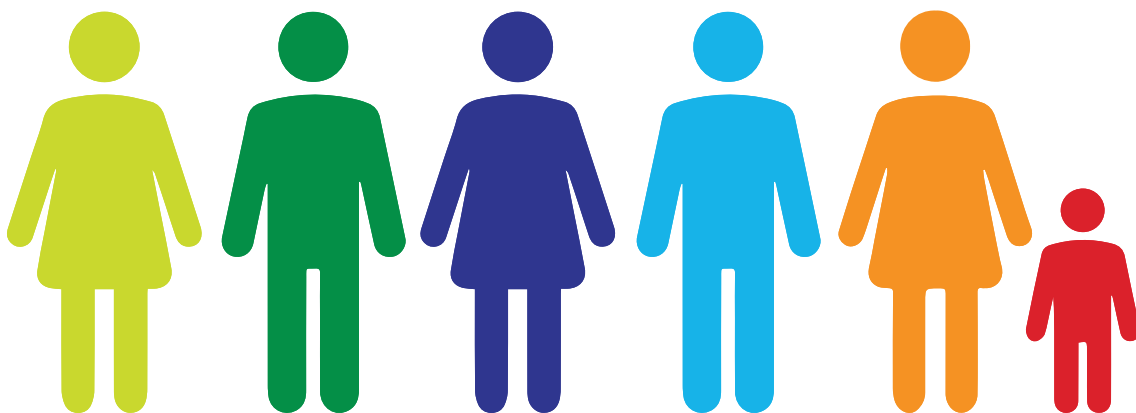


Monitoring mental health
and suicide prevention reform

Fifth National Mental Health and Suicide Prevention Plan, 2019

The consumer and carer perspective



Australian Government
National Mental Health Commission

About this Report

This report can be downloaded from our website www.mentalhealthcommission.gov.au

Requests and enquiries concerning reproduction and rights should be directed to:

The Director of Communications
PO Box R1463, Royal Exchange, NSW 1225.

This publication is the first in a series of annual reports. A complete list of the NMHC's publications is available from our website.

ISBN: 978-0-6484334-2-2
ISSN: 2652-1350

Suggested citation

National Mental Health Commission. Monitoring mental health and suicide prevention reform, Fifth National Mental Health and Suicide Prevention Plan, 2019: The consumer and carer perspective. Sydney: NMHC; 2019.

Learn more about our work

www.mentalhealthcommission.gov.au



Acknowledgement

The National Mental Health Commission would like to acknowledge the assistance and cooperation of:

The consumers and carers who participated in the survey and shared their experiences. Without these contributions, the NMHC 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 Fifth National Mental Health and Suicide Prevention Plan Consumer and Carer Survey, which formed the basis of this report.



© National Mental Health Commission 2019

This product, excluding the NMHC logo, Commonwealth Coat of Arms and material owned by a third party or protected by a trademark, has been released under a Creative Commons BY 3.0 (CC BY 3.0) licence.

The excluded material owned by a third party includes data, images, accounts of personal experiences and artwork sourced from third parties, including private individuals.

You may distribute, remix and build upon this work. However, you must attribute the NMHC as the copyright holder of the work in compliance with our attribution policy. The full terms and conditions of this licence are available at <http://creativecommons.org/licenses/by/3.0/au/>

Address copyright enquiries to:

The Director of Communications, NMHC,
PO Box R1463, Royal Exchange, NSW 1225.

Contents

Foreword	4	Respondent demographics	10
Executive summary	5	Findings against Fifth Plan Priority Areas	12
Introduction	7	Priority Area 1: Achieving integrated regional planning and service delivery	12
Methodology	8	Priority Area 2: Effective suicide prevention	14
		Priority Area 3: Coordinating treatment and supports for people with severe and complex mental illness	15
		Priority Area 4: Improving Aboriginal and Torres Strait Islander mental health and suicide prevention	16
		Priority Area 5: Improving the physical health of people living with mental illness and reducing early mortality	17
		Priority Area 6: Reducing stigma and discrimination	18
		Priority Area 7: Making safety and quality central to mental health service delivery	19
		Priority Area 8: Ensuring that the enablers of effective system performance and system improvement are in place	20
		Conclusion	21
		Acronyms	22
		Appendix	23
		Fifth National Mental Health and Suicide Prevention Plan Consumer and Carer Survey	24

Foreword

The National Mental Health Commission (NMHC) is responsible for monitoring and reporting on implementation of the Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan). In 2018, the NMHC delivered its first independent progress report, titled *Fifth National Mental Health and Suicide Prevention Plan, 2018: Progress report* to the COAG Health Council.

Mental health consumers and carers are at the forefront of our work at the NMHC. In my many interactions with consumers and carers throughout the NMHC's Connections Tour, it is becoming increasingly clear that ongoing consultation throughout the implementation of any mental health reform is critical to ensure accountability and to measure success.

To comprehensively monitor progress of the Fifth Plan, we need to understand if consumers' and carers' experiences of care are improving. This year, the NMHC undertook a consumer and carer survey for the first time to help us understand whether implementation of the Fifth Plan is affecting experiences of care. The results of the survey form the basis of this report, and I am pleased to present the *Fifth National Mental Health and Suicide Prevention Plan, 2019: The consumer and carer perspective* (2019 Consumer and Carer Report).

The 2019 Consumer and Carer Report presents baseline data for ongoing monitoring and reporting. The NMHC will use this baseline to track progress and measure change from the perspective of consumers and carers over the coming years. Stakeholders responsible for implementing the Fifth Plan should also use these reports to consider how their efforts are impacting consumers and carers as they interact with the mental health system.

The Fifth Plan is in the early stages of implementation and improvements to the mental health system will take time. As implementation progresses, the NMHC expects to see improvements in the aspects of the mental health system that the Fifth Plan identifies as priorities. To be effective, the benefit from these improvements must be passed on to consumers and carers and their experiences of care.

The NMHC will continue to independently survey consumers and carers throughout the life of the Fifth Plan. It is essential for the NMHC to continue to engage directly with consumers and carers in order to know if actions are translating into genuine improvements in experience and outcomes of care.

Thank you to all who have contributed to this report, both in survey design and participation. The NMHC is grateful for the engagement of consumers and carers who relayed their personal stories of accessing services. These contributions are critical for all of us as we continue to work towards sustainable reform of the system.



Christine Morgan
CEO



Executive summary

The ultimate aim of the Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan) is to improve the lives of people living with a mental illness, as well as the lives of their families, carers and communities. The Fifth Plan seeks to accomplish this by committing to a nationally agreed set of Priority Areas and actions that are designed to build a stronger, more transparent, accountable, efficient and effective mental health system.

There are eight Priority Areas identified in the Fifth Plan. These priorities represent what governments and more broadly, the mental health sector, believe are achievable and measurable improvements to the current functioning of the mental health system. These improvements are ambitious, and aim to address the inadequacies and inefficiencies experienced by consumers and carers currently accessing the mental health system in Australia.

The National Mental Health Commission (NMHC) has been given responsibility for delivering an annual report, for presentation to Health Ministers, on the implementation progress of the Fifth Plan actions and performance against the identified indicators. The first of these reports was delivered to the COAG Health Council (CHC) in October 2018 and described the progress made towards the implementation of the Fifth Plan actions in the first year of the plan. Measuring the progress of governments, Primary Health Networks (PHNs), mental health commissions and committees as they work towards implementing actions over the life of the Fifth Plan is a key indicator for determining the success of Fifth Plan reform. It doesn't however, tell the whole story.

Under the Fifth Plan consumers and carers are central to how services are planned, delivered and evaluated. The Fifth Plan specifically outlines "what will be different for consumers and carers" based on the successful implementation of actions within each of the eight identified Priority Areas. With this in mind, to accurately monitor and evaluate the success of the reform, it is critical that we also understand how consumers and carers experience the mental health system that the Fifth Plan seeks to improve. Monitoring implementation progress, in conjunction with monitoring how consumers and carers experience the mental health system, will allow for a broader assessment of whether the reform is successful.

In order to understand whether the Fifth Plan is making a difference to consumers and carers, the NMHC developed a public survey to capture consumer and carer experiences of mental health services in Australia. Of the 546 survey responses received, 64% were from consumers and 36% were from carers. The majority of responses were from people who identified as female (79%) and people between the ages of 35 and 64 (71%). The majority of consumer and carer respondents reported accessing multiple mental health services with general practitioner, psychologist and psychiatrist services the most common. The NMHC acknowledges that the sample size of the survey is small and that the results therefore might not be representative of the broader consumer and carer population in Australia.

The core aim of the Consumer and Carer Survey was to determine whether the actions currently being implemented under the Fifth Plan are translating into tangible improvements in how consumers and carers experience mental health care. By seeking to understand the experiences of consumers and carers throughout the life of the Fifth Plan reform, the NMHC can measure progress and, ultimately, determine whether the Fifth Plan has been successful in achieving its objectives. It is important to note the Fifth Plan was endorsed by Health Ministers, and therefore the actions under the plan are largely for governments and associated stakeholders to implement. For this reason, the Fifth Plan is limited in its ability to influence non-government and private organisations.

Across the Priority Areas of the survey, several key issues were identified by consumers and carers. The availability and adequacy of services were consistently raised as barriers impacting consumer experiences across multiple Priority Areas (Priority Area 1: Achieving integrated regional planning and service delivery, Priority Area 2: Effective suicide prevention, and Priority Area 3: Coordinating treatment and supports for people with severe and complex mental illness). Feedback described issues with access to appropriate support services and the lack of available services during times of need.

