The 'Missing Middle'
Lived Experience Perspectives
(Private Sector Report)

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

Lived Experience
AUSTRALIA

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Acknowledgements

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 for the private mental health sector, 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

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 main 'Missing Middle – Lived Experience Perspectives' research and has been analysed with a focus on those accessing private mental health services and hospitals AND with private health insurance cover. 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 and private psychiatric hospitals. It provides a detailed account of their experiences of seeking, receiving and disengaging from private mental health supports. We encourage you to access the full 'Missing Middle' research report covering all service types.

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

1. Consumers who have private health insurance and access private mental health services and hospitals, and the families and carers that support them.
2. Consumers who 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.

As some consumers may use a mix of both private and public mental health services, practitioners and hospitals, some of the data may relate to either or both of these mental health sectors, as stated throughout the report.

1.1 Key Findings:

The feedback from both consumers and carers regarding private mental health services was generally positive, with comments including the benefits of having a range of services available to them, the ability to be self-directed in their own care and the ability to generally access care when it is needed. Some consumers commented on concerns regarding affordability of services (such as the need for private health insurance and the limitations to the Mental Health Care Plan funded sessions with a private psychologist), and a desire to be able to access after-hours support that was not currently available to them.

Overwhelmingly, consumers accessing private mental health services and the families/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, with briefer waiting periods, 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 private mental health services, practitioners and hospitals to coordinate and collaborate together and with other services they use in relation to their care.

The results from this survey tell us that people 'fall through the gaps' when these needs cannot be met.

Key findings are outlined on the following pages.

[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

Consumers with private health insurance and those supporting someone with private health insurance reported using their GP, private mental health services/ hospitals, psychologist and psychiatrist as their primary mental health support due to feeling safe, trusting the provider, having a say or control in decision making, feeling listened to, being included in collaboration about their care or the person they support and briefer waiting times compared with those who primarily access public mental health services/hospitals/community teams.

Consumers who provided further comments indicated that they valued the coordinated approach and ongoing relationships with private practitioners, and the suite of care options they felt were more available to them with private health insurance cover. Some consumers commented on their experience of poor service delivery despite their private health insurance. Consumers primarily using private mental health services/ 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 for their main reason of using public services. Some consumers who primarily access public mental health services commented that they did so because they were unable to afford private services. Consumers who do not have private health insurance frequently commented on their desire to access private mental health services but were unable to due to costs and a lack of affordability.

Over one third of consumers with private health insurance and almost half of carers supporting someone with private health insurance were not able to access mental health services/practitioners within a reasonable time when they realised they needed support, nor were they supported for the length of time they felt they needed. Overwhelmingly, both consumers with private health insurance and those supporting someone with private health insurance agree that disengagement (stopping) use of mental health services is an issue.

Consumers who primarily access private mental health services/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). However, approximately one-third of consumers accessing private mental health practitioners who were not supported for the length of time they felt they needed, suggesting a clear gap. A number of comments received suggested that this was often due to the limitations in subsidised Mental Health Care Plan sessions with a private psychologist, particularly the costs involved in accessing ongoing treatment beyond their subsidised sessions. Carers highlighted a lack of goals/progress, the health practitioner not appearing engaged, or a loss of control as contributing factors to disengagement. Disengagement from support for consumers who primarily access private mental health services/hospitals was less likely to be due to a lack of choice compared with those who primarily access public mental health services/hospitals who disengage due to a lack of choice of providers in their area.

Consumers with private health insurance who decided not to continue with support identified that if they needed support in future they would likely engage with their GP, a Psychiatrist, or a Psychologist due to trust, determination to avoid the public system and seeking a collaborative approach.

Consumers who access private mental health services as their primary support were more likely to access a psychiatrist or private psychiatric hospital compared with those who primarily use public mental health services/hospitals/community teams.

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

Consumers who primarily access private mental health services/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 mental health services and hospitals was generally more positive than the public system, with consumers reporting having more say in their discharge planning and timeline, being involved in discussions and discharge planning and not feeling rushed to leave.

Qualities that support engagement with private mental health services/hospitals included 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 mental health services/hospitals that supported engagement, as rated by consumers and those that support them, included the service/practitioner/hospital helping them to feel more comfortable and engaged, kindness, respect, listening, knowledge and experience of the providers, validation, being 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 mental health services/hospitals for consumers with private health insurance is an issue of concern and often results in people falling through the gaps.

Almost half of consumers with private health insurance and two thirds of carers supporting someone with private health insurance said there was no coordination between mental health professionals/hospitals/services they were engaged with. 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.

Mental health deteriorates when there is a lack of access to support when needed which was reported as the primary reason for deterioration by consumers with private health insurance and carers supporting someone with private health insurance.

Consumers with private health insurance also indicated that deterioration in their mental health is caused by their regular health practitioner not being available, a lack of after-hours support, affordability, waiting lists, and finding that some services were available but not helpful.

Over half of consumers with private health insurance did not access an Emergency Department when in crisis which was not significantly different to those who do not have private health insurance.

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 also identified the need for increased funding for services that support people with severe and complex mental health conditions, addressing red tape to make re-engagement easier, having more options and choice of providers and improving the skills of mental health practitioners. Having more subsidised sessions with private psychologists was identified by a number of consumers to enable ongoing engagement without affordability being a significant barrier. Carers also highlighted the need for a key contact person and access to peer workers to support ongoing engagement and re-engagement.

Services that consumers with 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; these included 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 consumer respondents indicated that they had 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 had private health insurance, again providing a very small sample size, 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 services/hospitals and those using public mental health services/hospitals/ community teams and their geographic location.

Respondents with private health insurance 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 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 services/hospitals (26.03%, n=19).

No consumers or carers with private health insurance 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 with private health insurance took part in the survey (see Figure 1 and 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 uptake by people with mental health conditions.

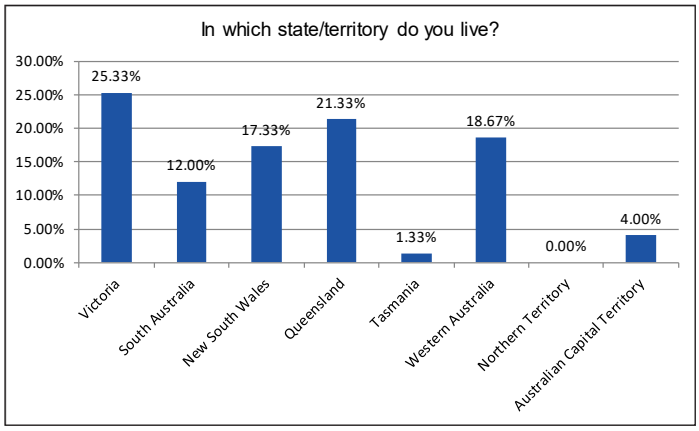


Figure 1: Consumers by state/territory

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 and Table 2).

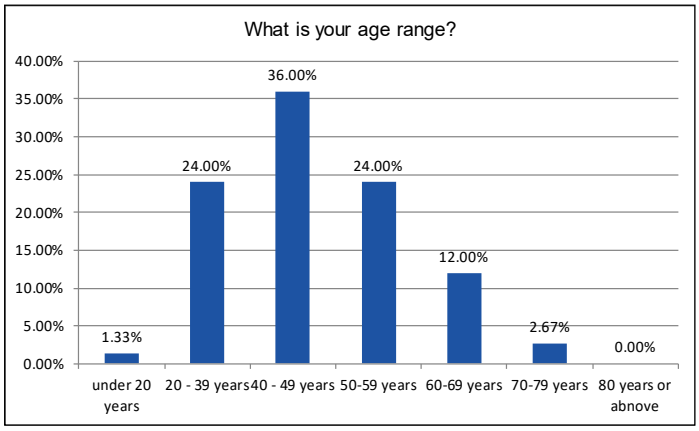


Figure 2: Consumers by Age

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) (Table 3).

Table 3: Consumers by Age: private versus public

Services predominantly used for mental health support	under 20 years		20 - 39 years		40 - 49 years		50-59 years		60-69 years		70-79 years		80 years or above		Total	
Public	0.99%	1	37.62%	38	23.76%	24	21.78%	22	12.87%	13	2.97%	3	0%	0	65.58%	101
Private	1.37%	1	26.03%	19	26.03%	19	24.66%	18	19.18%	14	2.74%	2	0%	0	47.40%	73
Total	1.30%	2	30.52%	47	26.62%	41	22.73%	35	15.58%	24	3.25%	5	0%	0	100.00%	154

Other Demographic Detail

No consumers 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.

Carer responses:

Geographic Location

The spread of carer respondents supporting someone by state or territory is provided in Figure 3 and Table 4 below. There was a relatively even spread across states and territories, however no respondents were located in Tasmania or the ACT.

