreat and just try to manage and solve mental health problems themselves

- Carer Comment

2.5 Communication and collaboration between health professions/services:

Summary:

Almost half of consumers who access private mental health practitioners/hospitals and two thirds of carers supporting someone who accesses private mental health services/hospitals said there was no coordination between health practitioners. 40% of consumers said they fell through the gaps and over half of carers said there were no referrals made to other services.

Consumer Responses:

Almost half of consumers who access private mental health practitioners/hospitals (49.09%, n=27 of 55) said that there was no coordination between health practitioners and/or services providing them with support, and 40% (n=22) said that they 'fell through the cracks' (see Figure 13, Table 17).

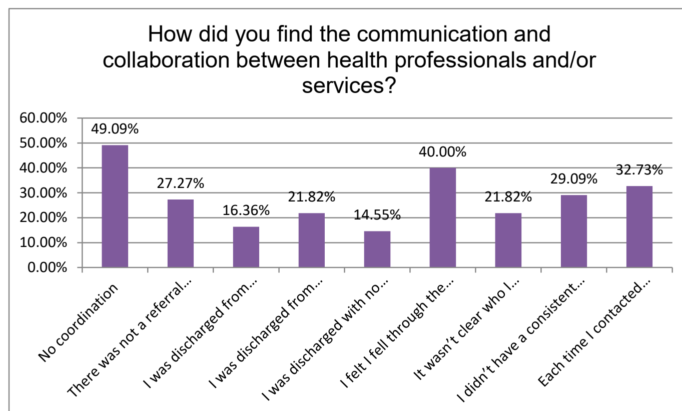


Figure 13: Consumer perceptions of communication and collaboration between health professionals and/or services

Table 17: Consumer perceptions of communication and collaboration between health professionals and/or services

Answer Choices	Responses	
No coordination	49.09%	27
There was not a referral to other services	27.27%	15
I was discharged from hospital with no referral or follow up	16.36%	9
I was discharged from community services before I was ready	21.82%	12
I was discharged with no other option	14.55%	8
I felt I fell through the cracks	40.00%	22
It wasn't clear who I could contact when I needed to	21.82%	12
I didn't have a consistent person who I could contact or speak to	29.09%	16
Each time I contacted them for help, I had to retell my story / they didn't seem to remember my situation, needs or preferences	32.73%	18

Carer Responses:

Almost two thirds of carers supporting someone who accesses private mental health practitioners/hospitals (60%, n=9 of 17) said that there was no coordination between health practitioners and/or services providing them with support, and over half (53.33%, n=8) said there was no referral to other services (see Figure 14, Table 18).

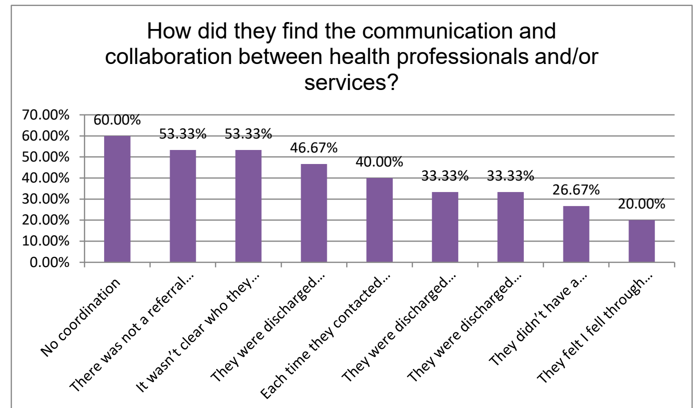


Figure 14: Carer perceptions of communication and collaboration between health professionals and/or services

Table 18: Carer perceptions of communication and collaboration between health professionals and/or services

Answer Choices	Responses	
No coordination	60.00%	9
There was not a referral to other services	53.33%	8
It wasn't clear who they could contact when they needed to	53.33%	8
They were discharged from hospital with no referral or follow up	46.67%	7
Each time they contacted them for help, they had to retell their story / they didn't seem to remember their situation, needs or preferences	40.00%	6
They were discharged from community services before they were ready	33.33%	5
They were discharged with no other option	33.33%	5
They didn't have a consistent person who they could contact or speak to	26.67%	4
They felt I fell through the cracks	20.00%	3

