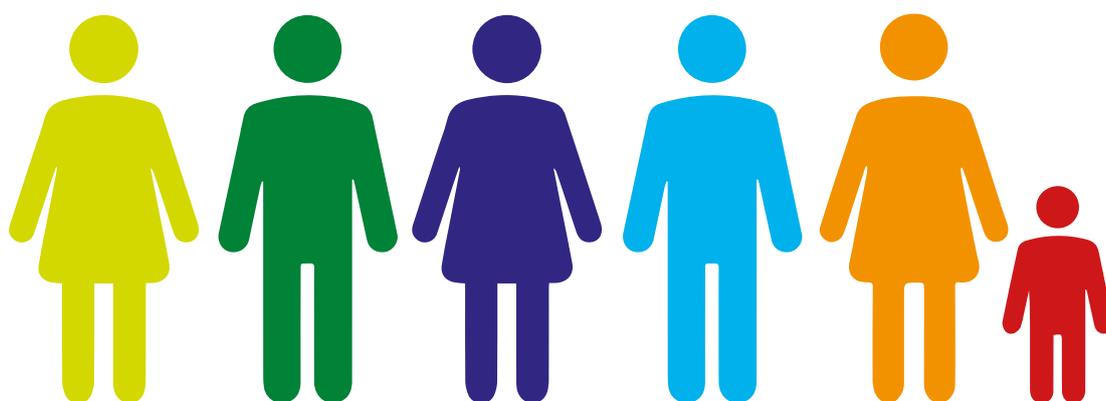


Monitoring mental health  
and suicide prevention reform

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# Fifth National Mental Health *and* Suicide Prevention Plan 2020

*The consumer and carer perspective*



Australian Government  
National Mental Health Commission

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- the consumers and carers who participated in the survey and shared their experiences. Without these contributions, the Commission would not be able to effectively monitor and report on the progress of the Fifth Plan.
- members of the Fifth Plan Technical Advisory Group who provided guidance and advice on the planning and design process of the Consumer and Carer Survey, which forms the basis of this report.

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# Contents

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<b>Message from the CEO</b>	2
<b>Executive summary</b>	3
<b>Introduction</b>	4
<b>Survey results by Fifth Plan priority area</b>	6
<b>Priority Area 1</b> Achieving integrated regional planning and service delivery	7
<b>Priority Area 2</b> Effective suicide prevention	8
<b>Priority Area 3</b> Coordinating treatment and supports for people with severe and complex mental illness	9
<b>Priority Area 4</b> Improving Aboriginal and Torres Strait Islander mental health and suicide prevention	10
<b>Priority Area 5</b> Improving the physical health of people living with mental illness and reducing early mortality	11
<b>Priority Area 6</b> Reducing stigma and discrimination	12
<b>Priority Area 7</b> Making safety and quality central to mental health service delivery	13
<b>Priority Area 8</b> Ensuring that the enablers of effective system performance and system improvement are in place	14
<b>Conclusion</b>	15
<b>Appendices</b>	16
<b>Appendix A</b> Survey methodology	17
<b>Appendix B</b> Consumer and Carer Survey 2020	20

# Message from the CEO

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**Australians with lived experience of mental health care are at the core of our work at the National Mental Health Commission (the Commission) and we are strongly committed to ensuring all Australians can live contributing lives within thriving communities. We acknowledge that 2020 was a challenging year for the mental health and wellbeing of all Australians, especially those with lived experience as we endured the ongoing effects of natural disasters and the pandemic.**

We are proud to continue our work of monitoring the progress of the Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan) for the second year and I am pleased to present the *Fifth National Mental Health and Suicide Prevention Plan, 2020: The consumer and carer perspective* (2020 Consumer and Carer Report). The 2020 Consumer and Carer Report builds on the baseline data provided in the 2019 Consumer and Carer Report by prioritising the experiences, and measuring the changing perspectives, of consumers and carers accessing mental health care.

We acknowledge that continued genuine engagement and collaboration with people with lived experience, their families and their support people is essential in achieving transformational person-centric change. This direct knowledge results in better targeted initiatives, more responsive services and positive experiences for users and providers.

In March 2020, the Commission conducted a consumer and carer survey to better understand the experiences of mental health care in Australia and to determine whether the implementation of the Fifth Plan has affected those experiences. The results of the survey form the basis of this report and identify a number of key issues raised by those with lived experience of our mental health system.

These issues require a strong policy commitment to partnering with consumers and carers in monitoring and reviewing system and service performance. I urge stakeholders implementing the Fifth Plan to use this report to consider the impact of changes and efforts on the individuals engaging with the mental health system.

We are grateful to everyone who contributed to this important work and participated in the survey. The ongoing engagement of consumers and carers who share their personal experiences of services is critical to the success of mental health and suicide prevention reform in Australia. These contributions are key for all of us as we continue to work towards sustainable reform of the system, so that all Australians can achieve the best possible mental health and wellbeing, and thrive.

Now, more than ever, it is important for us to prioritise our mental health, and for carers to take time out to look after their own wellbeing.



**Christine Morgan**  
Chief Executive Officer,  
National Mental Health Commission



# Executive summary

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Reporting on the progress of implementing the Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan) is essential in order to know if the commitments are being honoured and are making a difference. To this end, the National Mental Health Commission (the Commission) has been tasked with providing an annual report on the progress of implementing the Fifth Plan actions, and Australia's performance against a set of identified indicators.

The Commission has opted to extend its Fifth Plan reporting to include an annual survey of mental health consumer and carer perspectives (Consumer and Carer Survey), that aims to measure if consumers and carers are experiencing the improvements and benefits outlined in the 'what will be different for consumers and carers' section of the eight Fifth Plan priority areas.

This report summarises the results from the second Consumer and Carer Survey, which captures experiences of the mental health system during March 2019 to March 2020. Where possible, comparisons will be made with the results of the 2019 Consumer and Carer Survey.

## The results from the 2020 survey suggest that:

- The intended benefits of improving integrated regional planning and service delivery have not yet been realised for a significant proportion of consumers and carers.
- Most consumers and carers are aware of support services available to those at risk of suicide, but fewer people are aware of active follow-up care for people who had attempted suicide or services that are available for carers, families and communities affected by suicide.
- Access to the clinical and non-clinical community-based services required to live a contributing life has not yet been achieved for many consumers with severe and complex mental illness.
- The coordination of physical and mental health care continues to be limited.

- Experiencing stigma and discrimination remains common for people with mental illness, both in healthcare settings and in the broader community.
- While mental health services are a safe place for the majority of people, a significant proportion of respondents do not consistently feel safe using these services.
- Most consumers and carers have not observed improvements in mental health services and have not been invited to contribute to service improvement.

Overall, the Consumer and Carer Survey does not provide any evidence that the Fifth Plan has progressed in achieving its intended outcomes for consumers and carers between 2019 and 2020. However, any improvements in consumer and carer experiences resulting from the Fifth Plan are likely to be incremental and the known limitations of the Consumer and Carer Survey may be obscuring small changes in the experiences of consumers and carers.

This highlights the importance of including high quality data on the perspectives of consumers and carers in the formal evaluation of the Fifth Plan (occurring under action vi of the Fifth Plan). Quality data will ensure that any small improvements are measured and that learnings from the Fifth Plan about what creates improvements for consumers and carers can be applied to future reforms.

# Introduction

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**The Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan) establishes a national approach for collaborative government action to improve and better integrate mental health and related services in Australia, between 2017 and 2022. Under the Fifth Plan, governments have committed to undertaking 32 identified actions across eight priority areas.**

Reporting on the progress of implementing mental health reform is essential in order to know if the commitments of the Fifth Plan are being honoured and are making a difference. To this end, the National Mental Health Commission (the Commission) has been tasked with providing an annual report on the progress of implementing the Fifth Plan actions, and Australia's performance against a set of identified indicators. The Commission has opted to extend its Fifth Plan reporting to include an annual survey of mental health consumer and carer perspectives (Consumer and Carer Survey), that aims to measure if consumers and carers are experiencing the improvements and benefits outlined in the 'what will be different for consumers and carers' section of the eight Fifth Plan priority areas.