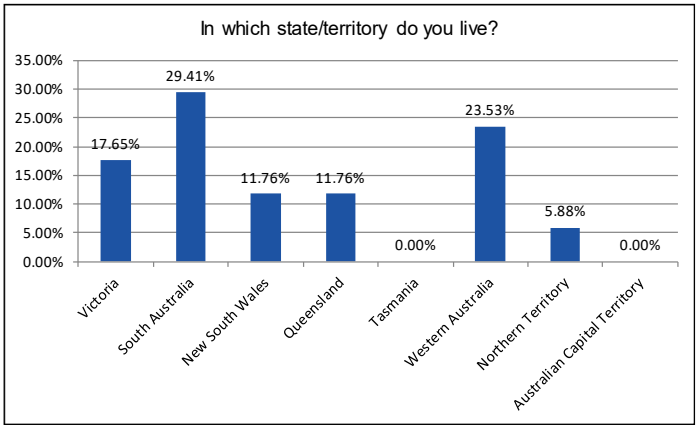


Figure 3: Geographic Location- Carers

Table 4: Geographic Location- Carers

Answer Choices	Responses	
Victoria	17.65%	3
South Australia	29.41%	5
New South Wales	11.76%	2
Queensland	11.76%	2
Tasmania	0.00%	0
Western Australia	23.53%	4
Northern Territory	5.88%	1
Australian Capital Territory	0.00%	0

Seventeen carer respondents provided information about their location with 76.47% (n=13) lived in a capital city, 23.53% (n=4) lived in a regional centre, and none lived in a rural/remote town.

Gender

Seventeen carer respondents provided information about their gender: 82.35% (n=14) identified as female, 17.65% (n=3) as male, and none identified as other.

Age

Seventeen carer respondents provided information about their age. Those aged 50-69 years were the most prominent carers (70.6% (n=12), followed by those aged 70-79 years (17.65%, n=3) and 40-49 years (11.76%, n=2). There were no carer respondents aged under 40 years or above 80 years.

Other Demographic Detail

No carer respondents indicated that they were of Aboriginal or Torres Strait Islander descent with 1 preferring not to say. Four (23%) indicated that they were born overseas which included Egypt, New Zealand, India and the UK); 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, psychologists and psychiatrists 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 services/ 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, feeling safe and not feeling judged/ stigmatised more highly when compared with consumers who use public mental health services/hospitals/ community teams as their primary support and their reasons for using the public system. Some consumers who access primarily access 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 with private health insurance. However, some consumers noted experiencing poor service quality from private practitioners.

Consumer responses:

Consumers who access private mental health services/ hospitals and have private health insurance, predominantly used a GP to support their mental health (60%, n=45), with psychologists, private mental health services/hospitals and psychiatrists as the next most prevalent sources of mental health support (see Figure 4 and Table 5).

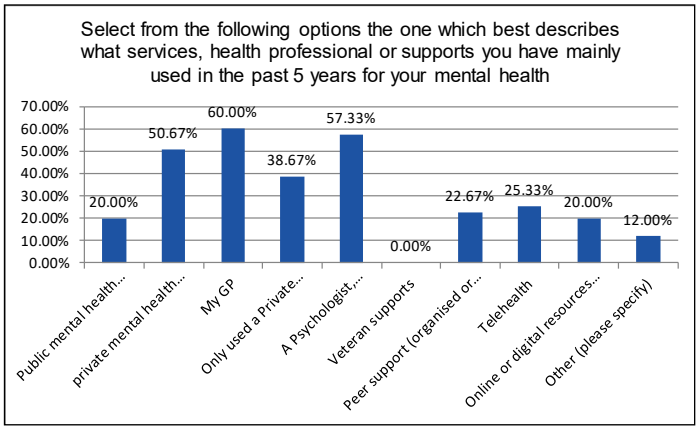


Figure 4: Services, health professional or supports mainly used in the past 5 years by Consumers for their mental health

Table 5: 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, health practitioners and supports as their primary mental health support, most consumers 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 5 and Table 6).

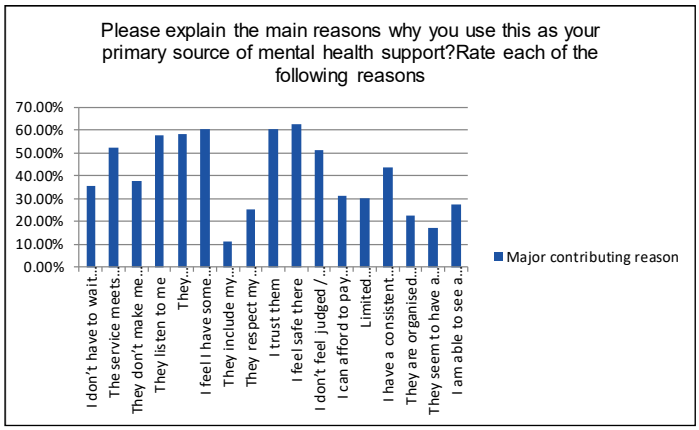


Figure 5: Consumers reasons for using primary source of mental health support

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 providers, and also with a suite of care options that they felt were more available to them with private health insurance cover.

- *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.*

Some consumers also experienced poor service, despite having private health insurance.

- *I want to get better and come out of the system because the system sucks. The system is abusive, expensive and offers no privacy or respect for human beings.*

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*

Table 6: 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 services/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 services/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 (Table 7):

- 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 services/hospitals (27.54%, n=19).

Table 7: 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? Rate each of the following reasons										
I don't have to wait too long to see someone	Major contributing reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		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 reason		Contributing reason		Not a contributing reason		Not Applicable		Total	
Q9: Public	17.35%	17	36.73%	36	33.67%	33	12.24%	12	64.05%	98
Q9: Private	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 reason		Contributing reason		Not a contributing reason		Not Applicable		Total	
Q9: Public	16.49%	16	23.71%	23	38.14%	37	21.65%	21	63.40%	97

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, reported that the person they support 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 6 and Table 8).

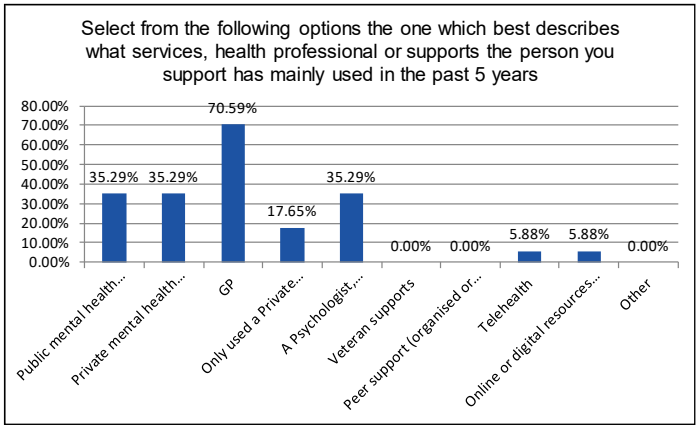


Figure 6: Carers- Services, health professional or supports mainly used in the past 5 years by Consumers for their mental health

Table 8: 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 non-organised)	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 uses the services, hospitals, health professionals and supports as their primary mental health support, most carers identified that the person can afford the service, the service listens to them, shorter wait times, the service meets their needs, they feel they have some control in making decisions, the service includes them as a family/carer, the person trusts them, feels safe, and has a consistent worker (Figure 7 and Table 9).

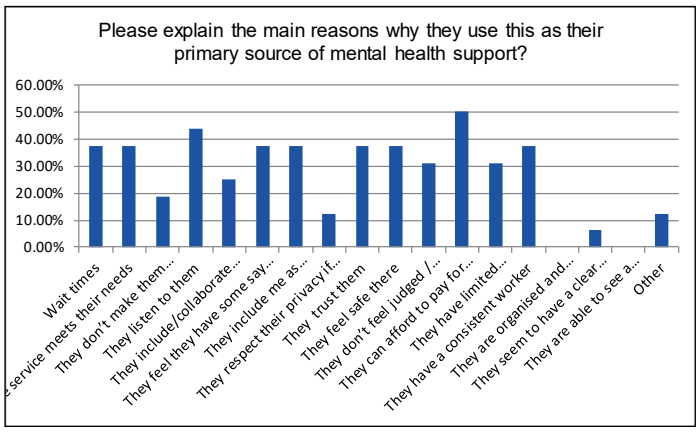


Figure 7: Carers– Consumers reasons for using primary source of mental health support

Table 9: Carers– Consumers 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 with them	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 include their 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 for this service	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

Four carers provided further comments which suggested a variety of reasons for using specific services or providers; the main reason being accessibility (located close to home), availability of the provider with one commenting that the person was "too ill for the private providers".

2.3 Use of Digital Health Services:

Summary:

Consumers with private health insurance who access online courses and support services indicated that they did so due to convenience when there is limited availability of other services in their area or when needing support outside of normal business hours. However, consumers also indicated that medication and face-to-face therapy with a mental health practitioner were their main sources of mental health support. There was no clear reason why consumers with private health insurance who access digital mental health services disengaged before completing, however one comment highlighting anxiety with technology was a preventative factor and provides an indicator that is notable because it suggests that some mental health consumers may not cope as well with online support.

Consumer responses:

Consumers were asked about their use of digital health services such as online courses and support services. More than half of consumers (52.2%, n=36) with private health insurance did not use digital health to access online courses for their mental health. Convenience due to limited availability of other mental health services in their area, and convenience of access outside of normal business hours were cited as the main reasons for using online courses for their mental health (see Table 10).