2.6 Contributing factors to deterioration in mental health and access to support:

Summary:

Consumers who access private mental health practitioners/hospitals and the carers that support them were asked to identify contributing factors to further deterioration in mental health during a crisis. The most prevalent reasons from both consumers and carers related to a lack of access to support when needed. Consumers also identified their regular private mental health practitioner not being available, a lack of after-hours support (including from private psychiatric hospitals), affordability, long waiting lists and finding some services that were available but were not helpful as contributing to deterioration of their mental health when in crisis.

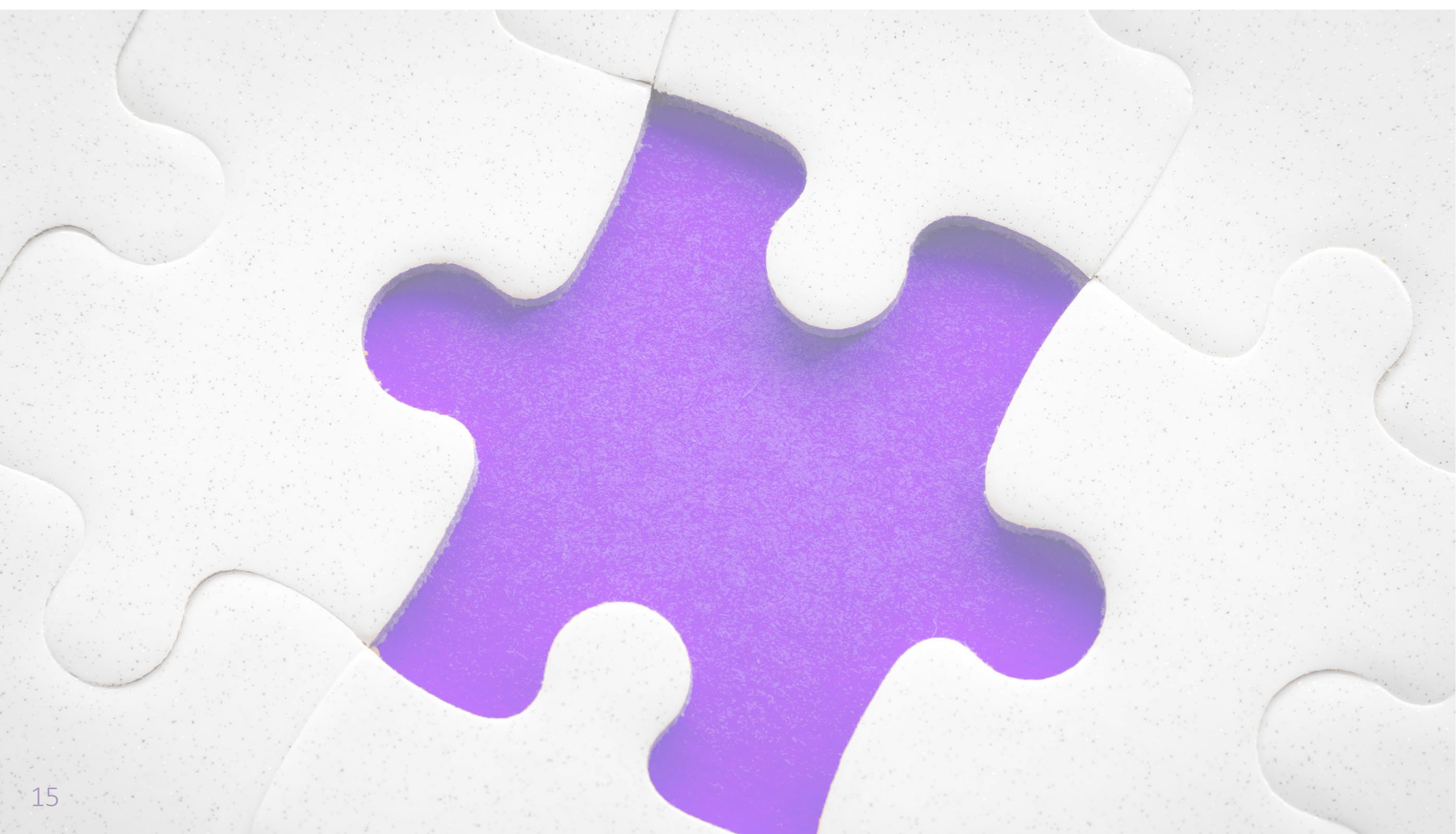
Consumers and carers were asked for suggestions about what would help people to stay engaged with health practitioners/hospitals or return to a health practitioner/hospital to receive mental health support. Consumers and carers both identified reducing costs and affordability and improving continuity of providers as key strategies to support engagement and re-engagement. Consumers also noted making private health insurance more affordable, having private psychiatric hospital care included in lower levels of insurance cover (i.e. not requiring the 'top level' of cover), providing more funding to services supporting people with severe and complex mental health conditions, addressing red tape to make re-engagement processes less bureaucratic, improving health professionals' skills and having more choice in who you access for support.

