

# Consumer and carer experience

of NSW mental health services during the 2020 COVID-19 pandemic



## Acknowledgments

We gratefully acknowledge the support of members of the YES and CES advisory committees and colleagues at BEING, Mental Health Carers NSW, the NSW Ministry of Health Mental Health Branch and the Bureau of Health Information. Many thanks to the NSW Health staff for ensuring people continued to have opportunities to give feedback during COVID-19. Most importantly, thank you to the many consumers and carers who took the time and effort to give feedback about their experience.

## Report produced by

InforMH  
System Information and Analytics Branch  
NSW Ministry of Health

Published February 2021

Please note that there is the potential for minor revisions of data in this report.

Please check with InforMH for any amendments.

[INFORMH@health.nsw.gov.au](mailto:INFORMH@health.nsw.gov.au)

SHPN (SIA) 210064  
ISBN: 978-1-76081-588-2



# Contents

Summary	2
Introduction	4
Methods	5
Limitations and cautions	5
1: Consumer experience of community mental health care	6
COVID-19 impacts on community mental health service delivery	6
Responses to COVID-specific questions	6
Responses to core YES questions	9
What changed most in community experiences?	10
Which groups reported the biggest change in experience in the community?	12
2: Consumer experience of hospital mental health care	14
COVID-19 impact on hospital mental health service delivery	14
Responses to COVID-specific questions	15
Responses to core YES questions	16
What changed most in hospital experiences?	17
Which groups reported the biggest change in experience in hospital?	19
3: Carer experience of community mental health care	21
COVID-19 impacts on community mental health service delivery	21
Responses to COVID-specific questions	21
Responses to core CES questions	23
4: Carer experience of hospital mental health care	25
COVID-19 impacts on hospital mental health service delivery	25
Responses to COVID-specific questions	25
Responses to core CES questions	27
Appendix 1. Technical information	29
Appendix 2. Your Experience of Service questionnaire	34
Appendix 3. YES domains	38
Appendix 4. Mental Health Carer Experience Survey	39

# Summary

This report uses the Your Experience of Service (YES) questionnaire and the Mental Health Carer Experience Survey (CES) to explore consumer and carer experiences of NSW mental health services during the height of the COVID-19 restrictions in 2020.

## Supplementary questions about experience since COVID-19 were added to YES and CES

To help understand the impact of COVID-19 on consumer and carer experience, NSW Health added three additional questions to the YES and CES questionnaires. Consumers and carers were asked for their views about the impacts of COVID-19 on service provision, frequency of contact and changes in overall experience. To further explore any changes in experience, responses to the core YES and CES questions from the 2020 COVID-19 period were compared with the same time in 2019. Free-text responses were also searched for any mention of COVID-19 related terms such as *pandemic*, *virus*, *COVID* or *corona*.

## In community mental health care, the amount of contact with the service had a larger impact than the mode of contact

Much discussion of community-based health care has focused on the impact of delivering care by phone or video. The responses to the COVID-specific questions suggest that the amount of care might be more important than the method. When consumers reported that they had more service contact during COVID, 60 per cent reported that the experience of care was more positive, and only 9 per cent reported that care was less positive. By contrast, when consumers reported that their contact had reduced during COVID, more than a third (34%) reported a less positive experience.

## Early in the pandemic, consumer experience in the community was more positive compared to the same period in 2019

There is no evidence that consumer experience worsened during COVID-19 and some evidence that aspects of care were better when compared to the same time last year. This is consistent with the responses to the COVID-specific questions which found that slightly more people reported their experience was more positive (27%) rather than less positive (17%).

## Many community consumers reported that services were more flexible, with more frequent contact and better access to staff

Experience related to family and carer involvement, access to doctors or psychiatrists and information about the service improved the most. The shift to telehealth was also reflected, with many consumers in the community reporting that the convenience of the location improved.

## Men, Aboriginal and/or Torres Strait Islanders and consumers aged 25–64 years reported more positive experiences in the community

Male consumers frequently mentioned that home visits, more frequent contact via telehealth and services being more flexible were the best things about the service. Aboriginal and/or Torres Strait Islander consumers rated their access to peer support, activities that suited them and staff more positively. For consumers aged 25–64, flexibility was a common theme with people mentioning home visits and quick and convenient access to services via email and phone.

## Hospital consumers reported diverse experiences during COVID-19

Of the consumers who responded to the COVID-specific questions, 34 per cent reported a more positive experience and 26 per cent had a less positive experience. This emphasises that COVID-19 may have had diverse impacts on consumers of hospital services. Overall experience did not change significantly during COVID-19 when compared with the same period in 2019. Consumers reported less opportunities for family and carer involvement and less activities in hospital.