Table 10: Consumer Responses – Use of Digital Health Services

Answer Choices	Responses	
My health professional recommended that I do the course	17.39%	12
My friends or family recommended that I do the course	5.80%	4
It was convenient for me to access due to limited availability of other mental health services in my local area	20.29%	14
It was convenient for me to access due to my limited availability to attend a face-to-face treatment	18.84%	13
It was convenient for me to access outside of the normal consultation (business) hours	20.29%	14
The cost of face-to-face services	14.49%	10
I chose to remain anonymous and limit personal information shared	10.14%	7
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)	8.70%	6
I was on the wait list for other services	5.80%	4
I previously used other services or treatments but was dissatisfied	8.70%	6
I previously used or was still using other services, but I wanted to try something new	14.49%	10
I prefer to use digital services rather than face-to-face services	2.90%	2
The reputation of the institutes providing the online course	5.80%	4
The scientific evidence supporting the online course	7.25%	5
Not Applicable	52.17%	36
Other (please specify)	7.25%	5

At the time of using these online services for their mental health, medication and face-to-face therapy with a mental health professional were the main sources of mental health support. Very few (4.35%, n=3) indicated that they had no other sources of mental health support during this time (Table 11).

Table 11: Private Health Insurance – Consumers main sources of face-to-face support whilst engaged in online mental health support

Answer Choices	Responses	
None	4.35%	3
Another online program	1.45%	1
Medication	31.88%	22
Face-to-face therapy with mental health professional (e.g., psychiatrist, psychologist, social worker, mental health worker)	34.78%	24
Group therapy (including as an outpatient in a hospital setting)	8.70%	6
Participation in an exercise group subsidised under Mental Health Treatment Plan	1.45%	1
Alternative medicine (e.g. naturopathy, homeopathy, acupuncture)	5.80%	4
Not Applicable	49.28%	34
Other (please specify)	1.45%	1

Consumers with private health insurance gave a range of reasons for not completing online mental health courses (Table 12); no one reason was of greater or lesser importance. Of the eight consumers who indicated 'other', only one provided further comments; however, their comment is notable because it suggests that some mental health consumers may not cope as well with online support:

- *All face to face stopped due to COVID and I can't manage phone calls/video, makes me highly anxious/dissociative. I was able to video with my psychologist, but it was more for her to 'maintain a connection' as she said than actually do 'therapy'.*

Table 12: Private Health Insurance – Consumers' reasons for not completing online mental health courses

Answer Choices	Responses	
I was not ready to commit to an online course at the time	8.33%	2
I wanted to discuss it first with my health professional	00.00%	0
I no longer felt that I needed to do the course	12.50%	3
The cost of the course was too high	12.50%	3
I accessed another service and/or started another treatment	8.33%	2
I experienced technical difficulties	12.50%	3
I didn't improve	12.50%	3
Other (please specify)	33.33%	8

I saw a psychologist weekly or fortnightly for a few months and always booked ahead. She was available weekends and evenings which helped.

- Consumer Comment

Private psychology was available within a few weeks, but public community teams and specialist programs had a wait of some months

- Carer Comment

2.4 Accessibility of services:

Summary:

Almost one third of consumers (32%, n=24) and almost half of carers (41%, n=7) were not able to access mental health support in a reasonable timeframe after they realised that they needed support. However, almost two thirds of consumers who use private mental health services/hospitals were able to access them when they needed to (62.8%, n=49).

Over one third of consumers and over half of carers identified that the mental health service/hospital did not support the consumer for the length of time they felt they needed. There was a significant difference in comparing those who use private mental health services/hospitals as their primary support with 65.27% (n=47) rating that they were helped for the length of time they needed, compared with those who 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).

Both consumer and carer respondents with private health insurance identified particular qualities of the mental health practitioner/hospital that helped them to feel more comfortable and engage. 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.

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 as a concern.

Consumer Responses:

Almost one third of consumers (32%, n=24) reported that they were not able to access a mental health service or health professional in a reasonable time after they realised they needed support (see Figure 8).

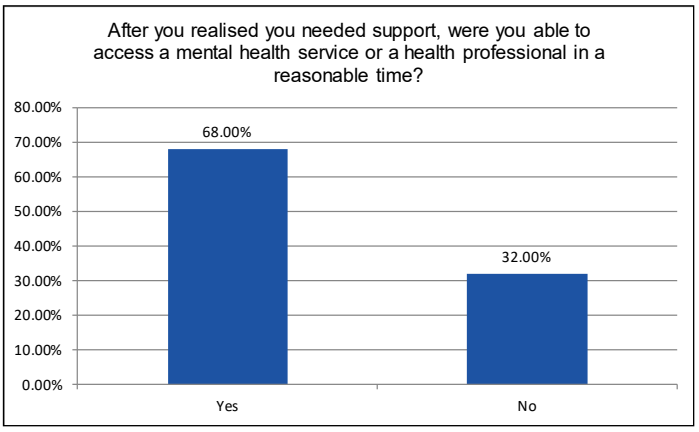


Figure 8: Consumer access to mental health support with a reasonable time

Of the 40 comments provided, flexibility of access to support was noted by several consumers, though several also noted that they experienced significant wait time initially to commence this support by mental health practitioners.

- *Yes, I saw a psychologist weekly or fortnightly for a few months and always booked ahead. She was available weekends and evenings which helped.*
- *I had a 4 month wait for Psychiatrist. But worth the wait for the great specialist.*
- *Again, the benefit of seeing a private psychiatrist with admitting rights to a private hospital.*

Two-thirds of consumers (66.22%, n=49 of 74) with 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 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.*
- *My psychologist's two offices she's had have been a bit basic but still inviting and comfortable. The neuropsychologist's office was in a big complex and a very modern, green inviting open area that we were alone in. So that was nice but maybe even kind of distracting. So maybe simpler is better then. The psychiatrist's office was small and simple too but still comfortable and a bit more modern.*
- *They were kind on the phone, the waiting room and therapy room were comfortable to be in.*
- *This psychologist when I made the appointment through email sent me a couple of questionnaires and forms to fill out and send to her before our first appointment. This gave her a good idea as to my personality, history etc and she was spot on about me and what areas I needed to work on. She was very professional.*
- *My psychiatrist is readily accessible to myself or my wife by email or having phone calls returned.*

More than three-quarters of consumers (78.67%, n=59 of 75) 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.*
- *This psychologist listened and seemed to understand the trauma I'd been through in different situations. She gave really good helpful advice and I felt she was non-judgemental which helped in me opening up to her.*
- *Empathy, compassion. Engaging with me as a human rather than an illness/object. Validating my perspectives.*
- *Good therapeutic engagement, sense of humour, empathy, solid clinical skills.*
- *Educated re mental distress, recovery & LGBTIQA inclusion.*

Almost half of consumers (43.24%, n=32 of 74) said that particular things about the services, practitioners or hospitals 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, and two consumers mentioned that the health practitioner appeared to become unwell.

- *I got lucky but met many health professionals along the way (such as GPs, dieticians and paediatricians) who were unprofessional and didn't know much about mental illness, such as eating disorders and left me feeling distressed. I had to repeat my story multiple times and felt unheard and like there was something wrong with me.*
- *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.*
- *Regular price increases so the gap was in excess of $50. When I asked for a concession discount, they refused despite me being unemployed due to poor mental health. I could not afford regular visits and rushed through appointments as cost went up with time. They also want to keep adding more and more drugs, ones that aren't on the PBS.*

Whilst many consumers said the length of time they received support was sufficient, over one-third of consumers (35.14%, n=26 of 74) said the practitioner/hospital did not help them for the length of time the consumer felt they needed (Figure 9).

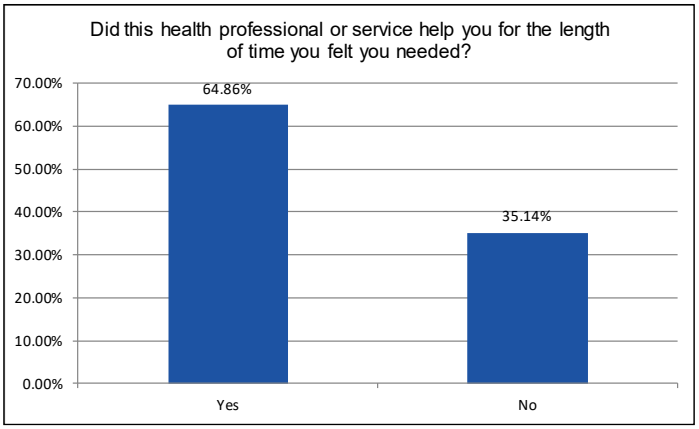


Figure 9: Did health professionals or services help for the length of time consumers needed?

A larger proportion of consumers who use private mental health practitioners/hospitals as their primary support rated them more highly with 65.27% (n=47) reporting being helped for the length of time they needed compared with those who use 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.

When asked who made the decision to end support from the mental health service/practitioner, 36 consumers responded, with almost half (47.22%, n=17) indicating that they made the decision themselves (see Figure 10). Of the 17 further comments received, several consumers cited costs as a significant reason for disengaging and feeling more traumatized/worse as a consequence of the treatment provided.

- *She did help for the most part, but the costs were too high, and I pretended all was well near the end.*
- *Considering ending due to high cost.*
- *She was traumatizing me and being medically negligent. So, I ended it and found a better psychiatrist.*
- *When I felt I was no longer improving, but getting worse, I made the decision to find a new psychiatrist*.

Of these consumer respondents, 61.11% (n=22 of 36) said they intended to find alternative help for their mental health.