Issues of availability and cultural appropriateness of services were also reported as barriers by Aboriginal and Torres Strait Islander respondents (Priority Area 4: Improving Aboriginal and Torres Strait Islander mental health and suicide prevention). Additionally, the majority of Aboriginal and Torres Strait Islander respondents indicated that service providers 'rarely' or 'never' consider all of their needs (clinical, social and emotional), provide culturally appropriate care, or provide appropriate support to navigate the system.

Respondents raised the need for consideration of broader consumer needs in conjunction with their mental health needs. For example, for people with severe and complex mental illness (Priority Area 3: Coordinating treatment and supports for people with severe and complex mental illness), income support, employment services and adequate housing were identified as relevant challenges to accessing services. Survey responses also indicated that consideration of physical health needs (Priority Area 5: Improving the physical health of people living with mental illness and reducing early mortality) by providers could be strengthened.

The importance of considering consumers' needs holistically in the context of their community is echoed by the reported rates of discrimination experienced by respondents (Priority Area 6: Reducing stigma and discrimination). Reported rates of discrimination experienced by respondents were high in the broader community (such as at work, school, social gatherings or events), with 43% of respondents reporting they were 'usually' or 'always' treated differently in this setting. Similar results were seen with regards to experiences of discrimination when accessing mental health services, with 38% of respondents reporting that they were 'usually' or 'always' treated differently in this setting.

The negative impact of mental health stigma and discrimination on consumer and carer experiences of health care is clear. Respondents reported across multiple Priority Areas that the quality of care they, or the person they care for, received over the last 12 months was impacted by encountering negative, unhelpful or uncaring attitudes among health providers (Priority Area 1: Achieving integrated regional planning and service delivery, Priority Area 2: Effective suicide prevention, Priority Area 3: Coordinating treatment and supports for people with severe and complex mental illness, Priority Area 7: Making safety and quality central to mental health service delivery, and Priority Area 8: Ensuring that the enablers of effective system performance and system improvement are in place).

More than two thirds of respondents indicated they had not noticed any improvements in the services that they, or the person they care for, had accessed in the past 12 months. However, as this report covers the first year of Fifth Plan implementation, service improvements cannot be expected immediately. The NMHC expects to see improvements in experiences of consumers and carers in future years as implementation of the Fifth Plan progresses.

Finally, whilst the survey did not directly ask respondents to rate the quality of services, service quality issues were raised by respondents in the free text comments across half of all Priority Areas (Priority Area 1: Achieving integrated regional planning and service delivery, Priority Area 2: Effective suicide prevention, Priority Area 3: Coordinating treatment and supports for people with severe and complex mental illness and Priority Area 8: Ensuring that the enablers of effective system performance and system improvement are in place).

Overall, the findings of this report reinforce the importance of the direction, Priority Areas and subsequent actions of the Fifth Plan. It is clear that improvements still need to be made across all Priority Areas. However, given the relative infancy of the Fifth Plan, improvements are likely to be seen incrementally as implementation of the plan progresses.

As this survey was the first of its kind, the NMHC sought to establish a baseline from which to measure progress over the life of the Fifth Plan. The NMHC will use this baseline report to monitor and report on the progressive impact of the Fifth Plan for consumers and carers over the coming years.

The NMHC is thankful to all of the consumer and carer respondents who participated in the survey. Many respondents clearly put considerable time and effort into their survey responses, providing detailed and compelling data to inform the NMHC's monitoring work. We thank these individuals for the valuable contribution they have made to support the reporting process on implementation progress of the Fifth Plan.

Introduction

The Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan) was endorsed by the Council of Australian Governments (COAG) on 4 August 2017, and is the latest in a series of National Mental Health Plans which set out national actions to achieve the intent of the National Mental Health Policy. The Fifth Plan builds on the foundation established by previous reform efforts and sets out a national approach for collaborative government effort over the period 2017 to 2022.

The Fifth Plan is underpinned by eight targeted Priority Areas, which align with the aims and policy directions of the National Mental Health Policy that are currently well-positioned for change in terms of need and opportunity. The eight Priority Areas are:

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

Like its predecessors, the Fifth Plan acknowledges that it is not possible to fix everything at once, or for all population groups, and that it is important to focus on significant issues that need to be addressed as part of a national approach. The supporting actions of the Fifth Plan set the direction for change and provide a foundation for longer-term system reform.

Significantly, this is the first plan to commit all governments to work together to achieve integration in planning and service delivery at a regional level. Of critical importance, in the Fifth Plan consumers and carers are central to the way in which services are planned, delivered and evaluated.

Reporting on the progress of mental health reform is fundamental to understanding whether the commitments made in the Fifth Plan are being honoured and are making a difference. To this end, the National Mental Health Commission (NMHC) has been given responsibility for independently delivering an annual report, for presentation to health ministers, on the implementation progress of the Fifth Plan and performance against the identified indicators.

The *Fifth National Mental Health and Suicide Prevention Plan, 2018 Progress Report* was delivered to COAG Health Council in October 2018. The report to Health Ministers outlined the progress achieved against the Fifth Plan Implementation Plan actions as of 30 June 2018. The report also presented a baseline for the available performance indicator data. Importantly, the progress described in the report is from the perspective of stakeholders named in the Fifth Plan Implementation Plan as they implement their actions.

With such an emphasis on the experience of consumers and carers throughout the Fifth Plan, the NMHC additionally sought to understand whether implementation progress has had any impact on how consumers and carers experience mental health care.

This report presents the findings from a survey of consumers and carers conducted by the NMHC in April 2019. The survey gathered information and feedback from consumers and carers on their experiences of accessing mental health services in relation to the Fifth Plan Priority Areas. The NMHC acknowledges that the survey sample size is small, and therefore results might not be representative of the broader consumer and carer population in Australia.

This report supplements the progress reported by stakeholders in the *Fifth National Mental Health and Suicide Prevention Plan, 2018 Progress Report*, and presents the experiences reported by consumers and carers as they interact with the mental health care system in Australia.

The Fifth Plan aims to improve the lives of people living with a mental illness and the lives of their families, carers and communities. By seeking to understand the experiences of consumers and carers throughout the life of the Fifth Plan reforms, the NMHC can measure progress and, ultimately, determine whether the Fifth Plan has been successful in achieving its objectives.

This report constitutes the first of the NMHC's annual reports on the consumer and carer experience and will serve as a baseline to understand the progressive impact of the Fifth Plan over the coming years.

Methodology

Background

To support the NMHC's role in monitoring and reporting on the progress of the Fifth Plan, a Fifth Plan Technical Advisory Group (FPTAG) was established by the NMHC to inform and guide the planning of reports from 2019 onward. The remit of the FPTAG also included the provision of guidance and advice on the planning and design process of the Fifth National Mental Health and Suicide Prevention Plan Consumer and Carer Survey, which forms the basis of this report.

The FPTAG is comprised of representatives from each state and territory government health department, the Australian Government Department of Health, the Australian Institute of Health and Welfare (AIHW), the Safety and Quality Partnership Standing Committee (SQPSC), the Suicide Prevention Project Reference Group (SPPRG), the Mental Health Information Strategy Standing Committee (MHISSC) and the Aboriginal and Torres Strait Islander Mental Health and Suicide Prevention Project Reference Group (ATSIMHSPPRG). Crucially, the group also includes consumer and carer representatives, whose contributions were particularly significant given the focus of the survey.

Survey design and delivery

The survey (see Appendix) was administered via Citizen Space, an online consultation tool, and accessed via the NMHC's website. The survey was open for completion from 1 April to 30 April 2019 and promoted via the NMHC's social media accounts, FPTAG and the NMHC's stakeholder networks – with a particular focus on consumer and carer-led organisations.

Survey questions were designed to capture the experiences of consumers and carers within each Priority Area of the Fifth Plan. The intention of the survey was to establish a baseline so that the NMHC can test whether the actions of the Fifth Plan are translating into real change for consumers and carers.

A total of 41 questions were included in the survey. These included a mix of yes/no questions as well as questions that asked respondents to rate the frequency of their experiences on a scale of never/rarely/sometimes/usually/always. Respondents were also invited to share additional information on their experiences through free text comments. In order to understand respondent experiences across Australia, key demographic information was also collected. However, no identifying or personal information was collected and all responses were anonymous. With the exception of the demographics, all questions were optional to answer.

Priority Area 3 of the Fifth Plan is focused on coordinating the treatment and supports for people living with a severe and complex mental illness. For this reason, respondents were asked a screening question before progressing to Section 3 of the survey. Only those respondents who indicated that they live with a severe and complex mental illness, or care for someone living with a severe and complex mental illness, were directed to answer questions in this section. All other respondents were redirected to Section 4 of the survey.

Similarly, as Priority Area 4 is focused on mental health and suicide prevention in Aboriginal and Torres Strait Islander communities, respondents were asked a screening question before progressing to Section 4 of the survey. Only those respondents who identified as Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander were directed to answer the questions in this section. All other respondents were redirected to Section 5 of the survey.

In total, 546 consumers and carers completed the survey in full. An additional 240 responses were partially completed, however only the 546 complete responses were used for data analysis.