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**This report summarises the results from the second Consumer and Carer Survey, which captures experiences of the mental health system during March 2019 to March 2020. Where possible, comparisons will be made with the results of the 2019 Consumer and Carer Survey.**

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## Survey respondents and data limitations

In 2020, 227 people (143 consumers and 84 carers) responded to the Consumer and Carer Survey. The majority of respondents in 2020 were female (79%) and over half were aged between 35 and 64 years (52%). This was similar to the distribution of respondents in the 2019 Consumer and Carer Survey. In 2020, nine respondents identified as Aboriginal and Torres Strait Islander. Due to the small number of Aboriginal and Torres Strait Islander respondents, it was not possible to analyse survey results by Indigenous status and survey results for Priority Area 4: Improving Aboriginal and Torres Strait Islander mental health and suicide prevention, should be interpreted with caution. Additional information can be found at [Appendix A](#).

The 2020 survey sample is less than half the size of the 2019 sample, and some demographic groups remain underrepresented. This is despite the Commission's efforts to increase the size and national representativeness of the survey sample between years. The timing of the survey (mid-March to early May 2020) may explain the reduced participation in 2020, as it coincided with the early stages of the COVID-19 pandemic.

Because of the size and characteristics of the 2020 survey sample, results of the Consumer and Carer Survey may not represent the typical experience of consumers and carers in Australia. The small sample size also means that the survey is unlikely to detect small changes in consumer and carer experiences between years.

## Introduction *continued*

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The Fifth Plan is one component of the National Mental Health Strategy. One long-term goal of the National Mental Health Strategy is to monitor mental health consumer and carer experiences of service. While the Your Experience of Service (YES) survey has been implemented by some jurisdictions for this purpose, national data is not currently available and available data is limited to public specialised mental health services. The Consumer and Carer Survey was developed and implemented by the Commission, with the assistance of the Fifth Plan Technical Advisory Group, with the aim of providing a broader picture of consumer and carer experiences of mental health services during the life of the Fifth Plan. The results of the Consumer and Carer Survey are not comparable to data from the YES survey, which is presented in the performance indicator section of the Commission's *Fifth National Mental Health and Suicide Prevention Plan, 2019: Progress Report 2*.

Each of the eight Fifth Plan priority areas includes a statement about 'what will be different for consumers and carers.' It is expected that consumer and carer experiences reported in the Consumer and Carer Survey will become increasingly aligned with these statements as the Fifth Plan is successfully implemented. However, it is not possible to relate changes detected in Consumer and Carer Survey results with the implementation of specific Fifth Plan actions.

# Survey results

## *by Fifth Plan priority area*

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<b>Priority Area 1</b> Achieving integrated regional planning and service delivery	7
<b>Priority Area 2</b> Effective suicide prevention	8
<b>Priority Area 3</b> Coordinating treatment and supports for people with severe and complex mental illness	9
<b>Priority Area 4</b> Improving Aboriginal and Torres Strait Islander mental health and suicide prevention	10
<b>Priority Area 5</b> Improving the physical health of people living with mental illness and reducing early mortality	11
<b>Priority Area 6</b> Reducing stigma and discrimination	12
<b>Priority Area 7</b> Making safety and quality central to mental health service delivery	13
<b>Priority Area 8</b> Ensuring that the enablers of effective system performance and system improvement are in place	14

## Priority Area 1

# Achieving integrated regional planning and service delivery

The Fifth Plan states the following will be different for consumers and carers:

- Consumers and carers will be included in shaping the way in which services are planned and delivered.
- Services will work with consumers and carers in a coordinated way to understand and holistically meet their needs and achieve outcomes that are important to them.

**The intended benefits of improving integrated regional planning and service delivery have not yet been realised for a significant proportion of consumers and carers.**

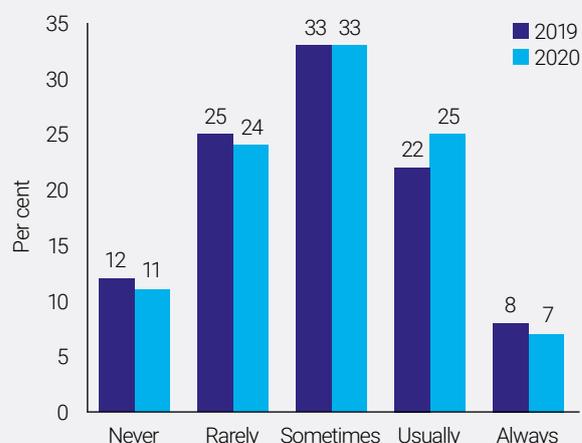
Almost all respondents (96%) indicated that they, or the person they care for, used more than one mental health service in the past 12 months. Of these people, 32% 'usually' or 'always' felt that the services accessed worked together to address their needs or the needs of the person they care for, and 35% 'rarely' or 'never' felt that way (compared to 30% and 37% respectively in 2019; *Figure PA1*).

Compared to consumer respondents, carers felt that the person they care for experienced the intended benefits of service integration less often. In 2020:

- 40% of consumers and 20% of carers reported that services 'usually' or 'always' worked together to address the consumers' needs.
- 55% of consumers and 39% of carers reported that they, or the person they care for 'usually' or 'always' had a say in how their treatment was planned.
- 51% of consumers and 39% of carers reported that they, or the person they care for 'usually' or 'always' had a say in how their treatment was delivered.
- 50% of consumers and 25% of carers reported that they, or the person they care for 'usually' or 'always' felt as though care providers understood the consumers' needs.
- 53% of consumers and 42% of carers reported that they, or the person they care for 'usually' or 'always' felt as though care providers worked with the consumer to meet their needs.

Comparison data for 2019 are not available.

**Figure PA1:** Frequency of consumer and carer experience of services working together in the past 12 months, 2019 and 2020



## Priority Area 2

# Effective suicide prevention

The Fifth Plan states the following will be different for consumers and carers:

- If you are at risk of suicide, you will have timely access to support and be clear about which services in your area are responsible for providing you care and support.
- Services will actively follow-up with you if you are at higher risk of suicide, including after a suicide attempt.
- There will be improved postvention support for carers, families and communities affected by suicide.

**Most consumers and carers are aware of support services available to those at risk of suicide, but fewer people are aware of active follow-up care for people who had attempted suicide or services that are available for carers, families and communities affected by suicide.**

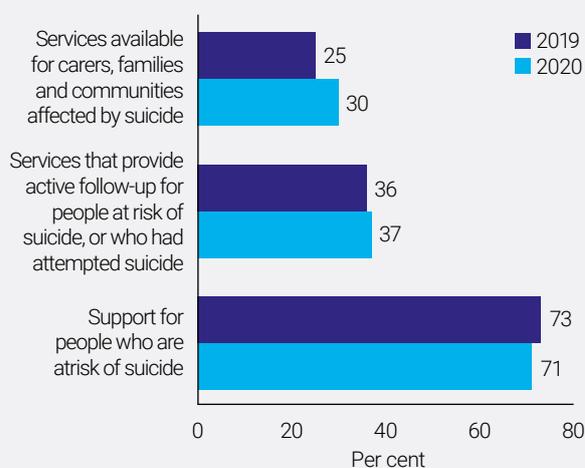
To reduce the possibility of respondents experiencing distress while completing the Consumer and Carer Survey, the survey does not include any direct questions about having access to support when at risk of suicide or when affected by suicide. The Consumer and Carer Survey used questions around awareness of available supports as an indirect measure of progress in this area.

Almost 3 out of 4 (71% in 2020 and 73% in 2019; *Figure PA2*) consumer and carer respondents were aware of support services available for people at risk of suicide. Fewer people were aware of active follow-up care for people at risk of suicide, or who had attempted suicide (37% in 2020 and 36% in 2019) or services that were available for carers, families and communities affected by suicide (30% in 2020 and 25% in 2019). It is not clear from the survey results whether the relatively low awareness of active follow-up services and supports for people affected by suicide is a result of low service visibility and availability in respondents' local areas, or whether respondents have not previously needed these services.

Respondents were not asked about their experience of needing or having access to suicide prevention support. However, 16% of carer respondents who opted to provide additional information in this priority area, indicated that they received little or no formal support for their role

as a carer before or after the person they cared for attempted suicide. Given the impact that caring for a person at risk of suicide can have on the carer's wellbeing and the important role carers play in the ongoing care and safety of the person they care for, this is an area that warrants further attention.

**Figure PA2:** Awareness of suicide-related support services, by type of service, 2019 and 2020



### Priority Area 3

## Coordinating treatment and supports for people with severe and complex mental illness

The Fifth Plan states the following will be different for consumers and carers:

- If you have severe and complex mental illness, you will have access to the clinical and community services you require to live a more contributing life.