Carers also suggested having a key contact person and access to peer workers to support engagement and re-engagement with mental health services.

Consumers who access private mental health practitioners/hospitals and the carers that support them provided their views on what people do/what happens after they disengage with services. Both consumer and carer groups agree that the person's situation ultimately worsens. Some consumers also identified that some people find alternative support through their informal networks.

When asked what private mental health services they would like to access that they cannot currently access, consumers and carers identified peer support, and more community groups (exercise, art, yoga, etc). Consumers also identified in-person appointments, bulk-billing psychiatrists, cheaper psychology services, more diverse services in regional/rural areas, more support for prevention and a free psychiatry helpline as services they cannot currently access but would like to. Carers also identified drop in centres and access to a regular psychologist.

Consumers frequently commented on the desire to access affordable psychology/psychiatry services, peer support workers and support groups/community hubs regardless of whether their current primary support was public or private mental health practitioners/hospitals.



Consumer Responses:

Sixty consumers who access private mental health practitioners/hospitals reported on issues that contributed to further deterioration in their mental health when they were in crisis. The most prevalent reasons given were lack of access to support when needed and their regular health practitioner not being available (see Figure 15, Table 19).

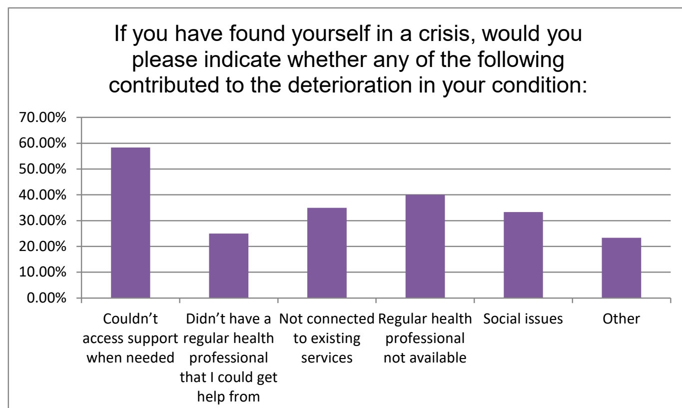


Figure 15: Consumers – Reasons for further deterioration in mental health when in crisis

Table 19: Consumers – Reasons for further deterioration in mental health when in crisis

Answer Choices	Responses	
Couldn't access support when needed	58.33%	35
Didn't have a regular health professional that I could get help from	25.00%	15
Not connected to existing services	35.00%	21
Regular health professional not available	40.00%	24
Social issues	33.33%	20
Other	23.33%	14

Twenty-three consumers provided further comments regarding mental health practitioners/hospitals; they noted lack of after-hours support, being unable to afford services, long waitlists, and finding some available services were not helpful contributed to deterioration in their mental health when in crisis.