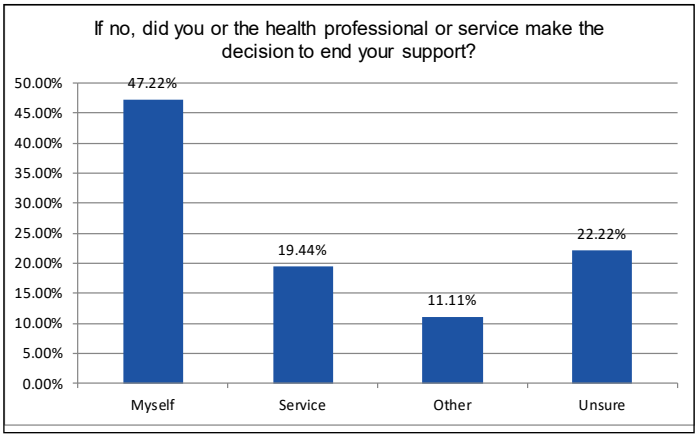


Figure 10: Who made the decision to end support?

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 12).

Table 12: Who made the decision to end support – private versus public mental health services as primary support?

Who made the decision to end support?	Myself		Service		Other		Unsure		Total	
Public	33.33%	21	33.33%	21	26.98%	17	6.35%	4	75.00%	63
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.

Consumers commented on affordability being a barrier to accessing private mental health services and hospitals due to costs associated with private health insurance cover and the need for a 'top level' of cover for private psychiatric hospital and other 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 mental health service/hospital in a reasonable timeframe, 58.8% (n=10) were able to and 41.2% (n=7) were not able to. Nine carer respondents provided further comments highlighting affordability (particularly when subsidised sessions had been used), difficulties with long waiting times (both in public and private mental health services), however also noting that access to private mental health services/hospitals appeared to be quicker than public, and some commenting that they generally have poor outcomes when the person they are supporting accessed an Emergency Department.

- *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.*
- *Cost of private services is prohibitive due to absence of bulk billing psychiatrists long term and limit of 10 Medicare rebated, psychological services.*
- *My loved one falls ill suddenly and severely. Of his 9 hospital admissions, 8 were as involuntary patient. He has always had to wait for hours (and sometimes overnight) in Emergency before a bed became available. He has never been discharged from High Dependency to Low Dependency when he was well enough. It has always been a case of the most well of the unwell. Often with poor outcomes.*
- *Private psychology was available within a few weeks, but public community teams and specialist programs had a wait of some months*

Less than half of carers (41.18%, n=7) said that particular qualities of the service or health practitioners/hospitals helped the person they care for feel comfortable to engage with them. Of the seven who provided further comments, qualities identified included continuity, being treated with respect, listening, not being rushed and being able to take their time.

- *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*
- *Case managers and therapists were very patient and careful in attempting engagement*

Almost two thirds of carers (64.71%, n=11) said that particular things about the services or practitioners/hospitals made them uncomfortable. Of the 11 further comments, carers highlighted a range of concerns, including not being engaged, loss of control, and a lack of goals or progress.

There were mixed responses regarding whether the mental health service/practitioner/hospital supported the consumer for the length of time they felt was needed. More than half (56.25%, n=9) said the health practitioner/hospital did not help them for the length of time the consumer felt they needed. Comments were wide ranging to this question with no clear themes other than two commenting on the limited time available at appointments with GPs. Over half of carer respondents reported that it was the consumer who decided to end the support (54.55%, n=6), with others rating the service (27.17%, n=3), other (9.09%, n=1) or unsure (9.09%, n=1). Reasons for ending support included the health practitioner/hospital not being engaging, difficulties with continuity of providers, lack of goals, location or inflexibility of the service. Three quarters (75%, n=9) of carers stated that the person they care for did or is intending to find alternative help for their mental health issues.

2.5 Disengagement from private mental health services:

Summary:

Over 87% of both consumers and families/carers with private health insurance overwhelmingly agreed that disengagement (stopping) use of mental health services was an issue of concern.

When asked why they rated in this way, consumers 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. Carers who support someone with private health insurance noted poor quality and a lack of continuity of providers were common reasons for disengagement.

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

For consumers and those that support someone who accesses private mental health services/hospitals, discharge notice was generally more positive than the public system, with consumers having more say in their discharge planning and timeline, or knowing up front how many sessions they would have with the practitioner.

Consumers who decided not to continue with support identified that if they needed support in future they would likely engage with their GP (60%, n=41), a Psychiatrist (62%, n=42) or a Psychologist (53%, n=36). The primary reason for this response was due to trust, a determination to avoid the public system, and a desire for a collaborate approach being the prominent reasons for re-engagement with certain private providers. Some consumers commented that they had given up trying to re-engage with services. Carer responses were consistent with those of consumers, with almost two thirds of carers saying they would try to re-engage with a GP (62.5%, n=10) or a psychiatrist (56%, n=9) in the future.

Consumers who use private mental health services/ hospitals as their primary support, were more likely to 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 with private health insurance 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 11). Of the 50 further comments received, several consumers felt that judgment, stigma and lack of a personalised, recovery-orientation by many practitioners/ hospitals was a major issue of concern. They also indicated that there were problems with overall affordability of services and the current guidelines regarding the number of subsidised sessions available which they felt did not always meet their ongoing needs.

- *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.*
- *Mental health services need to be affordable as it's not something that can be solved in 10 or so sessions. I found that in order to stay engaged I had to be seeing her weekly and focussing on the goals of that week and addressing any problems/issues I had during the week with her.*
- *People need regular check-ups for mental health just like physical health (e.g. dentist, vaccination, pap-smear, etc) but don't because of things such as money/hard to understand Medicare, ignorant primary health providers, stigma, and being disillusioned from being referred back and forth to different people.*
- *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 who access private mental health services/ hospitals 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.

- *People with mental illness need support, BUT, if they are not comfortable with the support that they are getting from drs, etc, I feel that they give up as they are afraid to find another doctor, etc.*

- *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".*

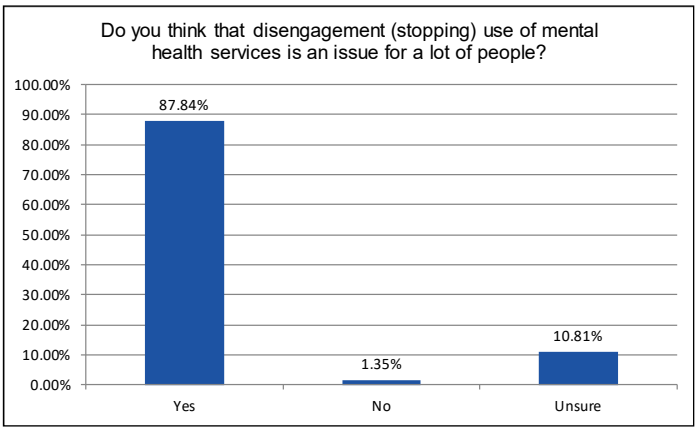


Figure 11 : Is disengagement an issue for a lot of people?

Less than half of consumers (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 12).

Table 12: Notice of impending discharge from the service

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

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*
- *No 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.*
- *Upon admission I had a goal to work towards. I knew the plan I wanted in place and spoke to my psychiatrist who communicated with other health professionals to help me work towards my goal. Consequently, I had a reasonable time frame within I could work to achieve my outcome and all those looking after me were on same page.*
- *We came to the end of the 10 sessions offered under the Better Access plan and this was communicated well ahead of the expiry time.*

A number of consumers who primarily access private mental health service had negative experiences regarding discharge notice with comments including:

- *A previous private health provider I completed therapy with last year didn't inform me when my medicare rebated sessions were over. I was just left feeling like things were unfinished....*
- *So many examples. The 8 years twice a week psychiatrist who phone dumped me on a Thursday evening then panicked and had me picked up and scheduled. The psychiatrist who assured me she could help then after two sessions mailed me a letter saying that she'd underestimated her expertise. The GP who just stopped appointments after years and told a social worker who was concerned I hadn't seen anyone since Feb and during covid lockdown that he didn't know anyone to refer me to. The mental health service who told a worker, phoning to enact my emergency plan that "it's crocodile tears, she has abandonment issues" and "She has every support known to man" when I had none. There was the service who exited me after no incidents and lots of set up and training staff because "she CAN be complex". Many who took me on with my large bucket of funding then realised I was "too complex", "we don't have capacity" "outside our expertise" (aka what do we do with someone who doesn't want to sit in our day centre) So many more.*
- *I cannot stress how important it is that if a person gets discharged from a service that a ref feral to another service is made and followed up that it has being successful.*
- *When I lost services it was due to the NDIS plan not being renewed appropriately so no one was prepared for the sessions to stop before they did. We thought that the funding would be renewed and I could continue as normal, but a review needed to be done which took months - during which I was unable to access services*

Consumers with private health insurance reported the primary reasons why they disengaged with health services/ 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 (Figure 12 and Table 13).