The survey aimed to provide consumers and carers with an easy, accessible forum in which to provide feedback on their experiences. The online format allowed respondents to complete the survey at a time and place that was convenient to them. Respondents also had the option of saving their answers part-way through, and returning to the survey at a later time. The use of an online survey allowed the NMHC to reach a larger number of consumers and carers, in a wider range of locations, than would have been possible with other data collection methods (such as one-on-one interviews).

Limitations

The NMHC acknowledges the limitations of the methodology used in this process, particularly in the use of the volunteer sampling (self-select) method. Relying on volunteer sampling, rather than random sampling, may have resulted in a bias towards respondents who are highly motivated and engaged in consumer and carer advocacy, or who had stronger incentives to share their experiences (for example, because their experiences were either particularly positive or negative).

The survey also lacked the capability for respondents to provide a single response as both a consumer and a carer. Respondents who identified as both a consumer and a carer were invited to complete the survey twice – once from each of these perspectives. Whilst the survey itself consisted of only 41 questions, the time and effort required to complete the survey twice may

have been considered onerous for some respondents. As a result, the NMHC may have missed the opportunity to adequately capture the experiences of people who identify as both consumers and carers.

It is also worth noting that the Fifth Plan itself is primarily focused on actions for governments and associated stakeholders to improve mental health and suicide prevention. The Fifth Plan does not include private, non-government or community organisations in its scope. This means that the actions implemented under the Fifth Plan are largely focussed on tertiary level services, so responses to the survey should not be used as a reflection on the mental health sector as a whole.

Other considerations

One of the key actions under Priority Area 7 of the Fifth Plan Implementation Plan is the development of a National Mental Health Safety and Quality Framework (NMHSQF) to guide delivery of the full range of health and support services required by people living with mental illness. This includes a revised National Mental Health Performance Framework to support reporting on performance and quality across all mental health service sectors. Given that this work is currently in progress, the NMHC decided not to measure quality until the framework is implemented. For this reason, questions in Section 7 of the survey focused on service safety only.

The NMHC will seek to measure consumer and carer understandings of service quality in future years once the NMHSQF has been implemented.

Future planning

As the first survey of its kind designed and administered by the NMHC, the NMHC is conscious that improvements can be made to the methodology in the future that will strengthen the data collection and reporting process.

Improvements include adapting the survey so that it is more accessible to culturally and linguistically diverse populations, and promoting the survey to populations underrepresented in this year's data (such as people who identify as male, and people within the age categories of 16–24 years and 75 years or older).

It is imperative to the NMHC that any data collected from consumers and carers represents the full breadth of the population, so that all experiences are considered when measuring the progress of the Fifth Plan reform.

The NMHC will continue to consult widely and extensively through the FPTAG, as well as with consumers and carers directly through the National Mental Health Consumer and Carer Forum (NMHCCF).

Respondent demographics

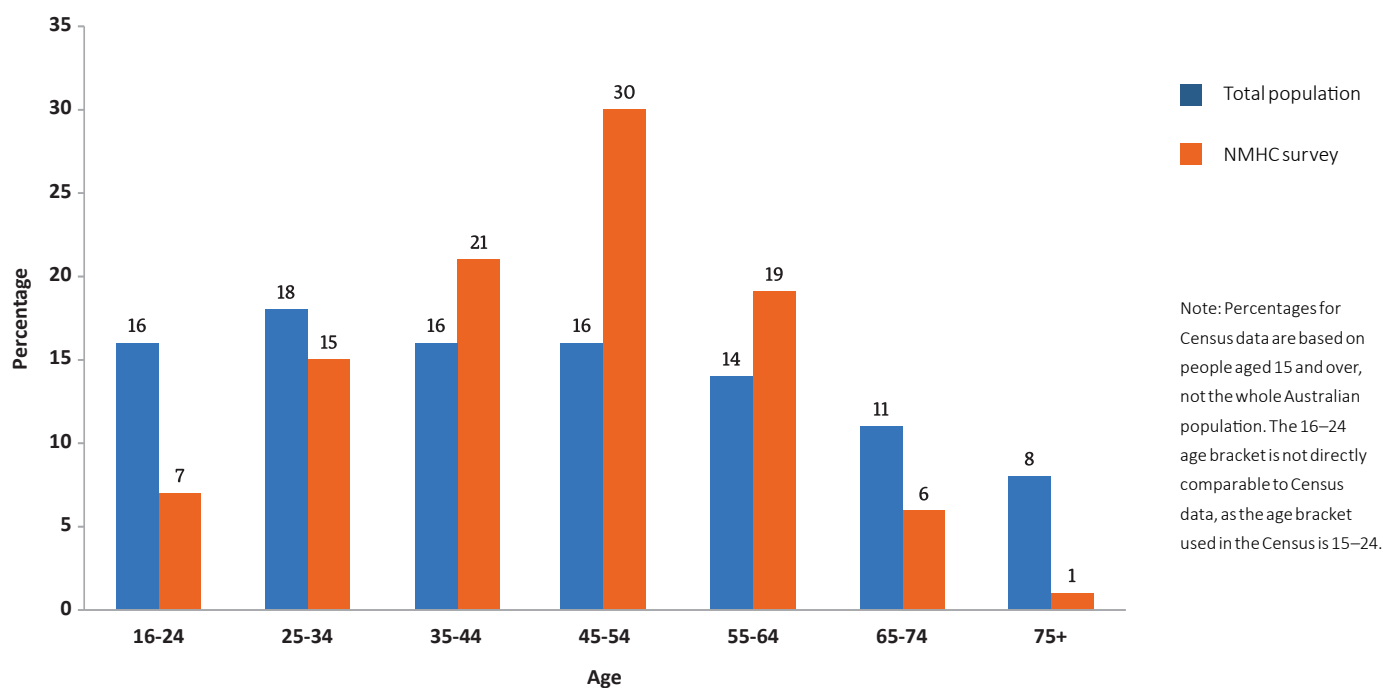
A total of 546 consumers and carers completed the survey in full. Around two-thirds (64%) of these respondents answered the survey as consumers, while the remaining one-third (36%) answered as carers.

Almost four in five respondents (79%) identified as female. Only 17% of respondents identified as male, with the remaining 3.5% identifying as transgender, gender diverse or non-binary, or indicating that they preferred not to identify their gender.

Considering the demographics of survey respondents is useful for assessing whether the findings of the survey apply, or can be generalised, to the wider Australian population. Of the responses collected, certain age groups were over-represented relative to the Australian population.

Of the 546 survey respondents, 71% were people aged between 35 and 64. In the total population, this age bracket comprises 47% of the population. Other age groups were under-represented relative to the Australian population, particularly those in the oldest age bracket (people aged 75 and over), who comprise 8% of the Australian population but made up less than 1% of survey respondents (Figure 1).

Figure 1: Age of survey respondents, compared to total population



Aboriginal and Torres Strait Islander people were well-represented among survey respondents relative to the Australian population. A total of 24 respondents (4.4%) reported that either they, or the person they care for, identify as Aboriginal and/or Torres Strait Islander, compared to 2.8% of the Australian population.

People who speak a language other than English as their main language were significantly under-represented among respondents relative to the Australian population. Almost all respondents (99%) reported that they spoke English as their main language, compared to 73% of the Australian population.

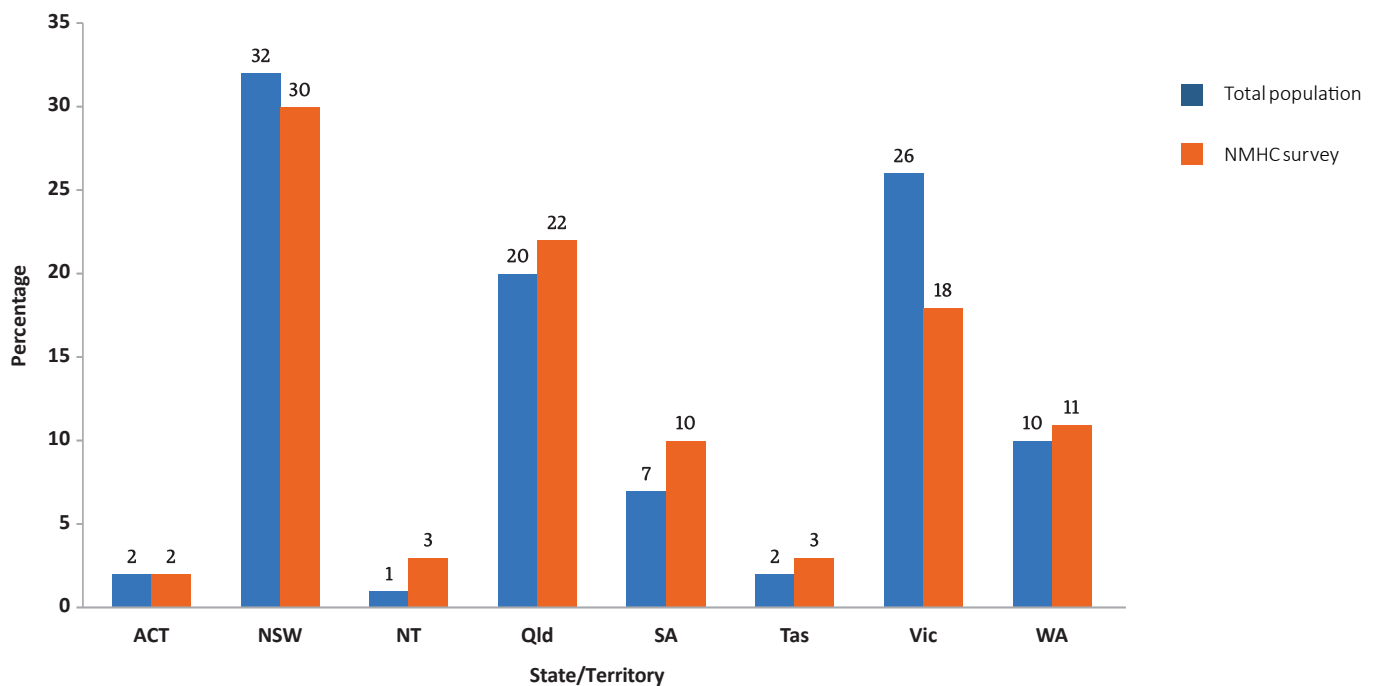
There was good representation of people from all states and territories among survey respondents. The only states that were under-represented were the two largest by population – New South Wales and Victoria – and only the latter was significantly under-represented.