## Younger people in hospital have been more impacted by COVID-19 than other age groups

Although not statistically significant, the largest decline in reported experience in hospital was for people aged less than 18 years. On average, 64 per cent rated their experience as excellent or very good from April to June 2020. This was a drop of 11 per cent from the same period in 2019. Young people in hospital frequently mentioned that their experience would have been better if there was more leave, fewer restrictions on visitors and more activities and social interaction.

## Many carers reported less contact with services throughout COVID-19

Around 61 per cent of carers in the community and 52 per cent of carers in hospital stated that they had less contact with services throughout COVID-19. Despite social distancing restrictions limiting face-to-face contact, around 19 per cent of carers in the community and 32 per cent of carers in hospital reported that none of their contact with the service was by phone or online.

## How often carers were contacted mattered more than how they were contacted

Where carers had more contact with the service during COVID-19 they were more likely to report a more positive experience (43% in community and 50% in hospital). In hospital settings, almost half of the carers (46%) who had no change in the amount of contact with the service reported a less positive experience. This feedback suggests that throughout COVID-19, carers needed more contact than they were previously provided in order to remain connected and involved in their loved one's care.

## For carers in the community, regular communication and being involved had a big impact on carer experience

Some carers commented that regular updates were especially helpful during COVID-19, as it provided reassurance and kept them involved in the care of their family member, partner or friend. Carer experience was varied throughout this time, but the benefit of regular communication and involvement was a common theme.

## Visiting restrictions had a big impact on carer experience of hospital services

Most of the free-text comments that related to COVID-19 mentioned visiting restrictions. Many carers commented that this was one of the most difficult aspects of COVID-19. Although many carers commented that they understood the need for these restrictions, carers felt less connected with their loved one and reported fewer opportunities to be involved.

# What changed in services?

In the first 2 months of COVID-19 in NSW there was a decrease in



Emergency department presentations

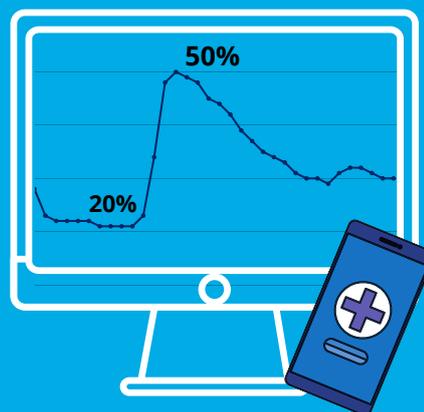


Community clients



Hospital admissions

The proportion of community mental health care provided by telehealth more than doubled from March to April 2020



## What did people say about their experience?



### Community

Consumer experience was more positive compared to 2019

- Experience improved most for
- Men
  - Aboriginal consumers
  - Consumers aged 25–64 years
- There was...
- Increased flexibility
  - Better access to staff
  - More frequent contact via telehealth

More contact with the service = more positive carer experience

- Most carers reported less contact with services
- Regular communication had the biggest impact on carer experience of services



### Hospital

Consumer experience in hospital didn't change significantly

- Experience was less positive for young consumers (less than 18 years)
- They said there...
- was less leave
  - were fewer visitors
  - were fewer activities
  - was less social interaction

Carer experience was varied

- Visiting restrictions affected carer experience in hospital settings
- Carers needed more frequent contact during the COVID-19 restrictions to remain connected and involved

# Introduction

This report examines how consumers' and carers' experience of NSW mental health services changed during the early stages of the COVID-19 pandemic.

COVID-19 (SARS-CoV-2) was declared a pandemic by the World Health Organization in March 2020. The pandemic has had a major impact on individuals, on community social and economic wellbeing, and on the delivery of health care services. At this stage, Australia has been fortunate in not experiencing high rates of community infection, hospitalisation or death in comparison to some other countries. However, the pandemic has still had a significant effect on Australian health services, including mental health services.

Health systems throughout Australia have experienced two related trends in response to COVID: (i) a short-term reduction in demand in the first three months of the pandemic and (ii) a rapid shift towards telehealth and virtual health care. During the early stages of the pandemic, NSW Health implemented many strategies to reduce the risk of acquiring or spreading COVID-19, and to prepare emergency care capacity in case of rapidly increasing need. Help-seeking may also have changed at that time, with some people being less likely to seek care for non-urgent conditions. Together these contributed to substantial reductions across the spectrum of health care in NSW, including primary care contacts, cancer screening, ambulance callouts, emergency department presentations, emergency hospital admissions and planned surgery.<sup>1</sup>

NSW Mental Health services have experienced similar changes. Emergency contacts, community referrals and hospital admissions reduced substantially during the first 2 months of the pandemic. The proportion of community mental health care delivered by phone or video more than doubled from March to April 2020, to nearly 50 per cent of total community care hours. Mental health admissions reduced, and inpatient units introduced changes aimed at protecting units from the introduction of COVID-19, including reducing day leave and access by visitors

It is important to understand how these service changes affected people's experience of mental health care. Some of these service changes may have improved the experience of care, for example making it more accessible or convenient. However, some changes have the potential to make people feel less connected, safe or empowered. Individuals are likely to have experienced these changes differently, so it is also important to assess how the experience of care has changed for different groups of consumers and carers.