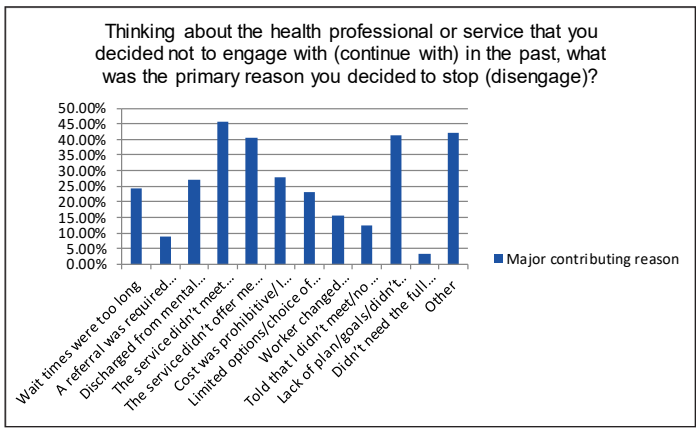


Figure 12: Consumers' reasons for disengagement with health practitioners and services in the past

Table 13: 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)?									
Answer choices	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. 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.

- *Psychologist had to retire (due to ill health) and didn't have a replacement. Also felt that I wasn't improving greatly anymore.*
- *My psychiatrist stopped private practice; I couldn't find a psychiatrist who wasn't just a pill pusher so decided to use a psychologist. She made the spots to suit herself not according to what I felt I needed. I don't think she wanted anyone other than worried well.*
- *Regular insensitive questioning about suicidality from a revolving plethora of nurses, shared bedrooms, disruptive environment were very hard in hospital (private) I left without having addressed the cause of admission.*

The most common reasons were that consumers felt the 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 (Figure 13 and Table 14).

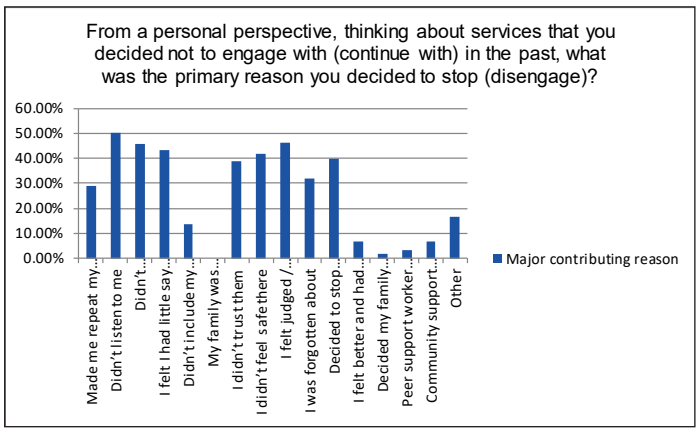


Figure 13: Primary reasons for not engaging and disengaging with services in the past, from a personal consumer perspective.

Table 14: Primary reasons for not engaging and disengaging with services in the past, from a personal consumer 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

Consumers 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).

Almost two-thirds of consumers said that they would try to re-engage with a psychiatrist (61.75%, n=42) or a GP (60.29%, n=41) in the future (Figure 14 and Table 15).

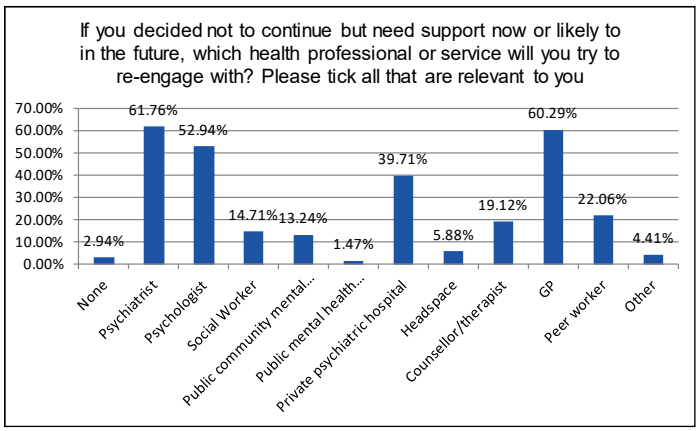


Figure 14: Who consumers would re-engage with in the future

Table 15: Who consumers would re-engage with in the future

Answer Choices	Responses	
None	2.94%	2
Psychiatrist	61.76%	42
Psychologist	52.94%	36
Social Worker	14.71%	10
Public community mental health	13.24%	9
Public mental health inpatient unit	1.47%	1
Private psychiatric hospital	39.71%	27
Headspace	5.88%	4
Counsellor/therapist	19.12%	13
GP	60.29%	41
Peer worker	22.06%	15
Other	4.41%	3

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. Of note, some consumers stated that they had given up trying to re-engage with practitioners.

- *I don't want to be referred to one after another psychiatrist/psychologist only to find that they are not interested or only want to push pills. I want someone who respects and collaborates with me.*
- *I will pay whatever I need to avoid the public services here in XXXX.*
- *None of them are worth the effort.*

Consumers who use private mental health services/hospitals as their primary support, were more likely to 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).

Table 16: 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	
Public	34.07%	31	30.77%	28	39.56%	36
Private	73.68%	42	14.04%	8	19.30%	11

Carer Responses:

Carers overwhelmingly held the view that disengagement from mental health services is an issue for many people, with 88.24% (n=15) saying yes, 11.76% (n=2) saying no and no-one responding that it wasn't an issue (Figure 15). 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*

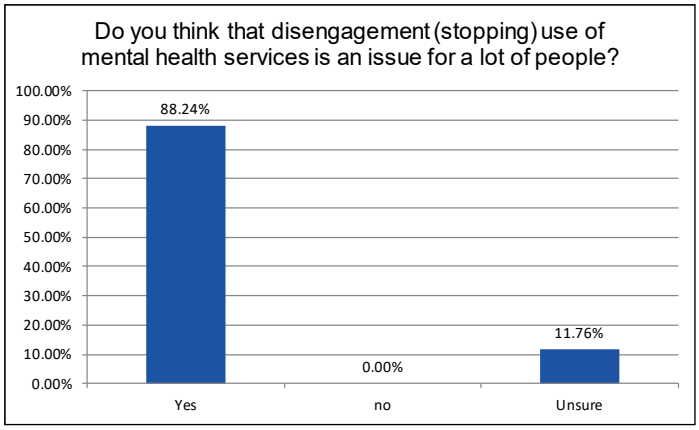


Figure 15 : Is disengagement an issue for a lot of people?

Less than one third of carers (29.41%, n=5 of 17) said that the health practitioner/service/hospital gave them and the person they care for sufficient notice of their impending discharge from the service (see Table 17).

Table 17: Carers: Notice of impending discharge from the service

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

Comments from carers varied with some noting they were not contacted regarding discharge, being discharged from a practitioner without further support, or discharge happening without notice (i.e. discharged on the day discharge was first discussed).

Carers of someone who accesses private mental health services/hospitals reported the primary reasons why the person disengaged with health service/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 and discharged from the mental health service/hospital with no follow-up (Figure 16 and Table 18). Two carers commented on barriers to affordability of private mental health services.

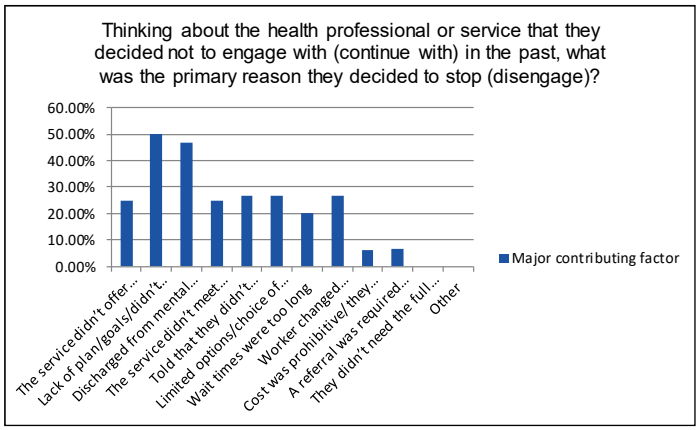


Figure 16: Carers- reasons for disengagement with health professionals and services in the past.

Table 18: Carers- reasons for disengagement with health professionals and services 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, practitioners/ hospital staff 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 (Figure 17 and Table 19).

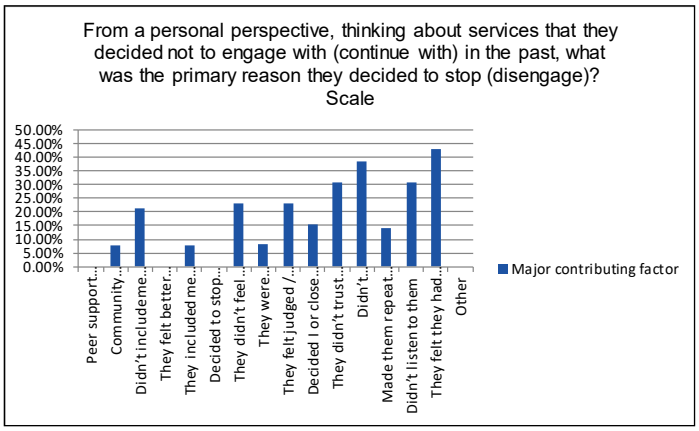


Figure 17: Carers- Primary reasons for not engaging and disengaging with services in the past, from a personal carer perspective.

Table 19: 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

Almost two-thirds of carers said that they would try to re-engage with a GP (62.5%, n=10) or a Psychiatrist (56.25%, n=9) in the future (Figure 18 and Table 20).