The majority of survey respondents (70%) indicated that they, or the person they care for, live with a severe or complex mental illness. This high proportion could be due to a range of factors. For example, people who live with, or care for a person with severe and complex mental illness may have been more motivated to respond to the survey, due to the fact that they have had a higher level of contact with the mental health system or have faced particular challenges in accessing the support they need.

In addition, the definition of severe and complex mental illness presented in the survey (which was based on the definitions used in the Fifth Plan) may have captured some respondents who may not meet clinical definitions for severe and complex mental illness. For example, the definition includes people whose needs can only be met by multiple care providers. People living with mild to moderate mental illness who receive support from multiple providers (such as a general practitioner and a psychologist) may have identified as falling within this category.

For future surveys, the NMHC will consider strategies for wider dissemination of the survey and engagement of groups that were under-represented among respondents to this survey.

Figure 2: State/territory of residence for survey respondents compared to total population



Findings against Fifth Plan Priority Areas

Priority Area 1: Achieving integrated regional planning and service delivery

Lack of integration and agreement between mental health services can create frustration for consumers and carers, and lead to poor treatment continuity, difficulty in maintaining treatment and poorer treatment outcomes. It can also lead to a loss of trust in the system.

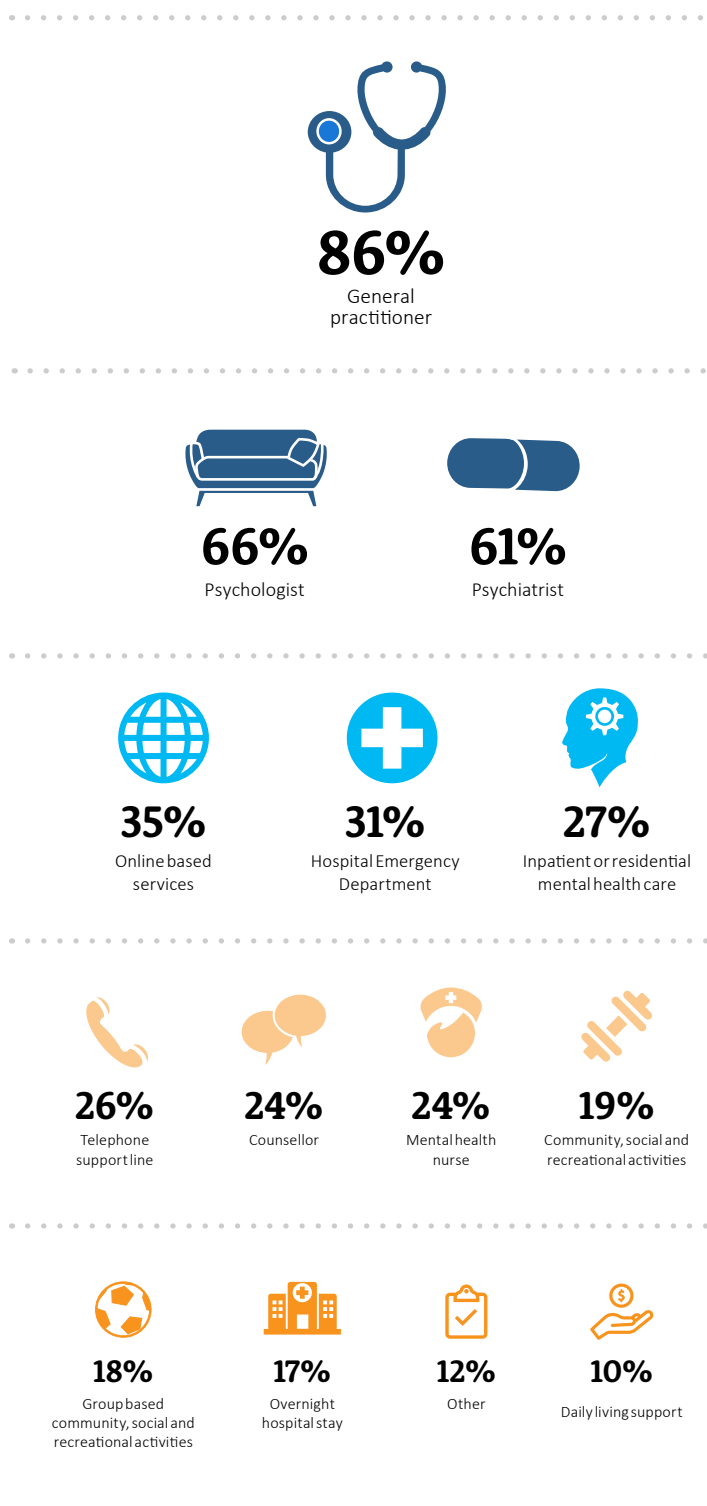
Priority Area 1 aims to establish a person-centred, holistic model of mental health care through improved planning, coordination and integration of services. In the context of the Fifth Plan, integration is concerned with building relationships between health-based organisations that are seeking similar aims to improve the outcomes and experiences of consumers and carers.

Integrated regional planning seeks to enhance consumer and carer experiences of mental health care through creating a service delivery system that:

- includes consumers and carers in shaping the way services are planned and delivered
- works in a coordinated way to holistically meet the needs of consumers
- provides personalised treatment, care and support, delivered by the right service, at the right place and at the right time
- is easier for consumers and carers to navigate.

To assess the impact of integrated regional planning and service delivery on the experiences of consumers and carers, the survey asked respondents a range of questions about their experiences of accessing mental health services over the past 12 months. Almost all respondents (97%) reported that they, or the person they care for, had accessed mental health services in the past 12 months. The most commonly-accessed service type was general practitioners (accessed by 86% of respondents), followed by psychologists (66%) and psychiatrists (61%). When respondents were asked how often services worked together to address their needs, or the needs of the person they cared for, only a small number of respondents reported that this 'always' occurred (8%). Over a third of respondents (37%) reported that they felt this had 'rarely' or 'never' happened. The majority of respondents reported that they felt this had occurred 'sometimes' (33%) or 'usually' (22%).

Figure 3:
Proportion of survey respondents accessing different service types



Compared to the integration of services, responses were more encouraging in relation to whether consumers had a say in the way their treatment was planned and delivered, with 15% of respondents reporting they 'always' had a say. Nonetheless, over a quarter of respondents (27%) reported that they, or the person they care for, 'rarely' or 'never' had a say in their care.

When asked whether care providers understood their needs, or the needs of the person they cared for, respondents most often reported that this 'sometimes' occurred (34%). Again, over a quarter of respondents (29%) reported that this 'rarely' or 'never' happened.

The majority of respondents (60%) provided additional comments on their experiences of care over the past 12 months. The comments revealed a range of concerns about barriers to accessing sufficient care and support. These barriers included the following:

- **Availability and adequacy of services:** Of the respondents who provided additional comments, more than 25% mentioned concerns about the availability and adequacy of services. Factors such as lack of services in their area, lengthy waiting times or insufficient hospital beds (leading to non-admission or premature discharge as a consequence) may result in services being unavailable to consumers at the time they were needed. It was also noted that, even when services were available, the level of support offered may not be sufficient to meet consumers' needs. This latter concern was typically raised in relation to people who experienced complex or chronic mental illness and required support over an extended period of time.
- **Affordability of services:** The cost of services was noted by 15% of respondents who provided additional comments. Factors highlighted by respondents included the limited number of mental health sessions covered by Medicare under the Better Access scheme, and the often high costs of mental health services that are not covered by Medicare. Affordability barriers were reported to be particularly significant for people who were on low incomes or unemployed (including people who were unable to work due to the severity of their mental illness).
- **Challenges in navigating the service system:** Comments regarding difficulty navigating the system were noted by 15% of respondents who provided additional comments. The examples provided by respondents of their experiences in accessing care suggest that the process of navigating the service system can be difficult, laborious or confusing at times. Respondents also provided examples of cases where mental health services had not communicated with each other well, or had not worked together effectively to meet consumers' needs.

Concerns were also raised about the degree to which services had included consumers and carers in the planning and delivery of care. Where these concerns were raised by consumers, key issues included: being treated in a dismissive manner, not having opportunities to participate in decision-making about their own care, and feeling as though they had not been 'heard' by service providers. Where these concerns were raised by carers, a key issue was that services had not adequately communicated with or involved them in care planning.