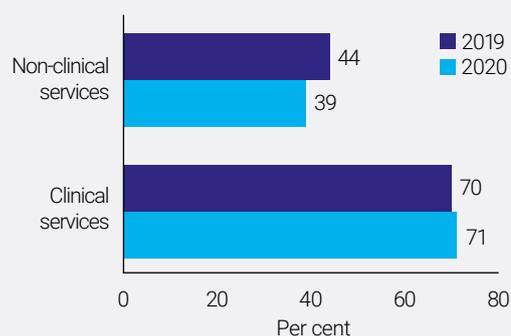
**Access to the clinical and non-clinical community-based services required to live a contributing life has not yet been achieved for many consumers with severe and complex mental illness.**

In 2020, 65% of consumers and carers indicated that they, or the person they care for, experienced a severe or complex mental illness as defined by the Fifth Plan (compared to 71% in 2019). Of these people, 71% of consumers and carers reported that they, or the person they care for had access to the clinical services they needed in the past 12 months, while only 39% had access to the non-clinical services they needed (compared to 70% and 44% respectively in 2019; *Figure PA3*).

Of the consumers who opted to provide additional information in this priority area, 26% said that the cost of services was a barrier to them receiving the services they need. Medication and specialised care such as psychologist and psychiatrist services were given as examples of care that was not affordable.

Of the carers who opted to provide additional information in this priority area, 20% indicated that in order to ensure the person they care for had access to the services they need to live a contributing life, they were required to source and coordinate the provision of services without support from the mental health system, or provide the service themselves. This suggests that gaps still exist in the mental health sector's ability to provide coordinated treatment and supports for people with severe and complex mental illness.

**Figure PA3:** Access to required supports in the past 12 months, by type of support, 2019 and 2020



## Priority Area 4

# Improving Aboriginal and Torres Strait Islander mental health and suicide prevention

The Fifth Plan states the following will be different for consumers and carers:

- Aboriginal and Torres Strait Islander consumers and carers will receive coordinated care and will be supported to navigate the mental health system.
- Aboriginal and Torres Strait Islander consumers and carers will have both their clinical and social and emotional wellbeing needs, and the needs of their community, addressed when care is planned and delivered.
- Aboriginal and Torres Strait Islander consumers and carers will receive culturally appropriate support.

Due to the small number of Aboriginal and Torres Strait Islander respondents, the 2020 survey results are unlikely to represent the experience of all Aboriginal and Torres Strait Islander people receiving mental health care. As such comparisons with survey results from 2019 have not been made and the Commission recommends caution when interpreting the following results.

Of the nine Aboriginal and Torres Strait Islander respondents in 2020, four respondents reported they, or the person they care for 'sometimes' received help or support to use the mental health system when they needed it, and two reported they 'always' received support when needed.

Three out of nine respondents reported all their needs and the needs of their community were 'rarely' considered when providers were planning their care, and a further four respondents reported this 'sometimes' happened.

Six out of nine respondents said they felt their treatment, care or support was 'usually' or 'always' culturally appropriate in the last 12 months.

## Priority Area 5

# Improving the physical health of people living with mental illness and reducing early mortality

The Fifth Plan states the following will be different for consumers and carers:

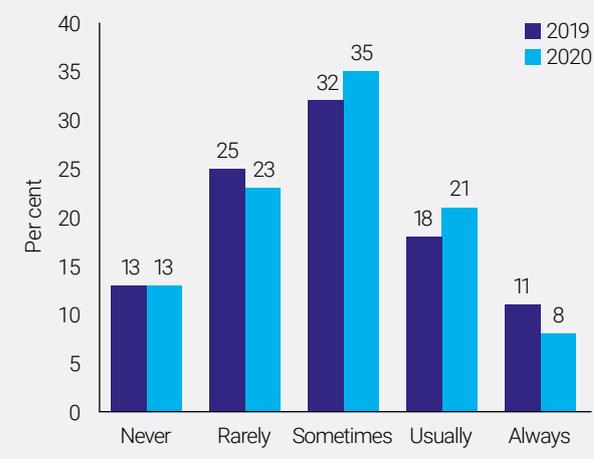
- Consumers' physical healthcare needs will be discussed and addressed.
- There will be better coordination of services at the local level that will support consumers and carers to address their physical health needs and improve their quality of life.

### The coordination of physical and mental health care continues to be limited.

Less than one-third (30% in 2020 and 29% in 2019) of respondents reported they or the person they care for 'usually' or 'always' experienced their mental health care provider discussing their physical health, while around a quarter of respondents (23% in 2020 and 25% in 2019) reported that this 'rarely' occurred (*Figure PA5*).

Less than half of all respondents (42% in 2020 and 38% in 2019) were aware of any arrangements between services to ensure both mental and physical health needs were addressed for consumers. Of the carers who opted to provide additional information in this priority area, 20% indicated that there was little or no coordination or integration of physical and mental health care services in their area.

**Figure PA5:** Frequency of experiencing mental health care providers discussing physical health in the past 12 months, 2019 and 2020



## Priority Area 6

# Reducing stigma and discrimination

The Fifth Plan states the following will be different for consumers and carers:

- There will be a better understanding of mental illness and improved attitudes towards people with mental illness.

## Experiencing stigma and discrimination remains common for people with mental illness, both in healthcare settings and in the broader community.

In 2020, around one-quarter (26%) of respondents said they or the person they care for 'usually' or 'always' get treated differently by their mental health care provider because of their mental illness, compared to 38% of respondents in 2019 (Figure PA6). A further 50% of respondents reported they, or the person they care for, 'never' or 'rarely' experienced being treated differently when accessing mental health services in 2020, compared to 35% in 2019.

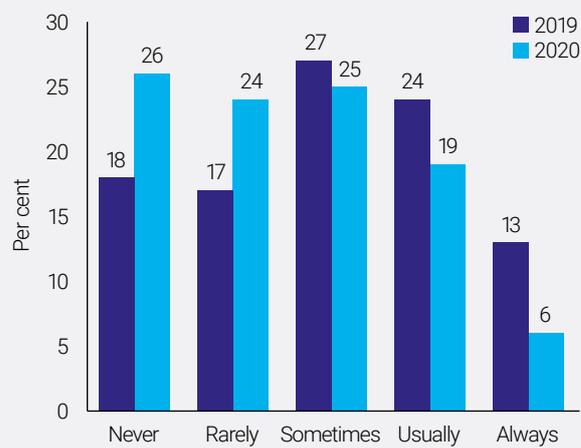
In 2020, 38% of respondents reported that they or the person they care for were 'usually' or 'always' treated differently in the community because of their mental illness, compared to 43% in 2019.

These apparent changes appear promising, however due to the limitations of the survey it is not possible to know if the changes are caused by real improvements in the experience of consumers and carers or whether they are the result of different people responding to the 2019 and 2020 surveys.

Of the consumers who opted to provide additional information in this priority area, 20% reported experiencing stigma and/or discrimination when seeking mental health support from the health system. Of the carers who opted to provide additional information in this priority area, 14% indicated that the person they care for had experienced stigma and/or discrimination when seeking mental health support from the health system. For both consumers and carers, emergency departments were the most commonly mentioned service where stigma and discrimination were experienced when seeking mental health support.

Of the consumers who opted to provide additional information in this priority area, 14% reported being discriminated against in the workplace, and 16% reported not disclosing or actively trying to hide their mental illness in a range of settings to avoid discrimination and stigma.

**Figure PA6:** Frequency of being treated differently due to mental illness, when accessing mental health services in the past 12 months, 2019 and 2020



## Priority Area 7

# Making safety and quality central to mental health service delivery

The Fifth Plan states the following will be different for consumers and carers:

- The treatment, care and support that consumers and carers receive will be safe.
- Information about the safety of services will be available so that consumers and carers can make informed choices about treatment, care and support.

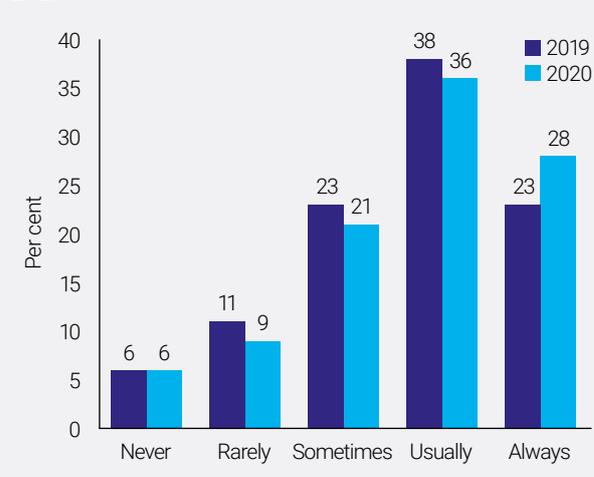
**While mental health services are a safe place for the majority of people, a significant proportion of respondents do not consistently feel safe using these services.**

The majority (64% in 2020 and 60% in 2019) of respondents reported that they, or the person they care for 'usually' or 'always' felt safe when using mental health services in the past 12 months (*Figure PA7*). Around one in five (21% in 2020 and 23% in 2019) respondents reported they, or the person they care for, 'sometimes' felt safe using mental health services.