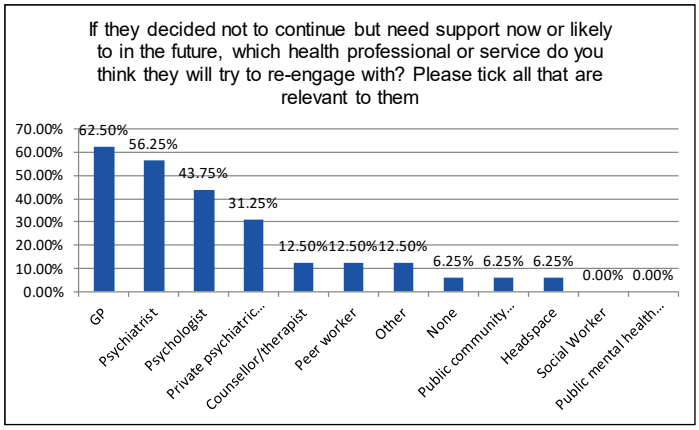


Figure 18: Carers: Who consumers would re-engage with in the future

Table 20: Carers: Who consumers would re-engage with in the future

Answer Choices	Responses	
GP	62.50%	10
Psychiatrist	56.25%	9
Psychologist	43.75%	7
Private psychiatric hospital	31.25%	5
Counsellor/therapist	12.50%	2
Peer worker	12.50%	2
Other	12.50%	2
None	6.25%	1
Public community mental health	6.25%	1
Headspace	6.25%	1
Social Worker	0.00%	0
Public mental health inpatient unit	0.00%	0

Two carers commented that the person they support has had traumatic experiences when accessing support from mental health practitioners and this will impact on future access; one of these was specific to the private mental health system.

> *Engaging with public mental health services has always seemed like a lottery and can never guarantee whether he will be assessed by someone who won't be stigmatising, cause more trauma, or simply not have the skills to be effective.*
>
> *- Carer Comment*

2.6 Coordination and collaboration between health professions/services:

Summary:

Almost half of consumers with private health insurance and two thirds of carers supporting someone with private health insurance said there was no coordination between mental health services/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 (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 Table 21).

Table 21: Consumer perceptions of communication and collaboration between health professionals and/or services

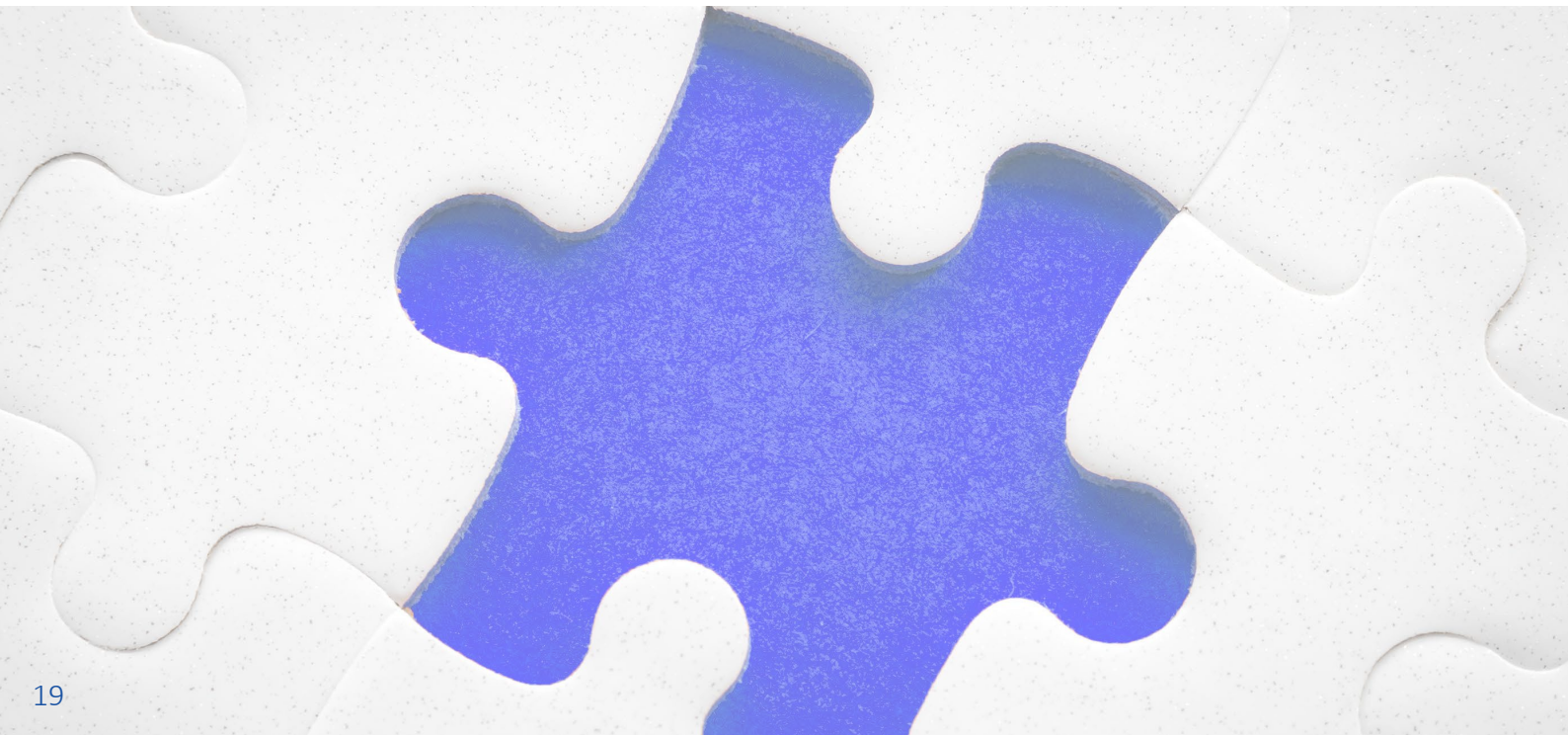
Answer Choices	Responses	
No coordination	49.09%	27
There was not a referral to other services	27.27%	15
I was discharged from hospital with no referral or follow up	16.36%	9
I was discharged from community services before I was ready	21.82%	12
I was discharged with no other option	14.55%	8
I felt I 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 with private health insurance (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 Table 22).

Table 22: 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



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

Summary:

Consumers with private health insurance and carers supporting someone with private health insurance 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 at 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.

When experiencing a crisis, more than half of consumers with private health insurance did not seek assistance from an emergency department which was not significantly different to the rating of consumers who do not have private health insurance. Of those who accessed a public Emergency Department but were discharged without being admitted to a ward, predominantly went home or to family or friends. Carers noted that the person they care for who was discharged without admission to a ward predominantly went home and a lack of follow up after discharge, putting increased reliance on the family to support the person.

Consumers and carers were asked for suggestions about what would help people to stay engaged with mental health services/hospitals or return to a mental health service/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 and carers provided their views on what people do/what happens after they disengage with services. Both consumer and carer respondents agreed that the person's situation ultimately worsens. Some consumers also identified that people find alternative support through their informal networks.

When asked what services they would like to access for their mental health and wellbeing that they cannot current access, consumers and carers supporting them with private health insurance identified peer support, and more community groups (exercise, art, yoga, etc). Consumers also identified in-person appointments, bulk-billing psychiatrists, more subsidised psychology sessions, 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 services/hospitals.

Consumer Responses:

Sixty consumers with private health insurance 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 (Figure 19 and Table 23).

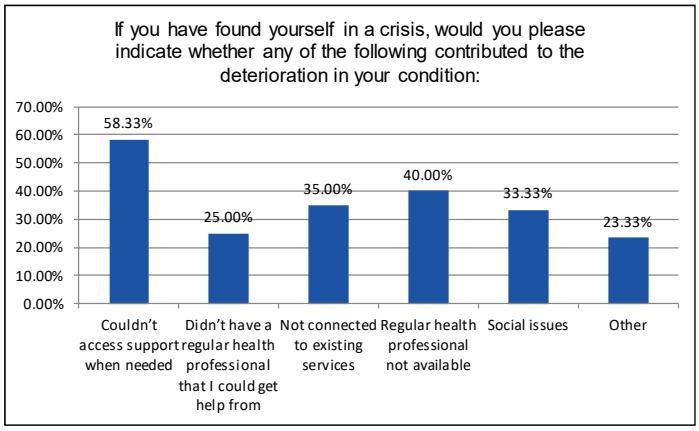


Figure 19: Reasons for further deterioration in mental health when in crisis

Table 23: 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 a lack of after-hours support, being unable to afford services, long waitlists, and finding some available services were not helpful, which 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.*
- *The helplines (e.g. lifeline, Being, beyond blue etc) are not equipped to deal with severe mental*
- *illnesses (e.g. bipolar). When help is needed, there is nothing they can say that will help in any way. The lack of help from these contributes to deterioration.*

When experiencing a crisis, more than half of consumers (54.93%, n=39 of 72) said that they did not seek help through an emergency department (see Figure 20). There was no statistical significance in this result when compared to consumers who do not have private health insurance (44.78%, n=30).