- *My private MH practitioners and hospital do not have an afterhours service.*
- *On one occasion - inability to afford psych. medication so went without for several days. Otherwise - crises are generally the result of the ebb and flow of my mental health, rather than a reflection of the supports available/ not available to me.*

Fifty-nine consumers who support someone that accesses private mental health practitioners/hospitals provided ideas about what would help people stay engaged with these services or return to a health practitioner/hospital to receive support for their mental health. They included the following range of practice and systems issues:

- Reduce costs and improve affordability
- Provide more funding to services supporting people with more severe and complex mental health conditions and improve continuity of funding.
- Address red tape to make the re-engagement process less bureaucratic.
- Improved health professional skills and having more choice in who you see for help.
- Improve continuity of provider.

Comments received appeared to reflect experiences with private mental health practitioners rather than private psychiatric hospitals specifically, however suggestions are relevant for consideration:

- *Should be easier/less complicated to be able to reengage. If something or someone isn't a good fit you should be able to have options instead of discharging and starting over on another waitlist, assuming you have the energy to research or make another 5000 phone calls or see a GP multiple times before being able to get onto a waitlist or find a service When you're ill it is all just too hard.*
- *Not having to repeat your story to every different person you see. A central list somewhere of all the meds you have tried that don't work. Just something we can dip in and out of to prevent relapse and crisis – not have to have constant appointments when they aren't required.*
- *Keeping an open door once discharged would be a good thing, knowing that if I got in trouble, I could access them again for support.*
- *Easier re-entry to services without new referrals etc.*
- *Written information about what services are available and how to connect to services. Follow up phone call or appointment to check in.*

3. Appendix 1- Survey Questions

Q1. In which state/territory do you live?

Victoria
South Australia
New South Wales
Queensland
Tasmania
Western Australia
Northern Territory
Australian Capital Territory

Q2. Are you located in a

Capital City
Regional Centre
Remote Town

Q3. Are you

Male
Female
Other

Q4. What is your age range?

under 20 years
20- 39 years
40- 49 years
50-59 years
60-69 years
70-79 years
80 years or above

Q5. Are you of Aboriginal or Torres Strait Islander descent?

Yes
No
Prefer not to answer

Q6. What is your country of birth if not Australia?

Q7. What language do you mostly speak at home?

English
Other (please specify below)

Q8. Are you completing this survey as a:

Consumer (someone with a mental illness or experience of mental ill-health)?
Carer or Family Member

Consumer Questions

Q9. Select from the following options the one which best describes what services, health professional or supports you have mainly used in the past 5 years for your mental health

Public mental health services/hospitals/community teams
Private mental health services/hospitals
My GP
Only used a Private Psychiatrist
A Psychologist, counsellor/therapist
Veteran supports
Peer support (organised or unorganised)
Telehealth
Online or digital resources or Apps
Other (please specify)

Q10. Please explain the main reasons why you use this as your primary source of mental health support? Rate each of the following reasons

Answer Choices a. Major Contributing Reason b. Contributing Reason c. Not a Contributing Reason d. Not Applicable

I don’t have to wait too long to see someone
The service meets my needs
They don’t make me repeat my story too much
They listen to me
They include/collaborate with me
I feel I have some say or control in making decisions
They include my family/carer
They respect my privacy if I don’t want to include my family
I trust them
I feel safe there
I don’t feel judged / stigmatised by them
I can afford to pay for this service
Limited options/choice of service providers in my area
I have a consistent worker
They are organised and coordinate the support services I need
They seem to have a clear plan/goals
I am able to see a worker whose gender is of my choosing
Other (please specify)

Q11. If you used digital resources or Apps, which of the following influenced your decision to commence an online course for mental health and wellbeing? (Select all that apply)

My health professional recommended that I do the course

My friends or family recommended that I do the course

It was convenient for me to access due to limited availability of other mental health services in my local area

It was convenient for me to access due to my limited availability to attend a face-to-face treatment

It was convenient for me to access outside of the normal consultation (business) hours

The cost of face-to-face services

I chose to remain anonymous and limit personal information shared

I wanted to control the level of contact I have with my service provider (e.g. no contact with doctor, only receive feedback via email)

I was on the wait list for other services

I previously used other services or treatments but was dissatisfied

I previously used or was still using other services but I wanted to try something new