In contrast with these concerns, some respondents reported positive experiences of accessing mental health services, providing examples of services that had offered high quality, inclusive care and support. Positive comments were smaller in number than comments reporting deficiencies in services, with only around 10% of comments providing explicitly positive feedback on services. However, where positive feedback was provided, it tended to be highly positive (for example, some described services as 'excellent' or 'fantastic') and these comments clearly indicated that quality care had made a significant difference to respondents' mental health and wellbeing.

Overall, the survey results indicate that services have had varying levels of success in achieving integrated regional planning and service delivery. The positive experiences reported by some respondents suggest that some services are meeting the needs of consumers and carers. However, it is evident that further work is still required to ensure that all consumers and carers are able to access timely and adequate support services, can navigate the service system with ease and are involved in shaping the planning and delivery of their care.

Priority Area 2: Effective suicide prevention

Suicide prevention efforts must consider how services respond to people who have attempted suicide or are at risk of suicide. By providing intensive follow-up care during the days and weeks after a suicide attempt, or following discharge from inpatient psychiatric care, it is possible to reduce the risk of future suicide attempts. Priority Area 2 aims to reduce the incidence of suicide and improve support for people at risk of suicide.

Suicide prevention support also includes assistance for carers, families and communities affected by suicide or a suicide attempt. The Fifth Plan refers to this type of support as ‘postvention support’.

Under the Fifth Plan, effective suicide prevention aims to embed improvements into mental health services so people at risk of suicide are accessing a system that:

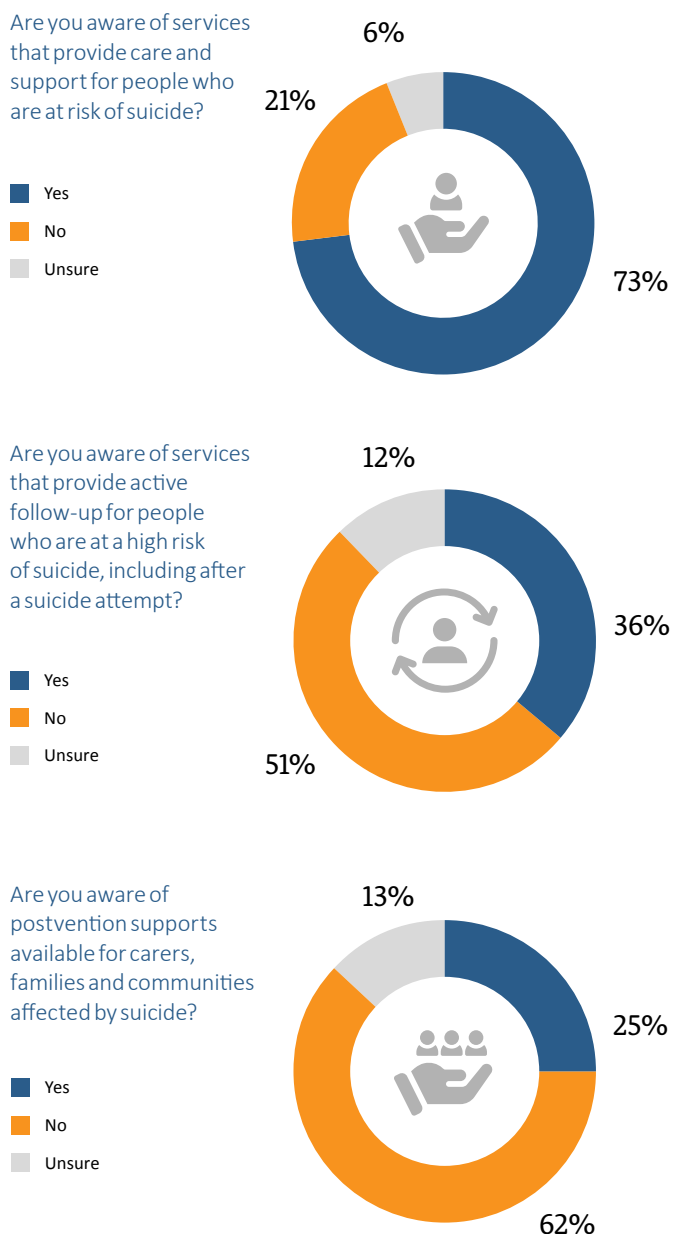
- ensures timely access to support and clearly articulates which services in their area are responsible for providing care and support
- actively follows up with people at a higher risk of suicide, including after a suicide attempt
- provides improved postvention supports to carers, families and communities affected by suicide, and support the carers of those at risk of suicide.

To assess consumers’ and carers’ experiences of accessing suicide prevention services, the survey asked respondents whether they were aware of these services in their local area. Most respondents (73%) reported that they were aware of services that provide care and support for people who are at risk of suicide. In comparison however, when asked if they were aware of active follow-up services for people at risk of suicide, half of respondents (51%) indicated that they were not aware of these services in their communities. Awareness of postvention supports for carers, families and communities affected by suicide was similar, with 62% of respondents indicating that they were not aware of these services in their local communities.

Additional comments on suicide prevention services were provided by 42% of respondents. Feedback relating to awareness of suicide prevention services was mixed. Some comments indicated that the respondent was aware of these services, often through their professional networks or through personal experience of accessing services. Other comments suggested that the respondent had limited or no awareness of suicide prevention services, or that there was a need for increased promotion of these services. The availability and sufficiency of suicide prevention services was consistently raised as an issue across the free text responses. Examples were provided of consumers attempting to access support through hospital emergency departments, but not being admitted or being discharged early due to the limited availability of beds. Particular concerns were raised about the lack of follow-up and postvention supports for people who had attempted suicide or experienced suicidal ideation (such as cases where people had been discharged from a service without adequate information or supported referrals).

The survey results suggest that there is still a significant need to enhance support for people at risk of suicide, their carers, families and communities, and to promote awareness of available services. Awareness of, and access to follow-up and postvention supports in particular appears to be an area in need of improvement.

Figure 4: Consumer and carer awareness of local suicide prevention services



Priority Area 3: **Coordinating treatment and supports for people with severe and complex mental illness**

The needs of people with severe and complex mental illness are not homogeneous. There are differences in the clinical and community-based supports that a person living with severe and complex mental illness may need over time. Despite the ongoing efforts of governments and service providers, many of these people still do not receive the supports that they need.

Priority Area 3 aims to ensure that people with severe and complex mental illness have access to the clinical and community services they need to live a more contributing life—a life where they can expect the same rights, opportunities and health as the wider community. It seeks to achieve this through improving the integration, quality and personalisation of care and support provided to people with severe and complex mental illness.

According to the Fifth Plan, 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 who have 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 issues with/dependence on drugs and alcohol
- people whose mental illness is adversely impacted by complex social factors such as homelessness or isolation from social or family supports, or who require assistance from multiple health and community services for day-to-day activities
- people with reoccurring acute mental health episodes that require frequent hospital care
- people who are at high risk of suicide.

Overall, a high proportion of survey respondents reporting that they live with or care for a person who lives severe and complex mental illness. The proportion of consumer respondents who reported they live with severe and complex mental illness was 66%. Among carer respondents, 79% reported that they care for someone living with a severe or complex mental illness. These respondents were then asked about their experiences in accessing clinical and non-clinical services over the past 12 months.

Clinical services were defined as those that provide assessment, diagnostic and treatment services for people with mental illness. Most respondents (70%) indicated that they, or the person they care for, had access to the clinical services they required over the past 12 months.

Non-clinical services were defined as those that focus on providing wellbeing support and assistance with a focus on recovery, to people who live with a mental illness. In contrast to clinical services, over half (56%) of respondents indicated that they, or the person they cared for, did not have access to the non-clinical services they required over the past 12 months.

Of those respondents who indicated that they, or the person they care for, live with a severe and complex mental illness, more than half (54%) provided additional comments about their experiences. Much of this feedback echoed the themes discussed in Priority Areas 1 and 2 regarding the adequacy and availability of services, with respondents noting concerns that they did not have access to the services they needed and/or required a higher level of support than was available to them.

Some of the barriers to accessing services identified by respondents included: the unavailability of services in particular geographic areas; service eligibility criteria that may exclude certain individuals, the cost of services, lengthy waiting times, challenges in navigating the service system, and difficulties in accessing support under the National Disability Insurance Scheme (NDIS). Challenges in accessing services that fall outside the health sector, but nonetheless play a critical role in supporting health and wellbeing (such as income support, employment services and adequate housing), were also highlighted.

The survey results indicate that many people living with severe and complex mental illness still face considerable challenges in accessing the supports they need to lead a contributing life. Access to non-clinical services in particular appears to be an area in need of improvement.

Priority Area 4: Improving Aboriginal and Torres Strait Islander mental health and suicide prevention

Aboriginal and Torres Strait Islander communities experience consistently higher rates of psychological distress, mental illness, substance use disorders and suicidality than non-Indigenous Australians, and face multiple barriers when accessing appropriate services and supports.

Most Aboriginal and Torres Strait Islander people want to be able to access services where the best possible mental health and social and emotional wellbeing strategies are integrated into a culturally capable model of health care. This approach needs an appropriate balance of clinical and culturally-informed mental health system responses, including access to traditional and cultural healing.