In 2020, around one-third (34%) of respondents reported that information about the safety of mental health services was 'usually' or 'always' available, compared to around one-quarter (26%) of respondents in 2019. Around half of respondents reported that safety information was 'rarely' or 'never' available (48% in 2020 and 53% in 2019). Of respondents who had received safety information in 2020, almost half reported that this 'usually' or 'always' helped them or the person they care for make informed decisions, compared to around one-third in 2019 (31%).

While these apparent changes appear promising, due to the limitations of the survey it is not possible to know if the apparent changes are caused by real improvements in the experience of consumers and carers or whether they are the result of different people responding to the 2019 and 2020 surveys.

**Figure PA7:** Frequency of feeling safe when using mental health services in the last 12 months, 2019 and 2020



## Priority Area 8

# Ensuring that the enablers of effective system performance and system improvement are in place

The Fifth Plan states the following will be different for consumers and carers:

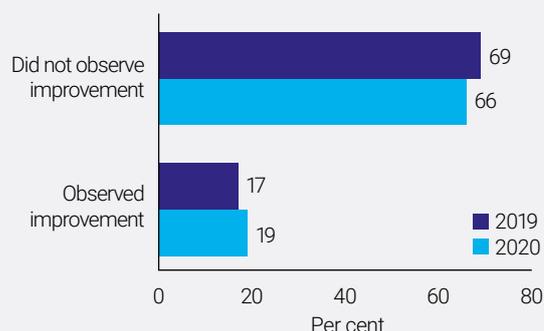
- Services will continue to improve over time.
- There will be improved opportunities to translate consumers' and carers' experiences into helping others to work through their own experience of recovery.

## Most consumers and carers have not observed improvements in mental health services and have not been invited to contribute to service improvement.

In 2020, the majority of respondents (66% in 2020 and 69% in 2019; *Figure PA8*) indicated that they had not observed any improvement in mental health services in the past 12 months, while almost one in five respondents had observed improvements (19% in 2020 and 17% in 2019).

In both 2019 and 2020, the majority (69% in 2020 and 65% in 2019) of respondents reported that they, or the person they care for, had not been asked or encouraged by their care providers to share their experience to help improve the service. This represents a significant missed opportunity for service improvement.

**Figure PA8:** Observed improvement in mental health services in the last 12 months, 2019 and 2020



# Conclusion

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In 2020, a significant proportion of consumers and carers told us that they are not experiencing integrated care, do not have access to the support services they need, do not receive coordinated physical and mental health care and have not seen any improvement in their mental health services in the last 12 months. Consumers and carers also told us that experiencing stigma and discrimination remains common, both in healthcare settings and the broader community, and that not everyone feels safe when using mental health services.

Overall, the Consumer and Carer Survey does not provide any evidence that the Fifth Plan has progressed in achieving its intended outcomes for consumers and carers between 2019 and 2020. However, any improvements in consumer and carer experiences resulting from the Fifth Plan are likely to be incremental and the known limitations of the Consumer and Carer Survey may be obscuring small changes in the experiences of consumers and carers.

This highlights the importance of including high quality data on the perspectives of consumers and carers in the formal evaluation of the Fifth Plan (occurring under action vi of the Fifth Plan), to ensure that any small improvements are measured and that learnings from the Fifth Plan about what creates improvements for consumers and carers can be applied to future reforms.

# Appendices

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<a href="#">Appendix A Survey methodology</a>	17
<a href="#">Appendix B Consumer and Carer Survey 2020</a>	20

# Appendix A

# Survey methodology

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## Survey design

To support the Commission's role in monitoring and reporting on the progress of the Fifth Plan, including the planning and design of the Consumer and Carer Survey, a Fifth Plan Technical Advisory Group (FPTAG) was established by the Commission.

FPTAG includes representatives from each state and territory government health department, the Australian Government Department of Health, the Australian Institute of Health and Welfare, the Safety and Quality Partnership Standing Committee, the Suicide Prevention Project Reference Group, the Mental Health Information Strategy Standing Committee and the Aboriginal and Torres Strait Islander Mental Health and Suicide Prevention Project Reference Group, and consumer and carer representatives.

To ensure high comparability between years, minimal changes were made between the 2019 and 2020 Consumer and Carer Surveys. Based on advice from the FPTAG, the following changes were made in the 2020 survey:

- An overarching screening question was added to the survey. It asked respondents if they or the person they care for had used mental health services in past 12 months. Only those who responded 'yes' were able to complete the survey.
- In Priority Area 1: Achieving integrated regional planning and service delivery, the 2019 survey asked about the frequency with which consumers had a say in the way their care was planned and delivered as a single question. In 2020, planning and delivery were asked about in two separate questions. As a result, comparisons cannot be made between years.
- Stylistic and language edits were made to questions to make the language simpler and easier to understand, and to better distinguish between questions asked of consumers and questions asked of carers.

The full survey can be found in [Appendix B](#).

## Survey administration

The survey was administered via the online platform Citizen Space and accessible on the Commission's website from 16 March to 11 May 2020.

The survey was promoted via the Commission's social media channels and targeted emails to Commission stakeholder networks.

In an attempt to improve the sample size and representativeness in 2020, additional organisations with a focus on groups that were underrepresented in the 2019 survey sample – youth, men, culturally and linguistically diverse communities and older people – were contacted and asked for assistance in distributing the survey among their networks.

## Survey respondent characteristics

A total of 227 people completed the 2020 consumer and carer surveys (*Table 1*). Of these, 143 (63%) were consumers, and 84 (37%) were carers. The majority of respondents (65%) indicated that they, or the person they care for, live with a severe or complex mental illness as defined by the Fifth Plan.

The largest number of respondents came from New South Wales and Victoria. Most respondents identified as female (77%), and over half were aged between 35 to 54 (52%; *Table 2*). Nine respondents (4%) identified as, or cared for an individual who identified as Aboriginal or Torres Strait Islander.

# Appendix A

## Survey methodology

**Table 1:** Respondent demographics, 2020

	Number of consumers (%)	Number of carers (%)	Total number (%)
<b>Total</b>	<b>143 (63%)</b>	<b>84 (37%)</b>	<b>227 (100%)</b>
<b>Gender</b>			
Female	110 (77%)	69 (82%)	<b>179 (79%)</b>
Male	27 (19%)	11 (13%)	<b>38 (17%)</b>
Gender diverse/transgender	4 (3%)	2 (2%)	<b>6 (3%)</b>
Prefer not to say	2 (1%)	2 (2%)	<b>4 (2%)</b>
<b>Aboriginal and/or Torres Strait Islander</b>	<b>3 (1%)</b>	<b>6 (3%)</b>	<b>9 (4%)</b>
<b>Have or care for someone with a severe or complex mental illness</b>	<b>86 (61%)</b>	<b>61 (73%)</b>	<b>147 (65%)</b>
<b>State or territory</b>			
NSW	48 (34%)	21 (25%)	<b>69 (30%)</b>
Vic	25 (24%)	30 (36%)	<b>65 (29%)</b>
Qld	24 (17%)	9 (11%)	<b>33 (15%)</b>
WA	13 (9%)	11 (13%)	<b>24 (11%)</b>
SA	16 (11%)	8 (10%)	<b>24 (11%)</b>
Tas	1 (1%)	1 (1%)	<b>2 (1%)</b>
ACT	6 (4%)	2 (2%)	<b>8 (4%)</b>
NT	0 (0%)	2 (2%)	<b>2 (1%)</b>

# Appendix A

## Survey methodology

Compared to the age distribution in the general population, people aged 16-24 and people aged 75 and over were particularly underrepresented in the 2019 and 2020 survey samples (*Table 2*).