I prefer to use digital services rather than face-to-face services

The reputation of the institutes providing the online course

The scientific evidence supporting the online course

Not Applicable

Other (please specify)

Q12. At the time when you enrolled into an online course, what other support or treatment were you receiving to manage or improve your mental health and well-being? (Select all that apply)

None

Another online program

Medication

Face-to-face therapy with mental health professional (e.g., psychiatrist, psychologist, social worker, mental health worker)

Group therapy (including as an outpatient in a hospital setting)

Participation in an exercise group subsidised under Mental Health Treatment Plan

Alternative medicine (e.g. naturopathy, homeopathy, acupuncture)

Not Applicable

Other (please specify)

Q13. If you didn't complete the online course, please indicate why: (Select all that apply)

I was not ready to commit to an online course at the time

I wanted to discuss it first with my health professional

I no longer felt that I needed to do the course

The cost of the course was too high

I accessed another service and/or started another treatment

I experienced technical difficulties

I didn't improve

Not Applicable

Other (please specify)

Q14. After you realised you needed support, were you able to access a mental health service or a health professional in a reasonable time?

Yes

No

Please Comment:

Q15. Were there particular qualities of the service that helped you to feel more comfortable engaging with them?

Yes

No

Please Comment:

Q16. Were there particular qualities of the health professional that helped you to feel more comfortable engaging with them?

Yes

No

Please Comment:

Q17. Were there particular things about them that made you feel uncomfortable and not want to engage with them?

Yes

No

Please Comment:

Q18. Did this health professional or service help you for the length of time you felt you needed?

Yes

No

Q19. If no, did you or the health professional or service make the decision to end your support?

Myself

Service

Other

Unsure

Please Comment:

Q20. If no, did/are you intending to find alternative help for your mental health issues?

Yes

No

Q21. Do you think that disengagement (stopping) use of mental health services is an issue for a lot of people?

Yes

No

Unsure

Please explain the main reasons for your response:

Q22. Did the health professional or service give you and your family and carer sufficient notice of your impending discharge?

Yes

No

Unsure

Please explain the main reasons for your response:

Q23. Thinking about the health professional or service that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

Answer choices
a. Major Contributing Reason
b. Contributing Reason
c. Not a Contributing Reason
d. Unsure

Wait times were too long

A referral was required but I didn't get one when I asked

Discharged from mental health professional/mental health service with no follow-up

The service didn't meet my needs (wrong care)

The service didn't offer me the right type of support that I needed

Cost was prohibitive/ I couldn't afford to pay for it

Limited options/choice of service providers in my area

Worker changed frequently/ no consistent worker

Told that I didn't meet/no longer met criteria of the service

Lack of plan/goals/didn't seem to be progressing/going anywhere

Didn't need the full number of appointments as I felt better quickly

Other

Please comment:

Q24. From a personal perspective, thinking about services that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

Answer choices
a. Major Contributing Reason
b. Contributing Reason
c. Not a Contributing Reason
d. Unsure

Made me repeat my story too much

Didn't listen to me

Didn't include/collaborate with me

I felt I had little say or control in making decisions

Didn't include my family/carer

My family was included and I didn't like that

I didn't trust them

I didn't feel safe there

I felt judged / stigmatised by them

I was forgotten about

Decided to stop because another service was better for me

I felt better and had recovered

Decided my family or close friends supported me better

Peer support worker was best suited to my needs

Community support groups were best for me

Other

Please comment:

Q25. How did you find the communication and collaboration between health professionals and/or services?

No coordination

There was not a referral to other services

I was discharged from hospital with no referral or follow up

I was discharged from community services before I was ready

I was discharged with no other option

I felt I fell through the cracks

It wasn't clear who I could contact when I needed to

I didn't have a consistent person who I could contact or speak to

Each time I contacted them for help, I had to retell my story / they didn't seem to remember my situation, needs or preferences

Q26. If you decided not to continue but need support now or likely to in the future, which health professional or service will you try to re-engage with? Please tick all that are relevant to you

None

Psychiatrist

Psychologist

Social Worker

Public community mental health

Public mental health inpatient unit

Private psychiatric hospital

Headspace

Counsellor/therapist

GP

Peer worker

Other

Please Comment:

Q27. If you have found yourself in a crisis, would you please indicate whether any of the following contributed to the deterioration in your condition:

Couldn't access support when needed

Didn't have a regular health professional that I could get help from

Not connected to existing services

Regular health professional not available

Social issues

Other

Please Comment

Q28. When you found yourself in a crisis, did you seek help through an emergency department?