Priority Area 4 aims to improve responses to the mental health needs of Aboriginal and Torres Strait Islander people. It envisages that Aboriginal and Torres Strait Islander consumers and carers will:

- have both their clinical and their social and emotional wellbeing needs, and the needs of their community, addressed when care is planned and delivered
- be supported to navigate the health system
- receive culturally appropriate care
- receive timely access to support (including active follow-up support) if they are at risk of suicide.

A total of 24 respondents (4.4% of total respondents) reported that either they, or the person they care for, identify as Aboriginal and/or Torres Strait Islander. The survey asked these respondents a number of specific questions about their experiences of accessing mental health services over the past 12 months. It is worth noting the percentages discussed are based on small numbers, however the story they tell is important.

When asked how often providers considered all of their needs (including clinical, social and emotional wellbeing) and the needs of their community when planning and delivering mental health care in the last 12 months, the majority of respondents indicated that this 'rarely' (46%) or 'never' (21%) occurred. Only a small number of respondents reported that these needs were considered 'usually' (8%) or 'always' (8%).

Compared to how often the needs of individuals and the community were considered, responses were more positive in relation to how often Aboriginal and Torres Strait Islander people were provided with support to navigate the mental health system. Almost a quarter of respondents indicated that they, or the person they care for, 'usually' or 'always' received this support.

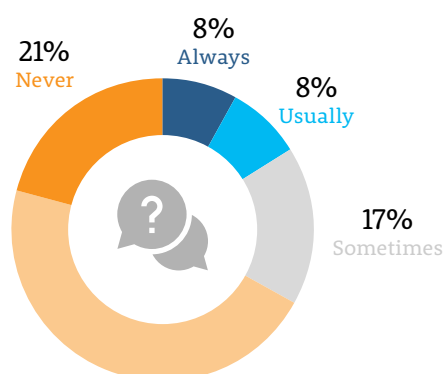
Whilst 25% of respondents indicated that they, or the person they care for, 'usually' received culturally appropriate care, another 25% indicated that they, or the person they care for, 'never' received culturally-appropriate care.

Eight of the 24 Aboriginal and Torres Strait Islander respondents (33%) provided additional comments about their experiences. These comments referred to various challenges in accessing culturally appropriate care, as well as difficulties in finding information about the services specifically available to them.

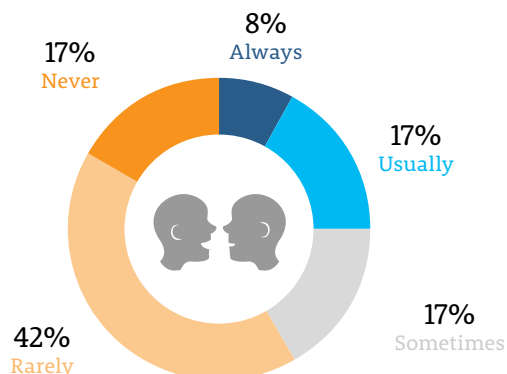
Without generalising the experiences of Aboriginal and Torres Strait Islander people on the basis of these 24 responses, it is worth noting that the majority of Aboriginal and Torres Strait Islander respondents reported that they 'rarely' or 'never' had all of their needs met, received support to navigate the system, or received culturally appropriate care. These findings suggest that there is still a need to improve targeted services and supports for Aboriginal and Torres Strait Islander consumers and carers.

Figure 5: Aboriginal and Torres Strait Islander mental health

How often did care providers consider all of consumer needs (including clinical, social and emotional wellbeing) when planning and delivering mental health care in the past 12 months?



How often did the consumer receive help or support to navigate the mental health system in the past 12 months?



Priority Area 5:

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

People living with mental illness have poorer physical health than other Australians, but their physical health needs are often overshadowed by their mental health condition. Physical health treatment rates for people living with mental illness are reported to be about 50% lower than for people with only a physical illness. This lower treatment rate reduces the diagnosis and treatment of physical conditions, which can prove fatal.

Priority Area 5 aims to ensure that people living with mental illness receive better screening for physical illness, and that interventions are provided early as part of a person-centred treatment and care plan. It envisages that people living with a mental illness will have:

- appropriate access to, and quality of, physical health care
- their physical health needs discussed and addressed
- better coordination of services at a local level that support consumers to address physical health care needs and improve their quality of life
- access to services at the regional level that are integrated, person-centred and easier to navigate.

The survey asked respondents about the extent to which their physical health needs, or the physical health needs of the person they care for, are being addressed. Respondents most commonly reported that, when seeking care for mental illness, physical health was discussed by their care provider 'sometimes' (32%).

However, over a third of respondents indicated that this 'rarely' (25%) or 'never' (13%) occurred. In addition, respondents indicated that they were mostly unaware (46%) or unsure (16%) of any coordination across services to address both physical and mental health needs.

Additional comments on physical health issues were provided by 41% of respondents. A key observation made within these comments was a divide between physical and mental health care services – with services tending to work separately from one another or operating in 'silos'. This was reported to result in poor coordination between, and integration of, mental health and physical health services.

Respondents also commented on the lack of consideration of physical health needs by some health care providers. Examples were provided of cases in which physical health needs had not been adequately considered when receiving mental health treatment, or had been overlooked by care providers due to the fact that the person receiving care had a history of mental illness.

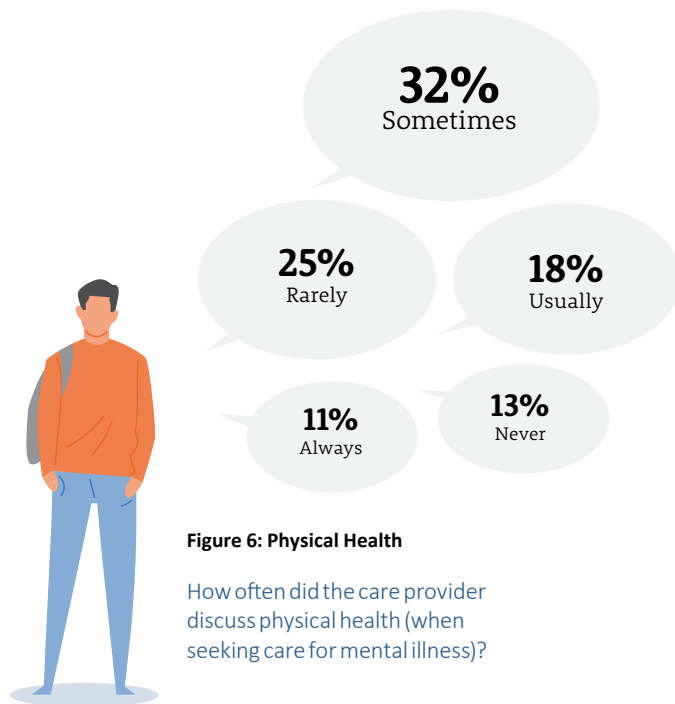
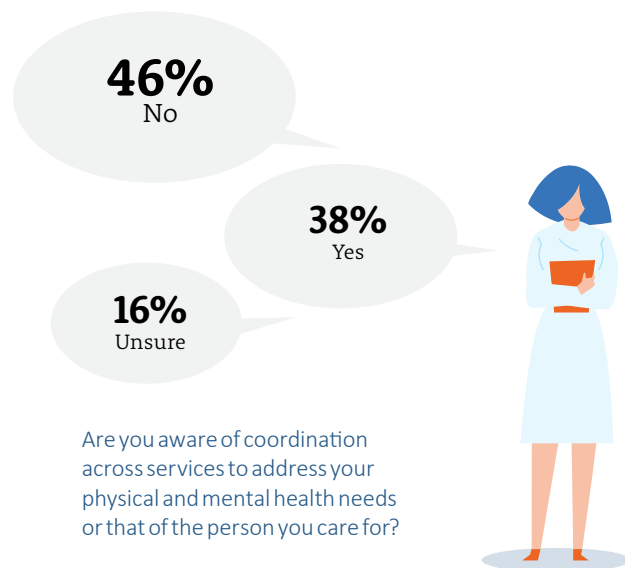


Figure 6: Physical Health

How often did the care provider discuss physical health (when seeking care for mental illness)?



Are you aware of coordination across services to address your physical and mental health needs or that of the person you care for?

Specific physical health challenges highlighted by respondents, that were related to or could be compounded by mental illness, included: access to affordable dental care, managing the side effects of certain medications (such as weight gain), and maintaining a healthy lifestyle (such as a healthy diet and adequate exercise).

The survey results suggest that, while the physical health needs of mental health consumers are considered by some care providers 'sometimes', there is a need to build towards more systematic consideration of these needs by all providers. In addition, there appears to be significant room for improvement in enhancing coordination between different health care services to ensure that physical and mental health needs are addressed holistically.

Priority Area 6: Reducing stigma and discrimination

Stigma against people living with mental illness is prevalent in Australia, with almost three out of four people with mental illness experiencing stigma. Discriminatory behaviours may include avoidance, withholding opportunities or withholding support.

Stigma and discrimination may discourage people from disclosing information regarding their mental health, decrease the likelihood of seeking support and create additional distress. This can result in exclusion and isolation, adversely affect personal relationships and affect opportunities for social interaction and community involvement.

People living with mental illness may experience stigma and discrimination by the health workforce as well as the broader community. This can have a significant impact on the wellbeing and recovery of people living with mental illness and people who experience suicidal behaviour, resulting in poorer outcomes. Stigma and discrimination by the health workforce may decrease the likelihood of seeking help, exacerbate psychological distress and decrease the likelihood of adhering to treatment.