**Table 2:** Age distribution of survey respondents, compared to total population, 2020

Age group	2020 sample	Australian Estimated Resident Population June 2019
16-24	4%	15%
25-34	16%	19%
35-44	21%	17%
45-54	31%	16%
55-64	16%	14%
65-74	10%	11%
75+	2%	9%

Source: Australian Estimated Resident Population is sourced from Australian Bureau of Statistics, Australian Demographic Statistics, December 2019.

Note: Percentages for Australian Estimated Resident Population data are based on people aged 16 and over, not the whole Australian population.

### Analysis caveats

The following points should be considered when interpreting the results presented in this report:

- Percentages are rounded and therefore totals may not add to 100%.
- Not all respondents answered all survey questions. Results for each question is presented as a proportion of those who responded to it.
- Due to the small number of respondents, significance testing of results between years was not appropriate and was not conducted. Any apparent differences between 2019 and 2020 results are indicative only and may not represent a significant change.
- Priority Area 3: Coordinating treatment and supports for people with severe and complex mental illness and Priority Area 4: Improving Aboriginal and Torres Strait Islander mental health and suicide prevention both started with screening questions about experience of complex mental illness and Aboriginal and Torres Strait Islander status respectively – only results for those who responded 'yes' to the respective screening question were presented with the relevant questions.
- Survey respondents were gathered via an online convenience sample, rather than a random sampling method. As a result, the sample may not be representative of the broader consumer and carer population.

## Appendix B

# Consumer Survey 2020

### Overview

Thank you for taking the time to complete this survey.

The National Mental Health Commission (the Commission) is seeking feedback from consumers and carers on their experiences of mental health services in Australia in the past 12 months.

Our annual consumer and carer survey helps to inform reporting on the progress of mental health and suicide prevention reform in Australia, specifically the Fifth National Mental Health and Suicide Prevention Plan.

Your insights are critical in driving sustainable reform of the mental health system and delivering care that suits the needs of Australians.

### Who can participate?

The Commission welcomes responses from consumers who have used mental health services in the past 12 months.

If you are a consumer of mental health services and also care for someone who is experiencing a mental illness, there is a **carer survey** you can complete from the perspective of a carer.

A printable version of the survey is available if required. Please contact:

[fifthplan@mentalhealthcommission.gov.au](mailto:fifthplan@mentalhealthcommission.gov.au).

### What is involved?

This survey should take between 10 to 30 minutes to complete, depending on how much information you'd like to provide. You do not need to give your name to complete the survey, and your answers will be kept confidential and anonymous.

You can save your responses and return to the survey at any time up until the closing date, using the save and return link provided. You will need to provide your email address if you choose to save and return. If you do not wish to provide your email address, you will not be able to save and return to your answers, and you will need to start the survey again.

### What will your responses contribute to?

We appreciate your time and honesty. Your answers are valuable to the Commission and will help us to monitor and report on efforts to improve mental health and suicide prevention in Australia. The Commission will use responses to this survey to inform our reports to government and the community on the performance of the mental health sector.

### Privacy

The Commission takes your privacy seriously. All responses will be treated as confidential, and, except where required by law, no personally identifying information from your response will be released or used for a purpose other than as set out above.

The Commission stores all personal information securely and restricts access to those employees who need access in order to perform their duties or to assist individuals.

For further information on privacy, please see the Commission's [privacy policy](#).

### Further information

You can read more about the *Fifth National Mental Health and Suicide Prevention Plan* on the Commission's [website](#).

### Help and support

Talking about your experiences of mental health can be challenging. If any questions cause distress, please stop and we encourage you to reach out for support. Help is always available at:

- [Lifeline](#) or call **13 11 14**
- [Kids Helpline](#) or call **1800 55 1800**
- [Beyond Blue](#) or call **1300 22 4636**

# Appendix B

## Consumer Survey 2020

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### Introduction

The Commission welcomes responses from consumers who have used mental health services in the past 12 months.

#### Definitions

In the context of the Fifth National Mental Health and Suicide Prevention Plan, a **consumer** is described as a person living with a mental illness who uses, has used or may use a mental health service.

Some mental health consumers also care for someone who has a mental illness. This means that they are both a **consumer** and a **carer**. If you identify as both a consumer and carer, then we welcome you to respond to the survey from the perspective of a consumer and then respond for a second time from the perspective of a carer via the **carer survey**.

Mental health services include **clinical** and **non-clinical** supports. **Clinical or medical services** are those that provide assessment, diagnostic and treatment services for people with mental illness. Clinical services include appointments with a GP, psychologist, counsellor, or psychiatrist, as well as care while admitted in hospital and residential settings.

**Non-clinical or community psychosocial services** focus on providing well-being, support and assistance with a focus on recovery, to people who live with a mental illness. These services include assistance to access community, social and recreational activities; group based community, social and recreational activities; assistance with household tasks and daily living; and individual skills training and development.

As this survey is focusing on the experiences of people who have recently used services, if you answer 'no' to the below question you will be directed straight to the end of the survey.

**Have you used mental health services in the past 12 months? (Required)**

*(Please select only **one** item)*

Yes     No     Unsure

# Appendix B

## Consumer Survey 2020

### SECTION 1 Mental health services

This section is about your experience using mental health services in the last 12 months, and whether these services were appropriate for your needs. This section is also interested in whether your care provider involved you in the planning process.

#### Definitions

As described in the introduction, mental health services include clinical and non-clinical supports.

**Clinical or medical services** are those that provide assessment, diagnostic and treatment services for people with mental illness. Clinical services include appointments with a GP, psychologist, counsellor, or psychiatrist, as well as care while admitted in hospital and residential settings.

**Non-clinical or community psychosocial services** focus on providing well-being, support and assistance with a focus on recovery, to people who live with a mental illness. These services include assistance to access community, social and recreational activities; group based community, social and recreational activities; assistance with household tasks and daily living; and individual skills training and development.

**What types of mental health service have you used in the past 12 months? You can select as many services as you like:**

(Please select all that apply)

- GP
- Mental health nurse
- Psychiatrist
- Psychologist
- Counsellor
- Telephone support line
- Online based services – such as websites, apps and programs, forums, web-based chat and email support
- Hospital emergency department
- Overnight hospital stay
- Inpatient or residential mental health care
- Community, social and recreational activities
- Group based community, social and recreational activities
- Daily living support
- Other – if other, please specify:

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# Appendix B

## Consumer Survey 2020

### SECTION 1 Mental health services

If you used more than one of these services, how often did you feel as though these services worked together to address your needs?

(Please select only **one** item)

- Never   Rarely   Sometimes   Usually   Always   N/A
- 

How often did you feel as though you had a say in the way your treatment was planned in the past 12 months?

(Please select only **one** item)

- Never   Rarely   Sometimes   Usually   Always
- 

How often did you feel as though you had a say in the way your treatment was delivered in the past 12 months?

(Please select only **one** item)

- Never   Rarely   Sometimes   Usually   Always
- 

In the past 12 months, how often have you felt as though care providers understood your needs?

(Please select only **one** item)

- Never   Rarely   Sometimes   Usually   Always
- 

In the past 12 months, how often have you felt as though care providers worked with you to meet your needs?

(Please select only **one** item)

- Never   Rarely   Sometimes   Usually   Always
- 

Is there anything else you'd like us to know about your experiences with mental health services in the last 12 months?

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# Appendix B

## Consumer Survey 2020

### SECTION 2 Suicide prevention services

The next section will ask questions about suicide prevention services and postvention support for carers, families and communities following a death by suicide. If you would prefer not to answer these questions, please skip to Section 3.

**If these questions raise any uncomfortable feelings for you, please reach out to your support network or contact one of the following services for support:**

- [Lifeline](#) or call 13 11 14
- [Kids Helpline](#) or call 1800 55 1800
- [Beyond Blue](#) or call 1300 22 4636

There are many services across Australia that provide suicide prevention support. This might include crisis support and intervention, free counselling support over the phone or prevention programs for people identified as being at risk of suicide. Suicide prevention support also includes supports for carers, families and communities affected by suicide or a suicide attempt. The Fifth Plan refers to this type of support as 'postvention supports'.