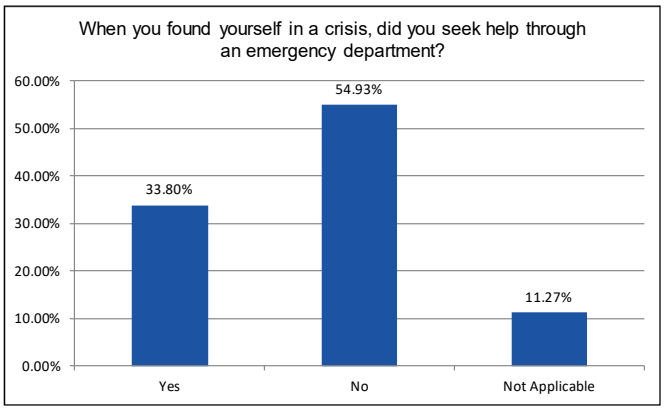


Figure 20: Seeking help through an emergency department when in crisis

Consumers who were not admitted to a public hospital after seeking help through an emergency department were asked what happened after discharge. Of the 23 consumers who responded, most simply went home (60.85%, n=14) and more than half (52.17%, n=12) received no follow-up or referral. Only approximately one-quarter were given a discharge letter to their GP, and only 1 consumer was referred to a psychiatrist or psychologist, despite having private health insurance (Figure 21 and Table 24).

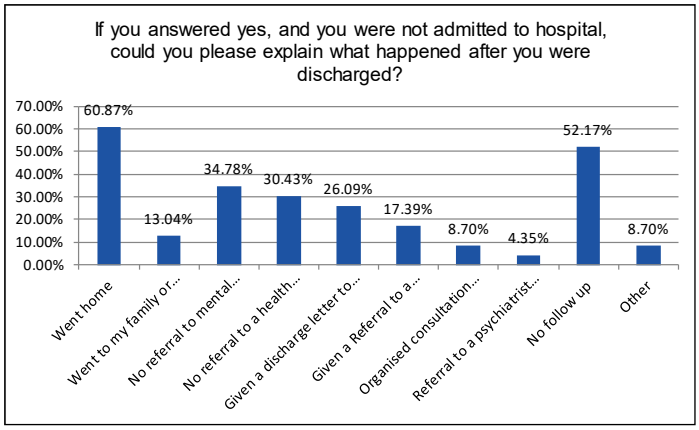


Figure 21: Follow-up support when in crisis and not admitted to hospital

Table 24: Follow-up support when in crisis and not admitted to hospital

Answer Choices	Responses	
Went home	60.87%	14
Went to my family or friends	13.04%	3
No referral to mental health services	34.78%	8
No referral to a health professional	30.43%	7
Given a discharge letter to my GP	26.09%	6
Given a Referral to a community mental health service	17.39%	4
Organised consultation with community mental health team	8.70%	2
Referral to a psychiatrist or psychologist	4.35%	1
No follow up	52.17%	12
Other	8.70%	2

Fifty-nine consumers provided ideas about what would help people stay engaged with mental health services/hospitals or return to a mental health service to receive support. They included the following range of practice and systems issues:

- Reduce costs, improve affordability, make bulkbilling more widely available.
- 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 included:

- *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.*

- *More Medicare funded psychology sessions, AT LEAST fortnightly more availability of sessions with chosen provider less stigma from both community and health professionals follow up / check ins from providers if you repeatedly cancel sessions.*
- *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. A safe place where people in mental health crisis can go that's not an emergency department, but gives them the support they need…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.*
- *Sense of longevity in the therapeutic relationship. If there is a change in worker, then it's important that there be a relevant, careful handover of information to the new worker. Clear boundaries (of/for both consumer and worker) which are stated at the beginning of the relationship and as often as is necessary throughout. Sense of trust (both ways). Reliability of service - i.e. appointments happen when they say they're supposed to happen - don't subject the consumer to repeated cancellations/pushbacks.*
- *Maintain continuity of funding for currently engaged persons with chronic mental health issues under a single MH funding scheme. Having a worker for 6 months under short term funding is pointless (PHaMs, One Door etc). Continuity allows more confidence and routine in supports and reduces the stress of reliving our story over and over. Confident workers who can rely on employment permanency also promotes confidence in the MH consumers that their supports are meaningful and worth the effort to engage.*
- *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. No gap fees for psychiatry and psychology. GP better educated about services.*
- *Having health professionals that want to be in their role and who genuinely care for the patient/client. Providing clients with choice, connection, and ongoing support.*
- *Written information about what services are available and how to connect to services Follow up phone call or appointment to check in.*
- *Workers who understand mental illness and are both compassionate as well as knowledgeable. Workers with a smaller case load and more time allocated to each case.*

Fifty-two consumers provided ideas about what mental health practitioners/services could do to support people to re-engage where they had previously disengaged. Many of their comments mirrored their suggestions above with regard to reducing costs and improving mental health practitioners' interpersonal skills and behaviours, in addition to the need for reducing referral paperwork and bureaucracy, and the need for services to be more proactive and understand that asking for help may be difficult.

- *Possibly removing the need for a GP referral for psychology services. This can sometimes be a stumbling block for people who do not have a regular GP or one they feel comfortable discussing MH issues with. Also, that one extra stumbling block can seem insurmountable for people who are really mentally unwell.*
- *People who have anxiety cannot just "reach out and reengage or make a phone call ". If services or health providers could check in or provide alternative means to communicate it would help.*

Fifty-seven consumers provided their views on what people do/what happens to them after they disengage with mental health services. They believed overwhelmingly that their situation worsens; a few indicating that some people find alternative supports through their informal networks, that they either have or must build.

- *Relapse, suicide attempts, re-hospitalisation - repeat. Then being restrained by the tribunal under CTOs that perpetuate the problem through an inhumane system - forcing medication, poor clinical care, poor community care, removal of choice and disempowered. Creating a message where the person is a problem not an unwell human being who needs assistance. Removal of hope.*
- *1.Their condition worsens. 2. They lose faith in the ability of anyone to help them. 3. They lose faith in the notion that they may ever feel better or get well. 4. The 'failure' in treatment can contribute to existing personal beliefs that they are worthless etc. 5. People who may have recovered or gotten an improvement in their quality of life (had they remained engaged in treatment) become long-term mentally ill and end up caught in that position with no way of getting out.*
- *Some are lucky enough to find local services, but many are left to their own devices.*
- *From my experience, people either try to look for other services or go back to GP.*
- *Various things... suicide, homelessness, addiction increased pressure on the forensic mental health system contact with the criminal justice system and incarceration or - their lives improve through building other support networks such as community, friendships, familial or - people find effective care through other means.*

Fifty-six consumers provided their views on how they think mental health services could best re-engage with people who have disengaged from mental health support. Again, they suggested practical solutions and personalised support actions.

- *Contact them and ask them how you can best support them. What they think would be helpful. Let them know that you're there for them and want to provide support that they feel is appropriate to them.*
- *Not by ringing, by visiting… Meeting them in their homes or in the community Engaging with peer support workers.*
- *Offer a point of difference - how will the services offered be different to last time? Instil trust - acknowledging that this needs to be earned.*

- *Start doing things differently! Look at other models of health care and try to reform services in line with powerful evidence from other countries.*
- *Personalised messages/emails asking how the person is doing so they feel as though there is someone who genuinely cares about their wellbeing. Just to check in and assure them that if they need more support that they are not a failure. Asking if there was something that stopped them from coming and if that was something that could work together to solve.*
- *Ask them what they need. If they are unable or afraid of attending a centre do outreach with the aim of helping them back into the community. Have activities beyond cut and paste and talking about 'what your drawing means to you' etc. That's insulting If people don't get anything meaningful TO THEM they won't attend Being able to see a worker, by appointment, at the same place Is the ideal. And for it to be the first stop for crisis support.*

Consumers were asked what mental health services they would like to access to support their mental health and wellbeing that they can't access at the moment. Fifty-six consumers responded, noting the following:

- In-person appointments
- Bulk-billing psychiatrists and more subsidised psychology sessions
- Peer support
- More diverse services in regional/rural areas
- More support for mental illness prevention
- More groups in the community – exercise, art, yoga, etc
- Free psychiatry helpline

Comments included:

- *Definitely in person appointments. I hopefully can go back to seeing my psychologist in person soon, but I find it's obviously better to get out of the house and just feels nicer than looking at a screen. Then again, this Telehealth can be helpful in other times when maybe I can't get to her practice.*
- *I would like a place where I can meet up with other people, but not in my town. It would be great to catch up with a group in a bigger town not very far from where I live. I would love to see professionals come out to the country and talk about mental illness so that family members can try and understand what the person is going through. I would love to join an exercise group which is tailored to people with mental illnesses but cannot see that happening in my town. Living in a country town when you have mental illness is hard, you have to rely on friends, family for support.*
- *A Mental Wellbeing Hub where there is information on relapse, recovery, ongoing management of mental health, and education centre for everyone. Not just for people who are in the system. As a preventative method to educate people on getting well and staying well.*
- *Regular peer conversations, peer contact, opportunities to learn about mental health etc. I am wondering where these are offered outside of navigating the mental health system and being put on wait lists for an agency. If a person is unwell, and something gets too hard, we give up. Things have to be easy when we are fatigued and have little energy left to self-advocate. We want to feel as though the support person "gets us".*

Consumers with private health insurance who use private mental health services/ hospitals were asked what services they currently rely on. Many of the sixty-seven consumers who responded said they relied on psychologists and psychiatrists. Some identified therapy support groups and day programs. Very few named GPs as a group they relied on for their mental health, most likely because they had private health insurance that enabled them to access more specialised mental health supports like services offered by private psychiatric hospitals.