Priority Area 6 aims to reduce the prevalence of stigma and discrimination experienced by people living with a mental illness, both when accessing services and within the community more broadly. It envisages a health system, and broader community, that supports consumers and carers in their recovery, better understands mental illness, and has improved attitudes towards people living with mental illness.

To assess consumers' and carers' experiences of discrimination, the survey asked respondents how often they, or the person they care for, had been treated differently due to their mental illness when accessing mental health services. Respondents most commonly reported they had been treated differently 'sometimes' (27%). Over a third of respondents indicated that they were 'usually' (24%) or 'always' (13%) treated differently in this context.

These findings were higher when respondents were asked how often they experienced stigma and discrimination in the broader community – such as at work, school, social gatherings or events. Respondents most commonly reported they were treated differently in the community due to their mental illness 'sometimes' (34%), and more than a third of respondents reported that they were 'usually' (27%) or 'always' (16%) treated differently in this context.

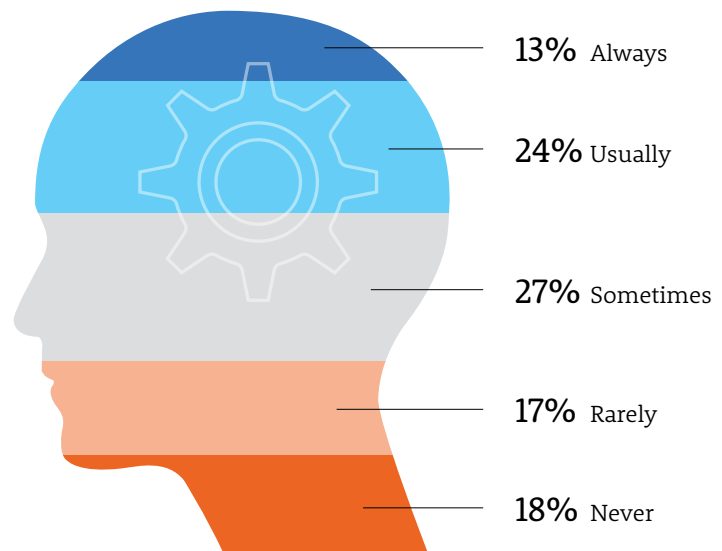
A significant number of respondents (46%) provided additional comments on their experiences of stigma and discrimination. These comments drew attention to the impacts of mental health stigma, such as discrimination in employment, social isolation, judgemental attitudes and a reluctance to disclose mental illness due to the fear of being treated less favourably.

The impacts of mental health stigma on health care were also highlighted. Respondents reported encountering negative, unhelpful or uncaring attitudes among health care providers, and indicated that such attitudes had affected the quality of the care they received. Similar comments were provided in response to free text questions in Priority Areas 1, 2, 3, 7 and 8.

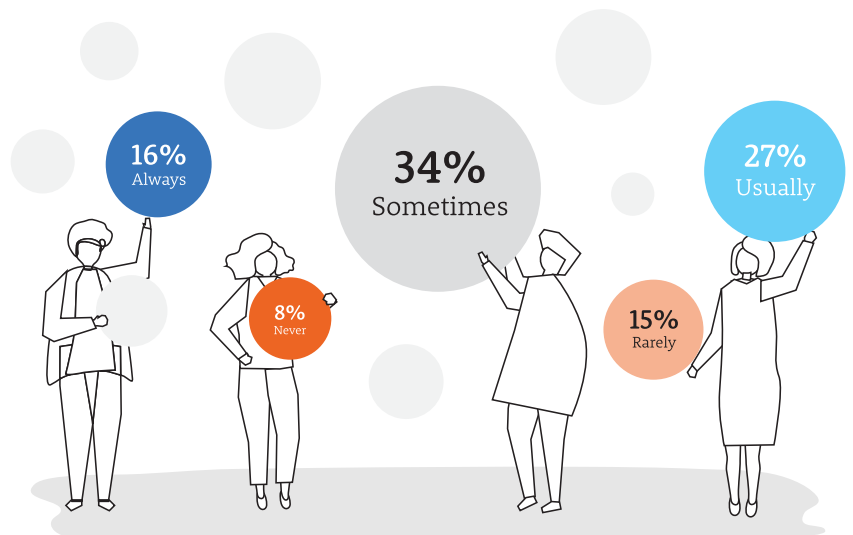
The survey results indicate that stigma and discrimination remain significant problems both within the health care sector and in the community more broadly.

Figure 7: Experiences of stigma and discrimination

How often were you treated differently, when accessing mental health services in the past 12 months?



How often were you treated differently by the community (at work, school, social gatherings or events etc) as a result of mental illness in the past 12 months?



Priority Area 7: **Making safety and quality central to mental health service delivery**

Safety and quality initiatives have been integral to mental health reform over the past three decades and the subject of significant collaboration between governments.

Priority Area 7 aims to ensure that the treatment, care and support provided to mental health consumers and carers is safe and of a high quality. A safe health system minimises or avoids potential or actual harm to consumers, and a quality health system provides the right care to consumers, improving health outcomes and optimising value.

In addition to improving safety and quality of services, Priority Area 7 also focuses on supporting informed decision-making by ensuring information about safety and quality is made available to consumers and carers.

To assess consumers' and carers' experiences of safety in mental health service delivery, the survey asked respondents about both their personal feelings of safety when accessing services and their level of access to information about safety in service delivery. Over a third (38%) of respondents reported that they, or the person they care for, 'usually' felt safe when accessing services. Encouragingly, consumers and carers responded they 'always' (23%) felt safe when accessing services more often than those who indicated that they 'never' felt safe (6%).

However, when asked how often information about safety had been made available to them, or the person they care for, over half of respondents reported that this 'rarely' (23%) or 'never' (31%) occurred. Only 10% of respondents indicated that they 'always' had information about safety available to them.

Of those who were provided with information about safety, over half reported that the information helped them, or the person they care for, to make informed decisions about mental health treatment 'sometimes' (25%), 'usually' (18%), or 'always' (13%). However, a higher proportion of respondents indicated that this information was 'rarely' or 'never' helpful (43%) than those who indicated it was 'usually' or 'always' helpful (31%).

Just over a quarter of respondents (27%) provided additional comments on safety in service delivery. These comments drew attention to a variety of safety issues, ranging from service provider expertise to the use of restrictive practices and involuntary treatment. Negative attitudes among service providers were also highlighted as a factor that had made people feel unsafe when accessing services.

The survey results suggest that some mental health services have been successful in ensuring safety in service delivery. However, there is still more work to be done to achieve safety across the board, and ensure that consumers and carers have access to adequate information about safety to support informed decision making.

Whilst the survey did not specifically ask respondents to rate the quality of the mental health services they access, issues relating to quality were raised by respondents in the free text comments relating to Priority Areas 1, 2, 3 and 8.

Priority Area 8:

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

The mental health system in Australia is complex and currently undergoing a period of reform. As the system transitions, it is critical that services are effective and continue to improve over time in response to changing needs and actual outcomes of service delivery.

Priority Area 8 aims to achieve targeted and collective action that supports enablers of a responsive and effective mental health system, now and into the future. This includes enhanced efforts in research, workforce development, adaptation to new information technology and improved data systems. It envisages a mental health system where services:

- continue to improve over time
- are more effective and accessible
- provide improved opportunities to translate the experiences of consumers and carers into helping others to work through their own experiences of recovery.

The survey asked respondents whether they had noticed improvements in the services that they, or the person they care for, had accessed in the past 12 months. More than two-thirds of respondents (69%) indicated that they had not noticed any improvements. Only 17% of respondents reported that they had noticed improvements, with the remaining respondents indicating that they were unsure.

The survey then asked respondents whether they, or the person they care for, had been invited or encouraged by care providers to share their experiences in order to improve service planning and delivery for others. Around two-thirds of respondents (65%) reported that this had not occurred, while 30% confirmed that they had been invited or encouraged to provide feedback (with the remaining respondents unsure).

Additional comments on service improvement were provided by 43% of respondents, highlighting areas of service delivery they regarded as being in need of improvement. For example, concerns were raised about the availability and adequacy of mental health services, with comments drawing attention to issues such as: current gaps in service provision, the need for additional Medicare subsidised mental health sessions, the importance of ensuring that services can be accessed in a timely manner, and the need for specialised services to address specific illnesses (such as eating disorders).

Other areas nominated as being in need of improvement included:

- building the skills and capacity of the mental health workforce, including through addressing staff shortages, enhancing expertise, recruiting peer workers, addressing negative attitudes and encouraging a person-centred approach to care
- engaging consumers and carers in mental health service delivery, both in making decisions about their own care and shaping the way services are delivered
- the quality of service delivery, with some respondents sharing their experiences of receiving unsatisfactory care or support
- the process of navigating the mental health system, such as the need for improved coordination between services.

The survey results suggest that there is a need for further work to ensure that the enablers of effective system performance and improvement (including engagement with consumers and carers, and the development of the mental health workforce) are in place.

Conclusion

The experiences of consumers and carers accessing the mental health system are critical for measuring the Fifth Plan's success. Implementation of the Fifth Plan reform will not be truly successful until it leads to meaningful change in how consumers and carers experience mental health care in Australia.

Understanding how implementation of the Fifth Plan is affecting the experiences of consumers and carers is a priority for the NMHC. This report provides baseline data for understanding consumer and carer experiences of accessing mental health care services in Australia. The consumer and carer experiences reported by survey respondents reinforce the importance of the Fifth Plan Priority Areas, and the need for continued action.