**Are you aware of any services available in your area that provide care and support for people who are at risk of suicide?**

(Please select only **one** item)

- Yes    No    Unsure

**Are you aware of any services that provide active follow-up for people who are at a high risk of suicide, including after a suicide attempt, in the area you live in?**

(Please select only **one** item)

- Yes    No    Unsure

**Are you aware of support services available for carers, families and communities affected by suicide in the area that you live in?**

(Please select only **one** item)

- Yes    No    Unsure

**Is there anything else you'd like us to know about suicide prevention, follow-up, or support services for those affected by suicide?**

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# Appendix B

## Consumer Survey 2020

### SECTION 3 Severe and complex mental illness

A **severe and complex mental illness** is not confined to a specific diagnosis. People with severe and complex mental illness may be people with persistent mental illness with complex needs that can only be met by multiple care providers, or people who have complexities that are not directly related to their mental illness. This includes:

- People who have a severe mental illness as well as a chronic physical illness or disability, or issues with/dependence on drugs and alcohol.
- People whose mental illness is adversely impacted by complex social factors such as homelessness, isolation from social or family supports, or who require assistance from multiple health/community services for day-to-day activities.
- People with reoccurring acute mental health episodes that require frequent hospital care.
- People who have experienced long term residential or hospital care.
- People who are at high risk of suicide.

This section seeks to understand the experiences of people living with a severe and complex mental illness as they access mental health services. We invite consumers living with a severe and complex mental illness to complete this section.

If you do not live with a severe and complex mental illness please select 'no' below to be directed to the next section.

**Do you live with a severe and complex mental illness?**

*(Please select only **one** item)*

- Yes  No

People who live with severe and complex mental illness may access clinical and non-clinical services. Taken together, clinical and non-clinical services should support the person to live a contributing life – a life that is enriched with close connections to family and friends, supported by good health, wellbeing and healthcare.

Clinical or medical services are those that provide assessment, diagnostic and treatment services for people with mental illness. Clinical services include appointments with a GP, psychologist, counsellor, or psychiatrist, care while admitted in hospital and residential care, as well as medications prescribed to treat or support your mental health.

**In the past 12 months, did you have access to the clinical services you required?**

*(Please select only **one** item)*

- Yes  No

Non-clinical or community psychosocial services focus on providing wellbeing support and assistance with a focus on recovery, to people who live with a mental illness. These services include assistance to access community, social and recreational activities; group based community, social and recreational activities; assistance with household tasks and daily living; and individual skills training and development.

**In the last 12 months, did you have access to the non-clinical services you required?**

*(Please select only **one** item)*

- Yes  No

**Is there anything else you'd like us to know about your experience using the services you require to continue to live a contributing life?**

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# Appendix B

## Consumer Survey 2020

### SECTION 4 Aboriginal and Torres Strait Islander mental health

This section seeks to understand the experiences of people who are Aboriginal and/or Torres Strait Islander as they access mental health services. We invite consumers who are Aboriginal and/or Torres Strait Islander to complete this section.

If you do not identify as an Aboriginal and/or Torres Strait Islander person, please select 'none of the above' and you will be redirected to the next section.

**Do you identify as:** *(Required)*

*(Please select only one item)*

- Aboriginal  Torres Strait Islander
- Aboriginal and Torres Strait Islander
- None of the above

The next set of questions seek to understand whether the treatment, care or support you received in the last 12 months was culturally appropriate and considered your social and emotional wellbeing needs alongside your clinical needs. This section also asks whether you received support to use the mental health system.

**In the past 12 months, how often have you felt as though care providers considered all of your needs (including clinical, social and emotional wellbeing), and the needs of your community, when planning your mental health care?**

*(Please select only one item)*

- Never
- Rarely
- Sometimes
- Usually
- Always

**In the past 12 months, how often have you felt as though care providers considered all of your needs (including clinical, social and emotional wellbeing), and the needs of your community, when delivering your mental health care?**

*(Please select only one item)*

- Never
- Rarely
- Sometimes
- Usually
- Always

**In the past 12 months, how often did you receive help or support to use the mental health system? This could include assistance with making appointments or referrals to other services; being provided with information on what services are available and how to contact them; or help accessing services and appointments.**

*(Please select only one item)*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not required

**In the past 12 months, how often was the treatment, care or support delivered to you culturally appropriate?**

*(Please select only one item)*

- Never
- Rarely
- Sometimes
- Usually
- Always

**Is there anything else you'd like us to know about your mental health care experience?**

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# Appendix B

## Consumer Survey 2020

### SECTION 5 Physical health

This section seeks to understand if relevant physical health needs are also being considered when you receive mental health treatment, care or support. This might involve the mental health care provider discussing the potential side effects of prescribed medication and how to manage these. The care provider may also enquire about your physical health and arrange for you to have regular physical health checks including blood pressure checks, blood tests or pap smears.

Depending on your health needs, the care provider may refer you to:

- a smoking cessation program or other drug or alcohol program;
- a dentist;
- other health services such as dietetics, physiotherapy, podiatry, speech therapy;
- maternal and child health services.

**When seeking care for your mental illness how often does your care provider discuss your physical health?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always

**Are you aware of any arrangements between services to address your physical and mental health needs? For example, your psychiatrist or community-based/allied health practitioner might share your treatment plans with your GP so that your GP can better manage your physical health.**

*(Please select only **one** item)*

Yes    No    Unsure

**Is there anything else you would like us to know about your experiences receiving care for your physical health when using mental health services?**

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# Appendix B

## Consumer Survey 2020

### SECTION 6 Stigma and discrimination

This section seeks to understand whether you have experienced stigma or discrimination as a result of living with a mental illness. People living with a mental illness may experience stigma and discrimination by the health workforce as well as by the broader community. For this reason, the questions below will ask about your experience in the community as well as within the healthcare system.

**In the past 12 months, when using mental health services, how often have you felt as though you were treated differently by care providers as a result of your mental illness?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always

**In the past 12 months, how often have you felt as though you were treated differently by people (at work, school, social gatherings or events) as a result of your mental illness?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always

**Is there anything else you'd like us to know about your experiences of stigma and discrimination?**

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# Appendix B

## Consumer Survey 2020

### SECTION 7 Safety in mental health care

This section is about how safe you felt when receiving mental health treatment, care or support in the past 12 months.

**In the past 12 months, how often have you felt safe when using mental health services?**

*(Please select only **one** item)*

- Never   Rarely   Sometimes   Usually   Always
- 

**In the past 12 months, how often was information available about the safety of the mental health services you were using?**

*(Please select only **one** item)*

- Never   Rarely   Sometimes   Usually   Always
- 

**When you have been provided with information on the safety of services, how often did this information help you to make informed decisions regarding your mental health treatment, care or support?**

*(Please select only **one** item)*

- Never   Rarely   Sometimes   Usually   Always   N/A
- 

**Is there anything else you would like us to know about your experience of safety while accessing and using mental health services?**

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# Appendix B

## Consumer Survey 2020

### SECTION 8 Improvements in the mental health care system

This section seeks to understand whether you think improvements have been made to mental health services, care or support in the past 12 months. You might have noticed that more services have become available, or that it has become easier to access existing services. Alternatively, your experience using mental health services for yourself may have stayed the same, or worsened.

**Have you noticed improvements in the services you used in the past 12 months?**

*(Please select only **one** item)*

Yes     No     Unsure

**Have you been asked or encouraged by mental health care or service providers to share your experiences to help improve service planning and delivery for others?**

*(Please select only **one** item)*

Yes     No     Unsure

**Is there anything else you would like us to know about mental health service improvement?**

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# Appendix B

## Consumer Survey 2020

### ABOUT YOU

To finish, we'd like to know a little bit about you.

**What is your age?** (Required)

(Please select only **one** item)

- |                                      |  |
|--------------------------------------|--|
| <input type="radio"/> 16 to 24 years | <input type="radio"/> 55 to 64 years   |
| <input type="radio"/> 25 to 34 years | <input type="radio"/> 65 to 74 years   |
| <input type="radio"/> 35 to 44 years | <input type="radio"/> 75 years or over |
| <input type="radio"/> 45 to 54 years |  |

**What is your postcode?** (Required)

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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**Which state or territory do you live in?** (Required)

(Please select only **one** item)

- |  |   |
|--|---|
| <input type="radio"/> ACT                | <input type="radio"/> South Australia   |
| <input type="radio"/> Northern Territory | <input type="radio"/> Tasmania          |
| <input type="radio"/> NSW                | <input type="radio"/> Victoria          |
| <input type="radio"/> Queensland         | <input type="radio"/> Western Australia |

**Do you identify as male, female or other?** (Required)

(Please select only **one** item)

- |   |                            |
|---|----------------------------|
| <input type="radio"/> Female                            | <input type="radio"/> Male |
| <input type="radio"/> Other – trans/transgender male    |                            |
| <input type="radio"/> Other – trans/transgender female  |                            |
| <input type="radio"/> Other – gender diverse/non-binary |                            |
| <input type="radio"/> Prefer not to say                 |                            |

**What is the main language you speak at home?**

(Required)

(Please select only **one** item)

- English
- Other – if other, please specify:

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**Did someone help you complete this survey?** (Required)

(Please select only **one** item)

- No
- Yes – family or friend
- Yes – language or cultural interpreter
- Yes – consumer worker or peer worker
- Yes – someone else

# Appendix B

# Carer Survey 2020

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## Overview

Thank you for taking the time to complete this survey.