There is currently very little evidence about the impact of COVID-19 on consumer experiences of health care. Research has primarily focused on the provision of telehealth in general health settings. Devin et al. (2020) found that patient satisfaction ratings did not change despite a rapid shift towards telemedicine and providers being inexperienced with virtual care.<sup>2</sup>

Locke et al. (2020) found that most participants assessed telephone appointments positively, however they found that people had diverse experiences, with some preferring face-to-face and others preferring telephone appointments. The distance required to travel for face-to-face appointments impacted people's preference, with telephone appointments being preferred by people who had a longer distance to travel.<sup>3</sup>

Only one published study has examined consumer views in an Australian mental health setting. Kavoor and colleagues<sup>4</sup> surveyed consumers in a regional public acute mental health setting. They found in the context of concerns about COVID-19, that consumers preferred telephone consultations over face-to-face contact.

<sup>1</sup> Sutherland K, Chessman J, Zhao J, Sara G, Shetty A, Smith S, Went A, Dyson S, Levesque J-F (2020). Impact of COVID-19 on healthcare activity in NSW, Australia. *Public Health Research & Practice* 30(4);3042030. DOI: 10.17061/phrp304030

<sup>2</sup> Mann DM, Chen, J, Chunara R, Testa PA, Nov O (2020). COVID-19 transforms health care through telemedicine: evidence from the field. *Journal of the American Medical Informatics Association*, 27(7): 1132-5. <https://doi.org/10.1093/jamia/ocaa072>

<sup>3</sup> Locke J, Herschorn S, Neu S, et al. (2020) Patients' perspective of telephone visits during the COVID-19 pandemic, *Canadian Urological Association Journal*, 14(9), E402-6. <http://dx.doi.org/10.5489/cuaj.6758>

<sup>4</sup> Kavoor AR, Chakravarthy K. and John T (2020). Remote consultations in the era of COVID-19 pandemic: preliminary experience in a regional Australian public acute mental health care setting. *Asian Journal of Psychiatry*, 51, 102074. <https://doi.org/10.1016/j.ajp.2020.102074>

## Methods

NSW Health has established a process of continuous collection and monthly reporting of consumer and carer experience. Each month around 2,000 YES questionnaires are returned from both inpatient and community mental health services. These provide feedback from a large and reasonably representative group of NSW service consumers, including good rates of return from all ages and genders, Aboriginal and/or Torres Strait Islander consumers, and people receiving both voluntary and involuntary care (Your Experience of Service. What consumers say about NSW Mental Health Services 2019–2020, p7).<sup>5</sup>

The CES has been implemented more recently in NSW to gather feedback about carers' experiences of care. For information about the development and validation of these tools see Appendix 1. Both YES and CES can be used to compare experience during the 2020 COVID-19 period with experience at the same time in 2019.

If YES and CES results changed in 2019 and 2020, how do we know whether those changes were due to COVID-19 and associated service changes? The most reliable method may be to ask the consumer or carer themselves for their view of what has changed. Therefore, NSW Health added three supplementary questions to YES and CES questionnaires, asking consumers and carers for their views about the impacts of COVID-19 on service provision, frequency of contact and changes in overall experience.

The supplementary questions added to the YES and CES questionnaires were:

***How much of your care/contact with this service was by phone or online (e.g. videoconferencing such as Skype/Pexip)?***

***How has COVID-19 changed the amount of contact you have had with the mental health service (including face to face and phone/online)?***

***How has your experience of care with this service changed during COVID-19?***

See Appendix 1 for a list of response options to these questions. The COVID-specific questions were made available in April 2020, so data is not available for questionnaires returned in the early weeks of the pandemic (March–April 2020). COVID-specific questions were first added to online YES and CES tools, then included as a separate page offered along with the paper questionnaires.

In addition to exploring the COVID-specific questions and change across the core questions, free-text responses were searched for any mention of COVID-19 related terms such as *pandemic, virus, COVID or corona*. These were then grouped into themes depending on their content.

The findings in this report are based on the number of questionnaires shown in Table 1.