Yes

No

Not Applicable

Q29. If you answered yes, and you were not admitted to hospital, could you please explain what happened after you were discharged?

Went home

Went to my family or friends

No referral to mental health services

No referral to a health professional

Given a discharge letter to my GP

Given a Referral to a community mental health service

Organised consultation with community mental health team

Referral to a psychiatrist or psychologist

No follow up

Other

Please Comment

Q30. What do you think would help people stay engaged with health professionals or services or return to a health professional or service to receive support for their mental health? Please tell us your ideas

Q31. What would assist/support people to re-engage with services where they had previously disengaged from them? Please tell us your ideas

Q32. From your experience, what do people do/what happens to them after they disengage with services? Please comment:

Q33. How do you think services could best re-engage with people who have disengaged with mental health support from services? Please tell us your ideas

Q34. What services would you like to access to support your mental health and wellbeing that you can't access at the moment? Please comment

Q35. If you use private mental health services and private hospitals do you have private health insurance?

Yes

No

Q36. If you use private mental health services and private hospitals, what services do you currently rely on? Please comment

Q37. Have you been able to access private hospital services when you needed to?

Yes

No

Not Applicable

Q38. If yes, what has been useful to you in accessing this private hospital care? Please comment

Q39. Have you been able to use your private health insurance to access the care you need?

Yes

No

Not Applicable

Q40. If yes, what services did it cover that were useful to you? Please comment

Q41. What services would you like to access that you can't access at the moment? Please comment

Q42. Why? Please comment

Carer Questions

Q43. Select from the following options the one which best describes what services, health professional or supports the person you support has mainly used in the past 5 years for their mental health

Public mental health services/hospitals/community teams

Private mental health services/hospitals

GP

Only used a Private Psychiatrist

A Psychologist, counsellor/therapist

Veteran supports

Peer support (organised or unorganised)

Telehealth

Online or digital resources or Apps

Other

Please Comment

Q44. Please explain the main reasons why they use this as their primary source of mental health support? Please tick all that are relevant

Wait times

The service meets their needs

They don't make them repeat my story too much

They listen to them

They include/collaborate with them

They feel they have some say or control in making decisions

They include me as family/carer

They respect their privacy if they don't want to include their family

They trust them

They feel safe there

They don't feel judged / stigmatised

They can afford to pay for this service

They have limited options/choice of service providers in their area

They have a consistent worker

They are organised and coordinate the support services they need

They seem to have a clear plan/goals

They are able to see a worker whose gender is of their choosing

Other

Please Comment

Q45. After you realised the person you care for needed support, were they able to access a mental health service or a health professional in a reasonable time?

Yes

No

Please Comment

Q46. Were there particular qualities of the service that helped them to feel more comfortable engaging with the service?

Yes

No

Please Comment

Q47. Were there particular qualities of the health professional that helped them feel more comfortable engaging with the health professional?

Yes

No

Unsure

Please Comment

Q48. Were there particular things about the health professional or service that made them feel uncomfortable and not want to engage?

Yes

No

Unsure

Please Comment

Q49. Did this health professional or service help them for the length of time you felt they needed?

Yes

No

Please Comment

Q50. If no, did they or the health professional or service make the decision to end their support?

Themselves

Service

Other

Unsure

Please Comment

Q51. If no, did/are they intending to find alternative help for their mental health issues?

Yes

No

Q52. Do you think that disengagement (stopping) use of mental health services is an issue for a lot of people?

Yes

No

Unsure

Please explain the main reasons for your response

Q53. Did the health professional or service give them or you as their carer, sufficient notice of their impending discharge

Yes

No

Unsure

Please explain the main reasons for your response

Q54. Thinking about the health professional or service that they decided not to engage with (continue with) in the past, what was the primary reason they decided to stop (disengage)?