Mental health reform is a complex task and it will take time for consumers and carers to see the benefits of reform activities. The NMHC will conduct annual surveys of consumers and carers to understand the progressive impact of the Fifth Plan for consumers and carers over time. As it is the first year of the Fifth Plan implementation, responses to the 2019 survey provide a starting point from which to measure improvements.

It is important to note that the Fifth Plan was agreed to by all Health Ministers and therefore includes actions for governments and associated stakeholders to contribute to mental health and suicide prevention reform. For this reason, the Fifth Plan is limited in its ability to influence non-government, private, and community based organisations. The experiences reported by consumers and carers in this report covered a wide range of services across the mental health sector.

Consumers and carers frequently highlighted a number of common issues in their responses. These issues included the availability and adequacy of mental health services, the availability and cultural appropriateness of services for Aboriginal and Torres Strait Islander communities, the consideration of broader consumer needs in conjunction with their mental health needs, and experiences of stigma and discrimination. These issues mirror the direction, Priority Areas and actions of the Fifth Plan, and are expected to improve incrementally as implementation progresses.

Of particular concern to the NMHC however, were responses detailing Aboriginal and Torres Strait Islander consumer and carer experiences of care that were not culturally appropriate, and consumer and carer experiences of stigma and discrimination. The lack of awareness of suicide postvention support is also a significant concern, given its potential impact on ongoing suicide prevention efforts and community mental health. The NMHC will continue to monitor and report on the significant issues raised by consumers and carers, and encourages Fifth Plan stakeholders to keep them at the forefront of ongoing implementation efforts.

Future surveys will address current methodological limitations to ensure responses better represent the full breadth of the consumer and carer population. In future years, the NMHC will adapt the survey to be more accessible to culturally and linguistically diverse populations. Additionally, there is a need to ensure that the survey will be circulated more widely to populations underrepresented in this year's respondents (people who identify as male, and people aged 16-24 and 75 years or older). Annual independent monitoring and reporting on outcomes for consumers and carers, in addition to stakeholders named in the Fifth Plan Implementation Plan, allows the NMHC to more broadly assess whether the reform is successfully achieving its objectives. The results of the consumer and carer surveys can also support and guide the ongoing implementation of the Fifth Plan by its stakeholders.

The NMHC wishes to acknowledge and thank the consumers and carers who shared their experiences through the survey. Without these contributions, the NMHC would not be able to effectively monitor and report on the progress of the Fifth Plan – and we hope to capture the experiences of even more consumers and carers in future reports.

Acronyms

AIHW	Australian Institute of Health and Welfare
ATSIMHSPPRG	Aboriginal and Torres Strait Islander Mental Health and Suicide Prevention Project Reference Group
COAG	Council of Australian Governments
FPTAG	Fifth Plan Technical Advisory Group
MHISSC	Mental Health Information Strategy Standing Committee
NDIS	National Disability Insurance Scheme
NMHC	National Mental Health Commission
NMHCCF	National Mental Health Consumer and Carer Forum
NMHSQF	National Mental Health Safety and Quality Framework
PHN	Primary Health Network
SQPSC	Safety and Quality Partnership Standing Committee
SPPRG	Suicide Prevention Project Reference Group

Appendix

Fifth National Mental Health and Suicide Prevention Plan Consumer and Carer Survey

Overview

In order to truly understand the progress towards improving mental health and suicide prevention in Australia, the National Mental Health Commission (NMHC) is seeking feedback from mental health consumers and carers on how mental health services may or may not have improved in the past 12 months since implementation of the Fifth National Mental Health and Suicide Prevention Plan commenced.

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.

How we will use your responses

We appreciate your time and honesty. Your answers are valuable to the NMHC and will help us to monitor and report on efforts to improve mental health and suicide prevention in Australia. The NMHC 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 NMHC 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.

For further information on privacy, please see the NMHC's privacy policy <http://www.mentalhealthcommission.gov.au/privacy-policy.aspx>

Further information

You can read more about the Fifth National Mental Health and Suicide Prevention Plan here <http://www.mentalhealthcommission.gov.au/ourreports/fifth-national-mental-health-and-suicide-prevention-plan.aspx>

Introduction

The NMHC welcomes responses from consumers who have accessed mental health services in the past 12 months, as well as carers of consumers who have accessed mental health services in the past 12 months. To get started, we'd like to know if you identify as a **consumer** or **carer**.

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. 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**. This survey requires the respondent to identify as either a consumer or 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.

Are you answering this survey as a consumer of mental health care services or as a carer of someone who has a mental illness? (Required)

(Please select only one item)

- I am answering as a consumer
- I am answering as a carer

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.

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.

Have you, or the person you care for, accessed mental health services in the last 12 months?

(Please select only one item)

- Yes No Unsure

What types of mental health service have you, or the person you care for, accessed in the last 12 months? You can select as many services as you like:

(Please select all that apply)

- | | |
|---|---|
| <input type="radio"/> GP | <input type="radio"/> Overnight hospital stay |
| <input type="radio"/> Mental health nurse | <input type="radio"/> Inpatient or residential mental health care |
| <input type="radio"/> Psychiatrist | <input type="radio"/> Community, social and recreational activities |
| <input type="radio"/> Psychologist | <input type="radio"/> Group based community, social and recreational activities |
| <input type="radio"/> Counsellor | <input type="radio"/> Daily living support |
| <input type="radio"/> Telephone support line | <input type="radio"/> Other |
| <input type="radio"/> Online based services – such as websites, apps and programs, forums, web-based chat and email support | If other, please specify |
| <input type="radio"/> Hospital emergency department | _____ |
| | _____ |
| | _____ |

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

(Please select only one item)

- Yes No Sometimes
 Usually Always

How often did you feel as though you, or the person you care for, had a say in the way your/their treatment was planned and delivered in the past 12 months?

(Please select only one item)

- Yes No Sometimes
 Usually Always

In the past 12 months, how often have you felt as though care providers understood your needs, or the needs of the person you care for, and worked with you/them to meet these needs?

(Please select one item only)

- Yes No 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?

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 by selecting 'continue' at the bottom of the page.

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 13 11 14

Men's Line 1300 789 978

Kids Help Line 1800 55 1800

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'.

Before today, were you aware of any services available in your local 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 postvention supports 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 postvention supports?

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 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 and community services for day-to-day activities.
- People with reoccurring acute mental health episodes that require frequent 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, as well as carers of people living with a severe and complex mental illness to complete this section.

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

Do you, or 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 more 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, or the person you care for, have access to the clinical services you/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 you, or the person you care for, have access to the non-clinical services you/they required?

(Please select only one item)

Yes No

Is there anything else you'd like us to know about your experience accessing the services you, or the person you care for, require to live a more contributing life?

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, as well as carers of 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, or the person you care for, identify as:

(Please select only one item)

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

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

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

(Please select one item only)

- Never Rarely Sometimes
- Usually Always

In the past 12 months how often did you, or the person you care for, receive help or support to navigate 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)

- Yes No Sometimes
- Usually Always

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

(Please select only one item)

- Yes No Sometimes
- Usually Always

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

Section 5: Physical health

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

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

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

When seeking care for your mental illness, or that of the person you care for, how often does your care provider discuss your/their physical health?

(Please select only one item)

- Yes No Sometimes
- Usually Always

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

(Please select one item only)

- Yes No Unsure

Is there anything else you would like us to know about your experiences, or that of the person you care for, receiving care for your/their physical health?

Section 6: Stigma and discrimination

This section seeks to understand whether you, or the person you care for, 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/their experience in the community as well as within the healthcare system.

In the past 12 months, when accessing mental health services, how often have you felt as though you, or the person you care for, were treated differently as a result of your/their mental illness?

(Please select one item only)

- Never Rarely Sometimes
 Usually Always

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

(Please select one item only)

- Never Rarely Sometimes
 Usually Always

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

Section 7: Safety in mental health care

This section is about the **safety** of the mental health treatment, care or support you, or the person you care for, accessed in the past 12 months.

In the past 12 months how often have you, or the person you care for, felt safe when accessing mental health treatment, care or support?

(Please select one item only)

- Never Rarely Sometimes
 Usually Always

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

(Please select one item only)

- Never Rarely Sometimes
 Usually Always

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

(Please select one item only)

- Never Rarely Sometimes
 Usually Always Not applicable

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

Section 8: Improvements in the mental health care system

This section seeks to understand whether you think improvements have been made to mental health treatment, 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 accessing mental health services, for yourself or the person you care for, may have stayed the same, or gotten worse.

Have you noticed improvements in the services you, or the person you care for, accessed in the past 12 months?

(Please select only one item)

- Yes No Unsure

Have you, or the person you care for, been invited or encouraged by mental health care providers to share your experiences in order to 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?

Demographics

To finish up, we'd like to know a little bit about you. This set of questions captures key demographic information to help us understand how consumers and carers are experiencing mental health treatment, care and support across Australia.

What is your age? (Required)

(Please select only one item)

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

What is the postcode where you live? (Required)

(Please select only one item)

Which state or territory do you live in? (Required)

(Please select only one item)

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

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

(Please select only one item)

- Female Male
- Other – trans/transgender male
- Other – trans/transgender female
- Other – gender diverse/non-binary
- 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

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