## Limitations and cautions

Before exploring the findings, it is important to acknowledge the following cautions. The supplementary COVID specific questions have not been psychometrically validated. In order to obtain feedback quickly throughout the COVID-19 period, these questions were temporarily added to questionnaires. The following groups provided feedback on the questions prior to release; the YES and CES advisory committees, Being, Mental Health Carers NSW and the Official Visitors Program.

Some groups may be under represented, and a selection bias may be present for those who completed the COVID-specific questions. For example, those who had better access to the online questionnaires were able to more easily complete the COVID-specific questions. See Appendix 1 for details of which consumers completed the COVID-specific questions. The COVID-specific questions were better able to capture the impacts of COVID-19 for people who had previous care or contact with the service. Some changes across questions and different groups of consumers or carers are small and may arise due to chance variation rather than a true impact of COVID-19.

The CES was implemented in NSW public mental health services in July 2018. As the CES is at a much earlier stage in its use in NSW compared to YES, we must be cautious when interpreting the feedback. Due to the low number of carer surveys returned in early 2019, a meaningful comparison with 2020 data is difficult and any changes are unlikely to reflect the true impacts of the pandemic.

Thematic analysis of the free-text comments occurred manually and did not utilise qualitative analysis software.

Table 1. Number of YES and CES questionnaires returned

Questionnaire	Questionnaires January–September 2019	Questionnaires January–September 2020	Supplementary questions May–September 2020
<b>CONSUMER EXPERIENCE (YES)</b>			
Community	5,687	4,482	829
Hospital	12,460	12,431	261
Total	18,147	16,913	1090
<b>CARER EXPERIENCE (CES)</b>			
Community	515	1,090	188
Hospital	799	1,221	68
Total	1,314	2,311	256

<sup>5</sup> <https://www.health.nsw.gov.au/mentalhealth/participation/Pages/partners.aspx>

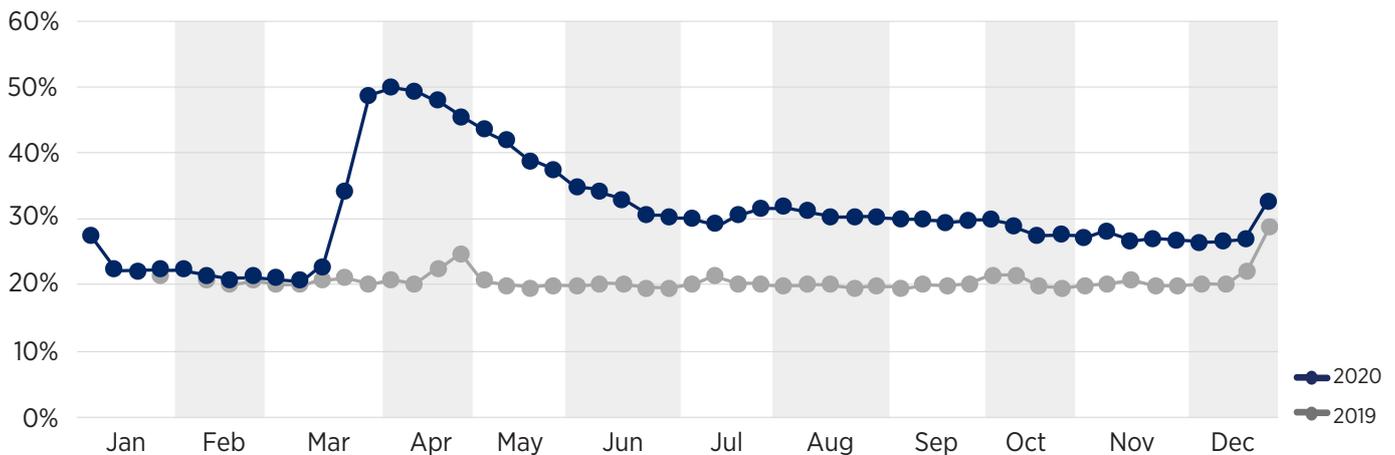
# 1: Consumer experience of community mental health care

## COVID-19 impact on community mental health service delivery

NSW community mental health care changed rapidly during the first months of the COVID-19 pandemic (March–April 2020). There was a brief but substantial reduction in the amount of community care provided. From early March to mid-April 2020 the number of new community mental health clients seen each week dropped by 48 per cent and the number of clinical care hours provided reduced by 36 per cent. By late May, these figures had returned to pre-COVID-19 levels and since then have either remained at or exceeded the 2019 baseline.

A more lasting change has been a rapid shift to telehealth. The proportion of clinical care hours provided by telehealth increased from around 20 per cent to 50 per cent in the final two weeks of March 2020. This proportion has reduced gradually, but remains well above 2019 levels.