Many consumers with private health insurance said they were able to access private psychiatric hospitals when they needed to (see Table 25).

Table 25: Consumers' access to private psychiatric hospital services

Answer Choices	Responses	
Yes	60.81%	45
No	13.51%	10
Not Applicable	25.68%	19

Of those who said yes, 43 consumers provided further comments about what has been useful about being able to access private psychiatric hospital care. Several consumers valued access and availability of inpatient support, choice and control, and being able to stay in hospital for the time they felt they needed, without pressure to be discharged early. Some consumers noted the types of programs and support available in private psychiatric hospitals.

- *No traumatic ED experience, no 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.*
- *1.Privacy - I used to work for the state health department. 2. Becoming familiar with the staff in this hospital, and the way it operates helps to alleviate any anxiety and reluctance connected to using this facility. 3. You do not feel pushed to discharge in a hurry, or too early, because you are paying them for the care you need.*
- *Specialised service e.g. trans magnetic stimulation. Program of things to do during hospital visit.*

Consumers were asked whether they have you been able to use their private health insurance to access the care they need, with most (74.32%, n=55 of 74) saying yes (Figure 22).

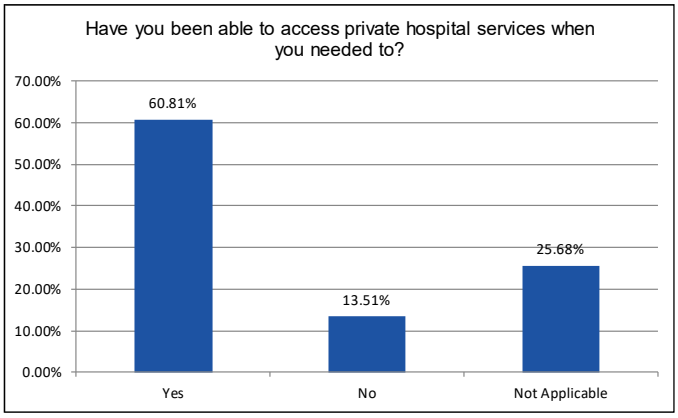


Figure 22: Consumers' use of private cover to access what they need

For those who were able to use their private health insurance to access the care they needed, the 49 consumers who responded to this question identified the main services it covered that were useful to them as:

- Psychologist
- Psychiatrists
- Private psychiatric hospital Inpatient care
- Private psychiatric hospital group programs

Fifty-one consumers provided details about mental health services they would like to access that they can't access at the moment. Of note, many people named the above services and indicated that their private health insurance either did not include some of these services, or provided only limited access to them, which did not meet their needs. Some consumers made further suggestions:

- Trauma-informed mindfulness
- To be able to access my NDIS funding
- Peer-led community services, drop-in centres, a network of 'buddy' type lived experience workers
- Respite
- Specific groups such as dialectical behaviour therapy
- Art therapy in the community, not just in hospital

Forty-two consumers provided further details to explain their responses. These included the following:

- *It's just too expensive and health insurance doesn't cover enough but I couldn't afford higher cover to pay for it anyway.*
- *Who better to have empathy and compassion towards mental health issues than somebody who has firsthand lived experience? Training volunteers with lived experience.*

Carer Responses:

Almost three quarters of carers reported on issues that contributed to further deterioration in the person's mental health when they were in crisis. The most prevalent reason given was lack of access to support when needed (Figure 23 and Table 26).

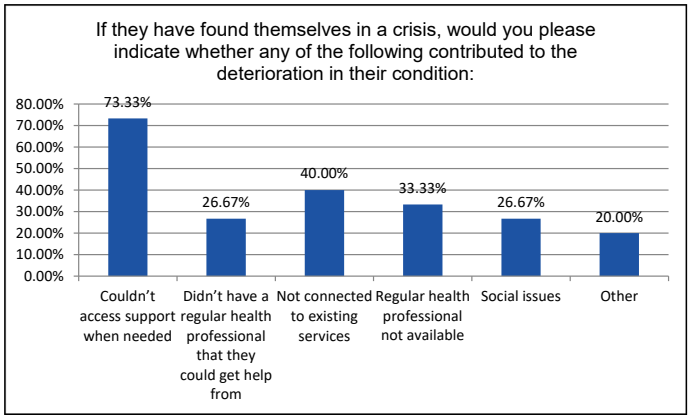


Figure 23: Carers: Reasons for further deterioration in mental health when in crisis

Table 26: Carers: Reasons for further deterioration in mental health when in crisis

Answer Choices	Responses	
Couldn't access support when needed	73.33%	11
Didn't have a regular health professional that they could get help from	26.67%	4
Not connected to existing services	40.00%	6
Regular health professional not available	33.33%	5
Social issues	26.67%	4
Other	20.00%	3

One carer highlighted the social impacts such as inability to connect with others and another commented on the waiting time to access private psychiatric hospital services (1-2 weeks) being problematic.

When experiencing a crisis, two thirds of carers (62.5%, n=10 of 17) said that they did seek help through a public emergency department (see Figure 24).

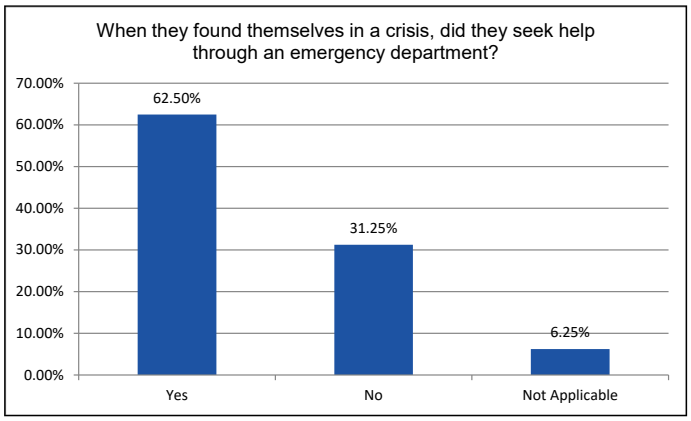


Figure 24: Carers: seeking help through an emergency department when in crisis

Carers were asked what happened after discharge if the person they care for was not admitted after seeking help through a public hospital emergency department. Of the 10 carers who responded, most said the person went to family or friends (40%, n=4) (Table 27). Four carers provided further comments which included a lack of discharge planning and follow-up, and a reliance on family to support the person.

Table 27: Carers: Follow-up support when in crisis and not admitted to hospital

Answer Choices	Responses	
Went home	20.00%	2
Went to family or friends	40.00%	4
No referral to mental health services	0.00%	0
No referral to a health professional	0.00%	0
Given a discharge letter to their GP	0.00%	0
Given a Referral to a community mental health service	0.00%	0
Organised consultation with community mental health team	10.00%	1
Referral to a psychiatrist or psychologist	10.00%	1
No follow up	20.00%	2
Other	0.00%	0

Ten carers provided ideas about what mental health services/ hospitals could do to support people to stay engaged with services. Common themes included accessibility, affordability, and continuity of providers to support ongoing engagement. Other suggestions included listening, having regular contact/ follow up, having a key contact person, trained staff and availability of peer support workers.

Thirteen carers provided comments on strategies to assist consumers to re-engage with mental health services they had previously disengaged from. Common themes included regular contact or follow-up. Two carers identified peer workers to support re-engagement, and others mirrored the comments above regarding strategies to support ongoing engagement.

When asked what happens to the person they care for after they have disengaged with mental health services, 13 carers provided comment. The common themes included relapse or decline in mental health, being isolated and the impact on family/carers to provide the support. One carer highlighted the serious risk of self-harm and engaging in risky behaviours.

- *They try to get on with life, but this is often isolating, confronting, and difficult especially when they have no friends etc. Families can also find it extremely difficult because they become the main carer, and don't have the clinical expertise to cope. Should be greater carer engagement when possible.*
- *Relapse and carer burn out is common. In our experience, it was not possible for a loved one to manage on their own without support*

Thirteen carers provided their views on how they think mental health services could best re-engage with consumers who have disengaged from support. Again, they suggested regular contact/follow up from the service and the key strategy.

Carers were asked what mental health services the person they care for would like to access to support their mental health and wellbeing that they can't access at the moment.

Eleven carers responded, noting the following:

- Support groups
- Peer support
- Drop-in centres
- Access to a psychologist on a regular basis

Carers supporting someone with private health insurance who primarily use private mental health services/ hospitals were asked what services they currently rely on. Many of the fourteen carers who responded said they relied on GPs, psychologists and psychiatrists. Some identified inpatient programs from private psychiatric hospitals.

Almost half of carers who support someone with private health insurance said the person was able to access private psychiatric hospitals when they needed to (see Table 28).

Table 28: Carers- Consumers' access to private hospital services

Answer Choices	Responses	
Yes	43.75%	7
No	56.25%	9

Of those who said yes, 9 provided further comments about what has been useful about being able to access private psychiatric hospital care. The main response related to shorter waiting times.

When asked if the person they care for has been able to use private health insurance to access the care they need, almost half said yes (45.67%, n=7), others said no (33.33%, n=5) or unsure (20%, n=3). Comments included not having the appropriate level of private health insurance cover, prohibitive waiting times and affordability (excesses) impacting access to private psychiatric hospitals. For those who were able to access private mental health services, the main services accessed included private psychiatric hospital admissions, inpatient care and outpatient groups.

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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