The National Mental Health Commission (the Commission) is seeking feedback from mental health consumers and carers on their experiences of mental health services in the past 12 months.

The annual consumer and carer survey helps inform reporting on the progress of mental health and suicide prevention reform in Australia, specifically the Fifth National Mental Health and Suicide Prevention Plan.

Your insights are critical in driving sustainable reform of the mental health system and delivering care that suits the needs of Australians.

## Who can participate?

The Commission welcomes responses from carers of consumers who have used mental health services in the past 12 months.

If you are also experiencing a mental illness and have used mental health services in the past 12 months, you can complete the survey a second time from the perspective of a **consumer**.

A printable version of the survey is available if required. Please contact:

[fifthplan@mentalhealthcommission.gov.au](mailto:fifthplan@mentalhealthcommission.gov.au).

## What is involved?

This survey should take between 10 to 30 minutes to complete, depending on how much information you'd like to provide. You do not need to give your name to complete the survey, and your answers will be kept confidential and anonymous.

You can save your responses and return to the survey at any time up until the closing date, using the save and return link provided. You will need to provide your email address if you choose to save and return. If you do not wish to provide your email address, you will not be able to save and return to your answers, and you will need to start the survey again.

## What will your responses contribute to?

We appreciate your time and honesty. Your answers are valuable to the Commission and will help us to monitor and report on efforts to improve mental health and suicide prevention in Australia. The Commission will use responses to this survey to inform our reports to government and the community on the performance of the mental health sector.

## Privacy

The Commission takes your privacy seriously. All responses will be treated as confidential, and, except where required by law, no personally identifying information from your response will be released or used for a purpose other than as set out above.

The Commission stores all personal information securely and restricts access to those employees who need access in order to perform their duties or to assist individuals.

For further information on privacy, please see the Commission's [privacy policy](#).

## Further information

You can read more about the *Fifth National Mental Health and Suicide Prevention Plan* on the Commission's [website](#).

## Help and support

Talking about your experiences of mental health can be challenging. If any questions cause distress, please stop and we encourage you to reach out for support. Help is always available at:

- [Lifeline](#) or call **13 11 14**
- [Kids Helpline](#) or call **1800 55 1800**
- [Beyond Blue](#) or call **1300 22 4636**.

# Appendix B

## Carer Survey 2020

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### Introduction

The Commission welcomes responses from carers of consumers who have used mental health services in the past 12 months.

### Definitions

In the context of the Fifth National Mental Health and Suicide Prevention Plan, a **carer** is a person who cares for, or otherwise supports, a person living with a mental illness and may be a family member, friend, neighbour, or member of the broader community. For the purposes of this survey, a carer does not refer to community care services provided on a fee-for-service basis.

Some mental health care consumers also care for someone who has a mental illness. This means that they are both a **consumer** and a **carer**. If you identify as both a consumer and carer, then we welcome you to respond to the survey a second time from the perspective of a consumer via the [consumer survey](#).

Mental health services include **clinical** and **non-clinical** supports. **Clinical or medical services** are those that provide assessment, diagnostic and treatment services for people with mental illness. Clinical services include appointments with a GP, psychologist, counsellor, or psychiatrist, as well as care while admitted in hospital and residential settings.

**Non-clinical or community psychosocial services** focus on providing well-being, support and assistance with a focus on recovery, to people who live with a mental illness. These services include assistance to access community, social and recreational activities; group based community, social and recreational activities; assistance with household tasks and daily living; and individual skills training and development.

As this survey is focusing on the experiences of people who have recently used services, if you answer 'no' to the below question you will be directed straight to the end of the survey.

Has the person you care for used mental health services in the past 12 months? (Required)

(Please select only **one** item)

Yes     No     Unsure

# Appendix B

## Carer Survey 2020

### SECTION 1 Mental health services

This section is about the experience of the person you care for when using mental health services in the last 12 months, and whether these services were appropriate for their needs. This section is also interested in whether their care provider involved the person you care for in the planning process.

#### Definitions

As described in the introduction, mental health services include clinical and non-clinical supports.

**Clinical or medical services** are those that provide assessment, diagnostic and treatment services for people with mental illness. Clinical services include appointments with a GP, psychologist, counsellor, or psychiatrist, as well as care while admitted in hospital and residential settings.

**Non-clinical or community psychosocial services** focus on providing well-being, support and assistance with a focus on recovery, to people who live with a mental illness. These services include assistance to access community, social and recreational activities; group based community, social and recreational activities; assistance with household tasks and daily living; and individual skills training and development.

**What types of mental health services has the person you care for used in the past 12 months? You can select as many services as you like:**

(Please select all that apply)

- GP
- Mental health nurse
- Psychiatrist
- Psychologist
- Counsellor
- Peer workers
- Telephone support line
- Online based services – such as websites, apps and programs, forums, web-based chat and email support
- Hospital emergency department
- Overnight hospital stay
- Inpatient or residential mental health care
- Community, social and recreational activities
- Group based community, social and recreational activities
- Daily living support
- Other – if other, please specify:

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# Appendix B

## Carer Survey 2020

### SECTION 1 Mental health services

If the person you care for used more than one of these services, how often did you feel as though these services worked together to address their needs?

(Please select only **one** item)

Never Rarely Sometimes Usually Always N/A

In the past 12 months how often have you felt as though care providers worked with the person you care for to meet their needs?

(Please select only **one** item)

Never Rarely Sometimes Usually Always

How often did you feel the person you care for had a say in the way their treatment was planned in the past 12 months?

(Please select only **one** item)

Never Rarely Sometimes Usually Always

Is there anything else you'd like us to know about the experience of mental health services of the person you care for in the past 12 months?

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How often did you feel the person you care for had a say in the way their treatment was delivered in the past 12 months?

(Please select only **one** item)

Never Rarely Sometimes Usually Always

In the past 12 months, how often have you felt as though care providers understood the needs of the person you care for?

(Please select only **one** item)

Never Rarely Sometimes Usually Always

# Appendix B

## Carer Survey 2020

### SECTION 2 Suicide prevention services

The next section will ask questions about suicide prevention services and postvention support for carers, families and communities following a death by suicide. If you would prefer not to answer these questions, please skip to Section 3.

**If these questions raise any uncomfortable feelings for you, please reach out to your support network or contact one of the following services for support:**

- [Lifeline](#) or call **13 11 14**
- [Kids Helpline](#) or call **1800 55 1800**
- [Beyond Blue](#) or call **1300 22 4636**

There are many services across Australia that provide suicide prevention support. This might include crisis support and intervention, free counselling support over the phone or prevention programs for people identified as being at risk of suicide. Suicide prevention support also includes supports for carers, families and communities affected by suicide or a suicide attempt. The Fifth Plan refers to this type of support as 'postvention supports'.

**Are you aware of any services available in your area that provide care and support for people who are at risk of suicide?**

*(Please select only **one** item)*

- Yes     No     Unsure

**Are you aware of any services that provide active follow-up for people who are at a high risk of suicide, including after a suicide attempt, in the area you live in?**

*(Please select only **one** item)*

- Yes     No     Unsure

**Are you aware of support services available for carers, families and communities affected by suicide in the area that you live in?**

*(Please select only **one** item)*

- Yes     No     Unsure

**Is there anything else you'd like us to know about suicide prevention, follow-up, or support services for those affected by suicide?**

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# Appendix B

## Carer Survey 2020

### SECTION 3 Severe and complex mental illness

A **severe and complex mental illness** is not confined to a specific diagnosis. People with severe and complex mental illness may be people with persistent mental illness with complex needs that can only be met by multiple care providers, or people who have complexities that are not directly related to their mental illness. This includes:

- People who have a severe mental illness as well as a chronic physical illness or disability, or issues with drugs and alcohol.
- People whose mental illness is adversely impacted by complex social factors such as homelessness, isolation from social or family supports, or who require assistance from multiple health/community services for day-to-day activities.
- People with reoccurring acute mental health episodes that require frequent hospital care.
- People who have experienced long term residential or hospital care.
- People who are at high risk of suicide.