Figure 1. Proportion of community hours provided by phone or telehealth



## Responses to COVID-specific questions

There were 829 responses to YES COVID-specific questions in the community from May to September 2020. Most of these were completed online (93%). A broad range of consumers responded to the COVID-specific questions. This range was similar to the consumers who completed full YES questionnaires. While we do not yet know which consumers accessed services throughout this period, we do know that in the past YES returns have been broadly representative of consumers accessing services.

People with brief contact with services (less than 24 hours) are typically under represented. The COVID-specific questions were consistent with this. Older consumers (65+ years) were also slightly under represented in responding to these questions. This group also utilised the online questionnaire less throughout this period compared with other age groups.

### My experience would have been better if...

I prefer face-to-face contact. However considering we are in a time of isolation because of COVID-19 there isn't much that can be done



**More than one-third of community consumers reported less contact with services during COVID-19**

Disruptions to services might be expected to result in less care for many consumers. However, responses to the YES COVID questions suggest that people’s experience was more diverse than this. More than one-third (38%) of respondents reported a reduction in the amount of contact with services, however 20 per cent reported an increase. The remainder (40%) reported no change in the amount of care.

The substantial shift to telepsychiatry was reflected in the responses: over three quarters of consumers reported that some or all of their care was provided by phone or online. More than half of consumers reported that their experience of care had not changed during COVID-19. However, some people (27%) reported that their experience was more positive, and slightly fewer (17%) reported that their experience was less positive.

*Figure 2. Responses to supplementary COVID questions, community consumers*



**The amount of contact with the service had the most impact on consumer experience**

Much discussion of community-based health care has focused on the impact of delivering care by phone or online. The responses to the YES-COVID questions suggest that the amount of care might be more important than the method. When consumers reported that they had had more service contact during COVID-19, the majority (60%) reported that their experience of care was more positive, while only 9 per cent reported that care was less positive.

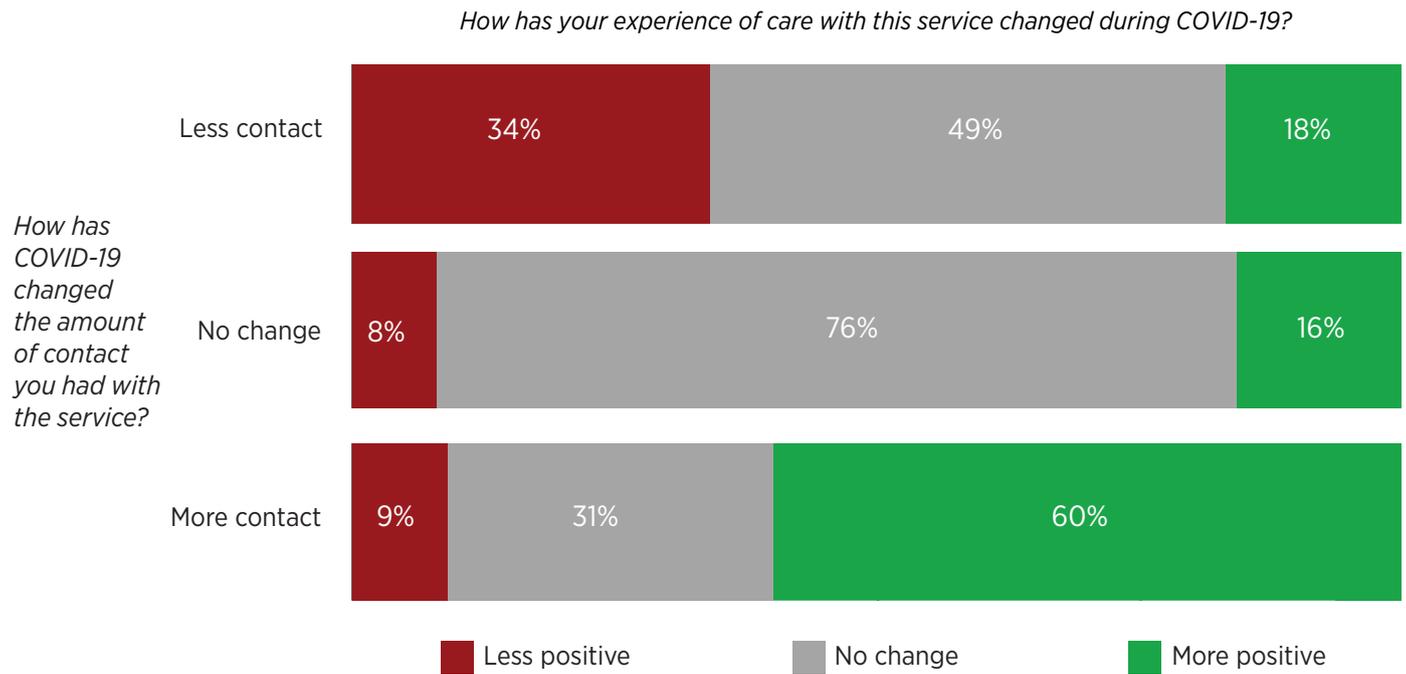
By contrast, when consumers reported that their contact had reduced during COVID-19, more than a third (34%) reported a less positive experience. Interestingly, even when care reduced in quantity, around 18 per cent of consumers reported a more positive experience. This may be for several reasons. For example, the amount of care provided may have been more appropriate for the consumers’ needs, or the care provided more effective or meaningful to the consumer, despite the reduction in its frequency.