Answer choices
a. Major Contributing Reason
b. Contributing Reason
c. Not a Contributing Reason
d. Not applicable

Wait times were too long

A referral was required but they didn't get one when they asked

Discharged from mental health professional/mental health service with no follow-up

The service didn't meet their needs (wrong care)

The service didn't offer them the right type of support that they needed

Cost was prohibitive/ they couldn't afford to pay for it

Limited options/choice of service providers in their area

Worker changed frequently/ no consistent worker

Told that they didn't meet/no longer met criteria of the service

Lack of plan/goals/didn't seem to be progressing/going anywhere

They didn't need the full number of appointments as they felt better quickly

Other

Please Comment

Q55. From a personal perspective, thinking about services that they decided not to engage with (continue with) in the past, what was the primary reason they decided to stop (disengage)? Scale

Answer choices
a. Major Contributing Reason
b. Contributing Reason
c. Not a Contributing Reason
d. Not applicable

Made them repeat their story too much

Didn't listen to them

Didn't include/collaborate with them

They felt they had little say or control in making decisions

Didn't include me as their family/carer

They included me but they didn't like that

They didn't trust them

They didn't feel safe there

They felt judged / stigmatised

They were forgotten about

Decided to stop because another service was better for them

They felt better and had recovered

Decided I or close friends supported them better

Peer support worker was best suited to their needs

Community support groups were best for them

Other

Please Comment

Q56. How did they find the communication and collaboration between health professionals and/or services?

No coordination

There was not a referral to other services

They were discharged from hospital with no referral or follow up

They were discharged from community services before they were ready

They were discharged with no other option

They felt I fell through the cracks

It wasn't clear who they could contact when they needed to

They didn't have a consistent person who they could contact or speak to

Each time they contacted them for help, they had to retell their story / they didn't seem to remember their situation, needs or preferences

Q57. If they decided not to continue but need support now or likely to in the future, which health professional or service do you think they will try to re-engage with? Please tick all that are relevant to them

None

Psychiatrist

Psychologist

Social Worker

Public community mental health

Public mental health inpatient unit

Private psychiatric hospital

Headspace

Counsellor/therapist

GP

Peer worker

Other

Please Comment

Q58. If they have found themselves in a crisis, would you please indicate whether any of the following contributed to the deterioration in their condition:

Couldn't access support when needed

Didn't have a regular health professional that they could get help from

Not connected to existing services

Regular health professional not available

Social issues

Other

Please Comment

Q59. When they found themselves in a crisis, did they seek help through an emergency department?

Yes

No

Not Applicable

Q60. If you answered yes, and they were not admitted to hospital, could you please explain what happened after they were discharged?

Went home

Went to family or friends

No referral to mental health services

No referral to a health professional

Given a discharge letter to their GP

Given a Referral to a community mental health service

Organised consultation with community mental health team

Referral to a psychiatrist or psychologist

No follow up

Other

Please Comment

Q61. What do you think would help people stay engaged with health professionals or services or return to a health professional or service to receive support for their mental health? Please tell us your ideas

Q62. What would assist/support people to re-engage with services where they had previously disengaged from them? Please tell us your ideas

Q63. From your experience, what do people do/what happens to them after they disengage with services? Please comment

Q64. How do you think services could best re-engage with people who have disengaged with mental health support from services? Please tell us your ideas

Q65. What services do you think they would like to access to support their mental health and wellbeing that they can't access at the moment? Please comment

Q66. Do they have private health insurance

Yes

No

Unsure

Q67. What services do they currently rely on? Please comment

Q68. Have they been able to access private hospital services when they needed to?

Yes

No

Q69. If yes, what has been useful to them in accessing this private hospital care? Please comment

Q70. Have they been able to use private health insurance to access the care they need?

Yes

No

Unsure

Please Comment

Q71. If yes what services did it cover that were useful to them? Please comment

Q72. What services would they like to access do you think that they can't access at the moment? Please comment

Q73. Why? Please comment

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