This section seeks to understand the experiences of people living with a severe and complex mental illness as they access mental health services. We invite carers of consumers who are living with a severe and complex mental illness to complete this section.

If the person you care for does not live with a severe and complex mental illness please select 'no' below to be directed to the next section.

**Does the person you care for live with a severe and complex mental illness?**

*(Please select only **one** item)*

Yes  No

People who live with severe and complex mental illness may access clinical and non-clinical services. Taken together, clinical and non-clinical services should support the person to live a contributing life – a life that is enriched with close connections to family and friends, supported by good health, wellbeing and healthcare.

Clinical or medical services are those that provide assessment, diagnostic and treatment services for people with mental illness. Clinical services include appointments with a GP, psychologist, counsellor, or psychiatrist, care while admitted in hospital and residential care, as well as medications prescribed to treat or support your mental health.

**In the past 12 months, did the person you care for have access to the clinical services they required?**

*(Please select only **one** item)*

Yes  No

Non-clinical or community psychosocial services focus on providing wellbeing support and assistance with a focus on recovery, to people who live with a mental illness. These services include assistance to access community, social and recreational activities; group based community, social and recreational activities; assistance with household tasks and daily living; and individual skills training and development.

**In the last 12 months, did the person you care for have access to the non-clinical services they required?**

*(Please select only **one** item)*

Yes  No

**Is there anything else you'd like us to know about the services the person you care for requires to continue to live a contributing life (including access to services and coordination of treatment)?**

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# Appendix B

## Carer Survey 2020

### SECTION 4 Aboriginal and Torres Strait Islander mental health

This section seeks to understand the experiences of people who are Aboriginal and/or Torres Strait Islander as they access mental health services. We invite carers of consumers who are Aboriginal and/or Torres Strait Islander to complete this section.

If you do not identify as a carer of an Aboriginal and/or Torres Strait Islander person, please select 'none of the above' and you will be redirected to the next section.

**Does the person you care for identify as:** *(Required)*

*(Please select only one item)*

- Aboriginal     Torres Strait Islander
- Aboriginal and Torres Strait Islander
- None of the above
- Unsure

The next set of questions seeks to understand whether the treatment, care or support of the person you care for was culturally appropriate and considered their social and emotional wellbeing needs alongside their clinical needs. This section also asks whether person you care for received support to use the mental health system.

**In the past 12 months, how often have you felt that care providers considered all of the needs of the person you care for (including clinical, social and emotional wellbeing), and the needs of their community, when planning their mental health care?**

*(Please select only one item)*

- Never    Rarely    Sometimes    Usually    Always
- 

**In the past 12 months, how often have you felt that care providers considered all of the needs of the person you care for (including clinical, social and emotional wellbeing), and the needs of their community, when delivering their mental health care?**

*(Please select only one item)*

- Never    Rarely    Sometimes    Usually    Always
- 

**In the past 12 months, how often did the person you care for receive help or support to use the mental health system? This could include assistance with making appointments or referrals to other services; being provided with information on what services are available and how to contact them; or help accessing services and appointments.**

*(Please select only one item)*

- Never    Rarely    Sometimes    Usually    Always    Not required
- 

**In the past 12 months, how often was the treatment, care or support delivered to the person you care for culturally appropriate?**

*(Please select only one item)*

- Never    Rarely    Sometimes    Usually    Always
- 

**Is there anything else you'd like us to know about the mental health care experience of the person you care for?**

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# Appendix B

## Carer Survey 2020

### SECTION 5 Physical health

This section seeks to understand if physical health needs are also being considered when the person you care for receives mental health treatment, care or support. This might involve the mental health care provider discussing the potential side effects of prescribed medication and how to manage these. The care provider may also enquire about their physical health and schedule them for regular physical health checks including blood pressure checks, blood tests or pap smears.

Depending on their health needs, the care provider may refer them to:

- a smoking cessation program or other drug or alcohol program;
- a dentist;
- other allied health services such as dietetics, physiotherapy, podiatry, speech therapy;
- maternal and child health services.

**When seeking care for their mental illness, how often do care providers discuss the physical health of the person you care for?**

*(Please select only **one** item)*

- Never   Rarely   Sometimes   Usually   Always   N/A
- 

**Are you aware of any arrangements between services to address the physical and mental health needs of the person you care for? For example, their psychiatrist or community-based/allied health practitioner might share their treatment plans with their GP so that their GP can better manage their physical health.**

*(Please select only **one** item)*

- Yes    No    Unsure

**Is there anything else you would like us to know about the experiences of the person you care for, receiving care for their physical health when using mental health services?**

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# Appendix B

## Carer Survey 2020

### SECTION 6 Stigma and discrimination

This section seeks to understand whether the person you care for has experienced stigma or discrimination as a result of living with a mental illness. People living with a mental illness may experience stigma and discrimination by the health workforce as well as by the broader community. For this reason, the questions below will ask about their experience in the community as well as within the healthcare system.

**In the past 12 months, when using mental health services, how often have you felt as though the person you care for was treated differently by care providers as a result of their mental illness?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always

**In the past 12 months, how often have you felt as though the person you care for was treated differently by people (at work, school, social gatherings or events etc) as a result of their mental illness?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always

**Is there anything else you'd like us to know about the experiences of stigma and discrimination of the person you care for?**

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# Appendix B

## Carer Survey 2020

### SECTION 7 Safety in mental health care

This section is about how safe the person you care for felt when receiving mental health treatment, care or support in the past 12 months.

**In the past 12 months, how often has the person you care for felt safe when using mental health services?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always   Unsure

**In the past 12 months, how often was information about the safety of mental health services available to the person you care for?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always

**When information on the safety of services has been provided, how often did this information help the person you care for to make informed decisions regarding their mental health treatment, care or support?**

*(Please select only **one** item)*

Never   Rarely   Sometimes   Usually   Always   N/A

**Is there anything else you would like us to know about the safety of the person you care for when accessing and using mental health services?**

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# Appendix B

## Carer Survey 2020

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### SECTION 8 Improvements in the mental health care system

This section seeks to understand whether you think improvements have been made to mental health services, care or support in the past 12 months for the person you care for. You might have noticed that more services have become available, or that it has become easier to access existing services. Alternatively, the experience of using mental health services may have stayed the same, or worsened.

**Have you noticed improvements in the services the person you care for has used in the past 12 months?**

*(Please select only **one** item)*

Yes     No     Unsure

**Has the person you care for been asked or encouraged by mental health care providers to share their experiences to help improve service planning and delivery for others?**

*(Please select only **one** item)*

Yes     No     Unsure

**Is there anything else you would like us to know about mental health service improvement?**

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# Appendix B

## Carer Survey 2020

### ABOUT YOU

To finish, we'd like to know a little bit about you.

**What is your age?** (Required)

(Please select only **one** item)

- |                                      |  |
|--------------------------------------|--|
| <input type="radio"/> 16 to 24 years | <input type="radio"/> 55 to 64 years   |
| <input type="radio"/> 25 to 34 years | <input type="radio"/> 65 to 74 years   |
| <input type="radio"/> 35 to 44 years | <input type="radio"/> 75 years or over |
| <input type="radio"/> 45 to 54 years |  |

**What is your postcode?** (Required)

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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**Which state or territory do you live in?** (Required)

(Please select only **one** item)

- |  |   |
|--|---|
| <input type="radio"/> ACT                | <input type="radio"/> South Australia   |
| <input type="radio"/> Northern Territory | <input type="radio"/> Tasmania          |
| <input type="radio"/> NSW                | <input type="radio"/> Victoria          |
| <input type="radio"/> Queensland         | <input type="radio"/> Western Australia |

**Do you identify as male, female or other?** (Required)

(Please select only **one** item)

- |   |                            |
|---|----------------------------|
| <input type="radio"/> Female                            | <input type="radio"/> Male |
| <input type="radio"/> Other – trans/transgender male    |                            |
| <input type="radio"/> Other – trans/transgender female  |                            |
| <input type="radio"/> Other – gender diverse/non-binary |                            |
| <input type="radio"/> Prefer not to say                 |                            |

**What is the main language you speak at home?**

(Required)

(Please select only **one** item)

- English
- Other – if other, please specify:

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**Did someone help you complete this survey?** (Required)

(Please select only **one** item)

- No
- Yes – family or friend
- Yes – language or cultural interpreter
- Yes – consumer worker or peer worker
- Yes – carer peer worker
- Yes – someone else