**The best things about this service were...**

My case manager came to see me during the COVID-19 restrictions. Thank you!



Figure 3. How the frequency of contact impacted overall experience, community consumers



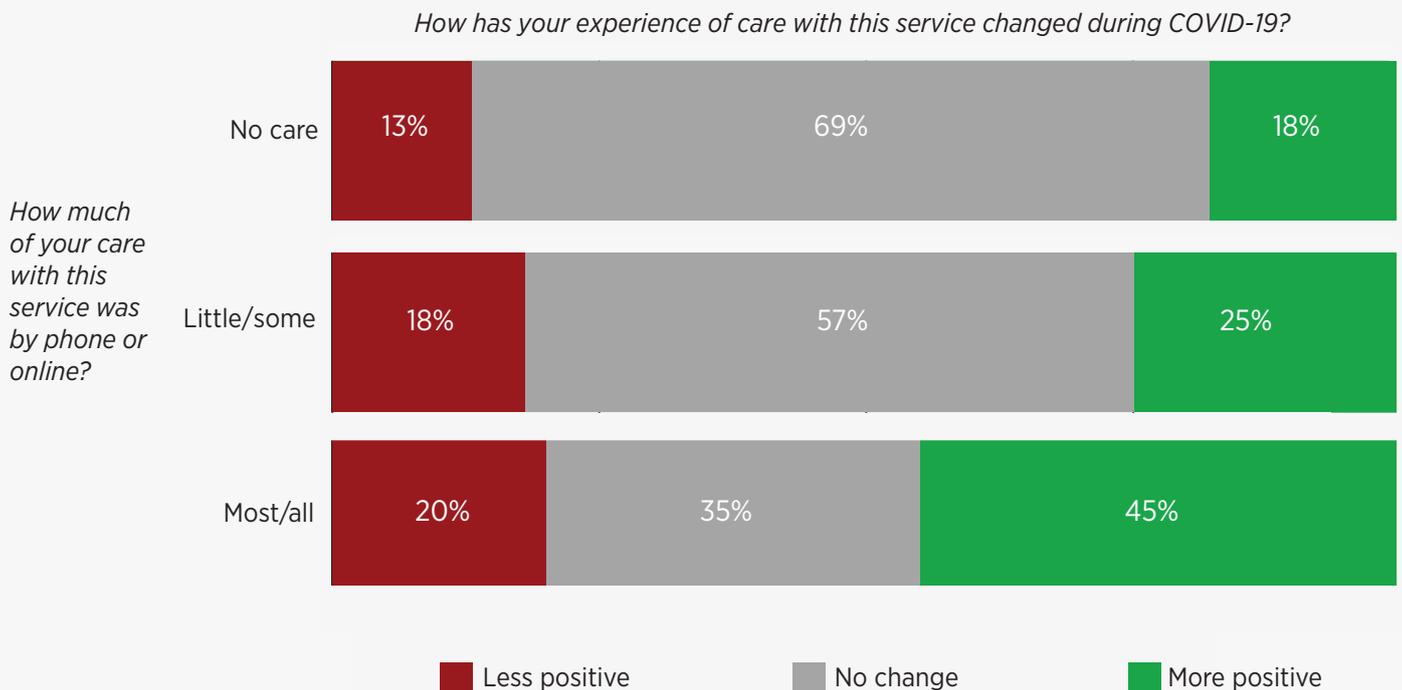
**Receiving more care by phone or video was polarising: both positive and negative experiences were reported**

It appeared that the more care that was provided by phone or video, the more polarised respondents were in their view of its impact on their experience of care. Of consumers receiving most or all of their care by telehealth, many (45%) reported that this change improved their experience, while 20 per cent reported a less positive overall experience.

Some of these differences may be due to differences in the quantity of care. For example, if telehealth allowed more frequent contact this may have contributed to a more positive experience. When exploring the free-text comments, people’s responses were influenced by many considerations.

Many consumers expressed a preference for face-to-face contact where this was available, and many commented that although this was not always in the services’ control it still had an impact on their experience.

Figure 4. How the method of contact impacted overall experience, community consumers



## Responses to core YES questions

Next we examined responses to the core YES questions, comparing January to September 2019 (see figure 5) with the same period in 2020. This allows comparison of a larger number of questionnaires. From April to June 2020, 1,153 YES questionnaires were returned from community services. This was a drop of 50 per cent from the same period in 2019 (2,279 YES questionnaires returned April–June 2019).

To test whether changes from 2019 to 2020 may have been caused by a different mix of consumers, we calculated the proportion of YES responses from different groups and compared this over the two time periods (see Appendix 1). In 2020 there was a small decrease in the proportion of responses from people aged Under 18 years and consumers who had brief contact with the service (less than 24 hours). Otherwise, the proportion of responses across groups remained similar to the previous year.

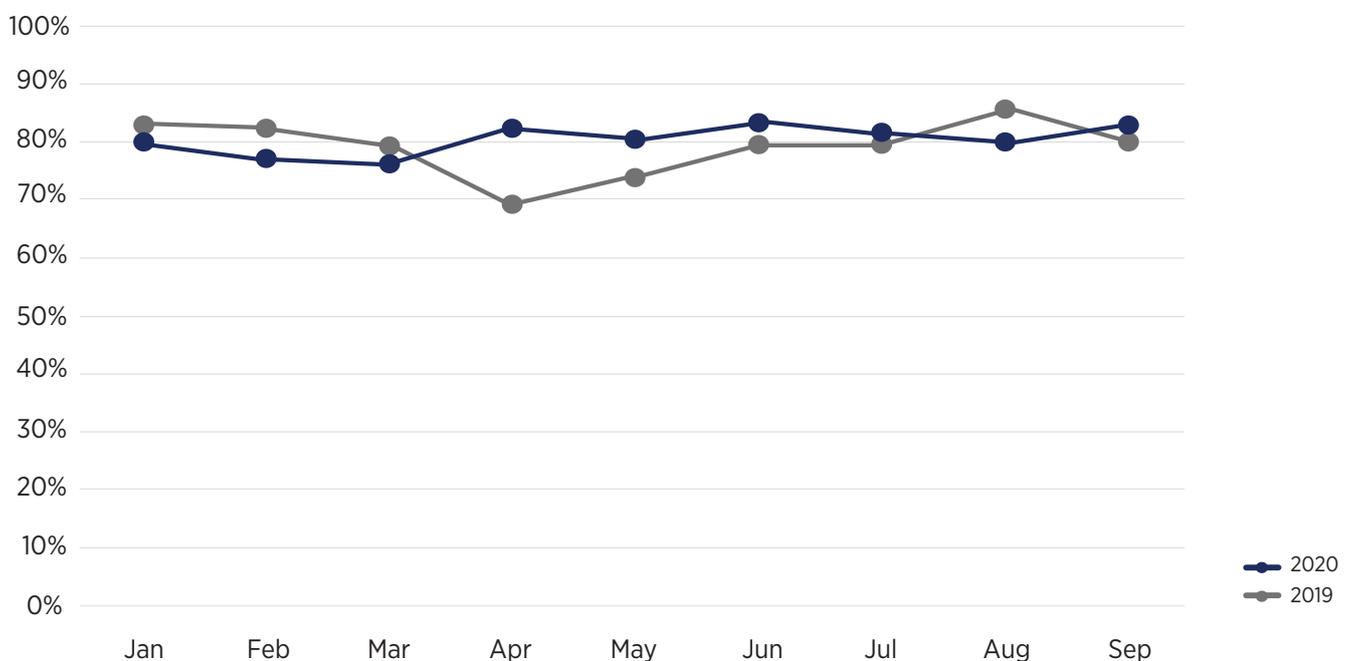
### Early in the pandemic, overall experience in the community was more positive compared to the same period in 2019

From April to June 2020 slightly more consumers reported an excellent or very good overall experience compared with the same time in 2019. It is important to note that there was also a decrease in the percentage of consumers reporting an excellent or very good experience in April 2019. A specific cause was not identified for this drop and it is possibly the result of chance variation.

The April to June 2020 period marks the height of COVID-19 restrictions in NSW. It is also important to note that in April 2020 the amount of community care provided by phone or telehealth increased to around 50 per cent.

Our strong conclusion is that there is no evidence that consumer experience worsened during COVID-19 and some evidence that aspects of care were better when compared to the same time in 2019. This is consistent with the responses to the COVID-specific questions which found that slightly more people reported their experience was more positive rather than less positive.

Figure 5. Percentage of consumers reporting an excellent or very good experience in the community



### Comparisons will focus on the April–June period

Comparisons of different time periods were explored to help understand the impacts of COVID-19 on consumers' experience. As the largest changes were noted during the height of the COVID-19 restrictions in NSW (April–June 2020) this period will be focused on in this report and compared to the same period in 2019.

## What changed most in community experiences?

To help understand the possible causes for the change in overall experience, responses to each of the YES questions were compared with the same period in 2019.

Figure 6 on page 11 shows the average rating of each YES question throughout the first three quarters of the year. Interestingly, during the January to March quarter, most questions were rated less positively compared to 2019.

However in April to June this reversed, and all questions (except for Q17 (You had opportunities for your family and carers to be involved in your treatment and care if you wanted) and Q23 (The effect the service had on your hopefulness for the future) were rated significantly more positively than in 2019.

Following the easing of restrictions, we then see a return to baseline rating levels in the July to September quarter with very little difference between the 2019 and 2020 ratings. During the April to June quarter the following changes were highlighted:

### **Opportunities for family and carer involvement improved (Q10, Q17)**

YES questions related to the involvement of family members and carers were rated better throughout the first few months of COVID-19 compared to the same period in 2019. When consumers mentioned 'family' in the free text comments throughout this period they often said the best thing about the service was that it supported the whole family and staff were caring towards family members.

### **Consumers reported better access to their doctor or psychiatrist (Q8)**

In the free-text comments, many people mentioned that the best thing about the service throughout this time was access to their doctor or psychiatrist when needed. Consumers specifically mentioned the availability of frequent telehealth appointments and follow ups with doctors as well as home visits.

### **More consumers recalled being provided information about the service (Q18)**

Throughout the COVID-19 pandemic in 2020, services have needed to trial different ways of providing information to consumers. Despite reports that some services removed paper resources and materials for infection control reasons, there was an increase in the number of consumers who recalled receiving information about the service. This may suggest that services were able to find other ways to provide information throughout this period to meet the needs of consumers.

### **The convenience of the location (Q22) improved**

Throughout this period a higher proportion of community support was provided via phone or telehealth and may explain the improved experience reported by respondents to Q22. In the free-text comments many consumers also mentioned the greater availability of home visits as having a positive impact on their experience.

Figure 6. Average rating of YES questions in the community comparing 2019 to 2020



○ 2019 ● 2020

## Which groups reported the biggest change in experience in the community?

After understanding what has changed, the next step was to understand whose experience was impacted most by COVID-19 and why. The YES questionnaire includes several demographic questions where consumers can provide information about themselves and the care they were received while remaining anonymous.

To understand whose experience changed most we used these demographic questions and looked at the percentage of consumers reporting an excellent or very good experience. This was then compared to the same period in 2019 as shown in Figure 7.

Testing of significant differences was conducted using 95 per cent confidence intervals. Differences were assessed as statistically significant where the 95 per cent confidence intervals for proportions did not overlap. YES questions are grouped into domains depending on what the measure (see Appendix 3). Where a group had a significant change in experience, we then explored the domains, individual questions and free-text responses to understand possible causes for this change.

### Males in the community reported improvements across all YES questions

Around 15 per cent more male consumers rated their experience as excellent or very good in April to June 2020 compared with the same period in 2019. This is the largest increase of any group. Male consumers reported improvement across all YES questions with the largest increase in the Participation and Individuality domains (14% increase).

Using the free-text comments, it appeared that many men preferred the flexibility of home visits, and that access to telehealth meant they could have more frequent contact with services. Men also reported that services were more flexible and there was greater opportunity for family and carer involvement.

### The experience of Aboriginal and/or Torres Strait Islander consumers significantly improved

In April–June the proportion of Aboriginal and/or Torres Strait Islander consumers reporting an excellent experience increased from 61 per cent in 2019 to 73 per cent in 2020 (12% increase). The largest changes were in the Making a difference domain (20% increase in excellent or very good).

Aboriginal and/or Torres Strait Islander consumers reported the largest improvements in their access to peer support (Q20) and activities that suited them (Q16). The accessibility of staff also improved with improved ratings for Q7 (Staff made an effort to see you when you wanted) and Q8 (You had access to your treating doctor or psychiatrist when you needed).

### Consumers aged 25–64 years reported a significant improvement

On average, 9 per cent more consumers between 25–64 years reported an excellent or very good experience during the COVID-19 period in 2020. The largest increases were in the domains of Individuality and Participation (9% increase).

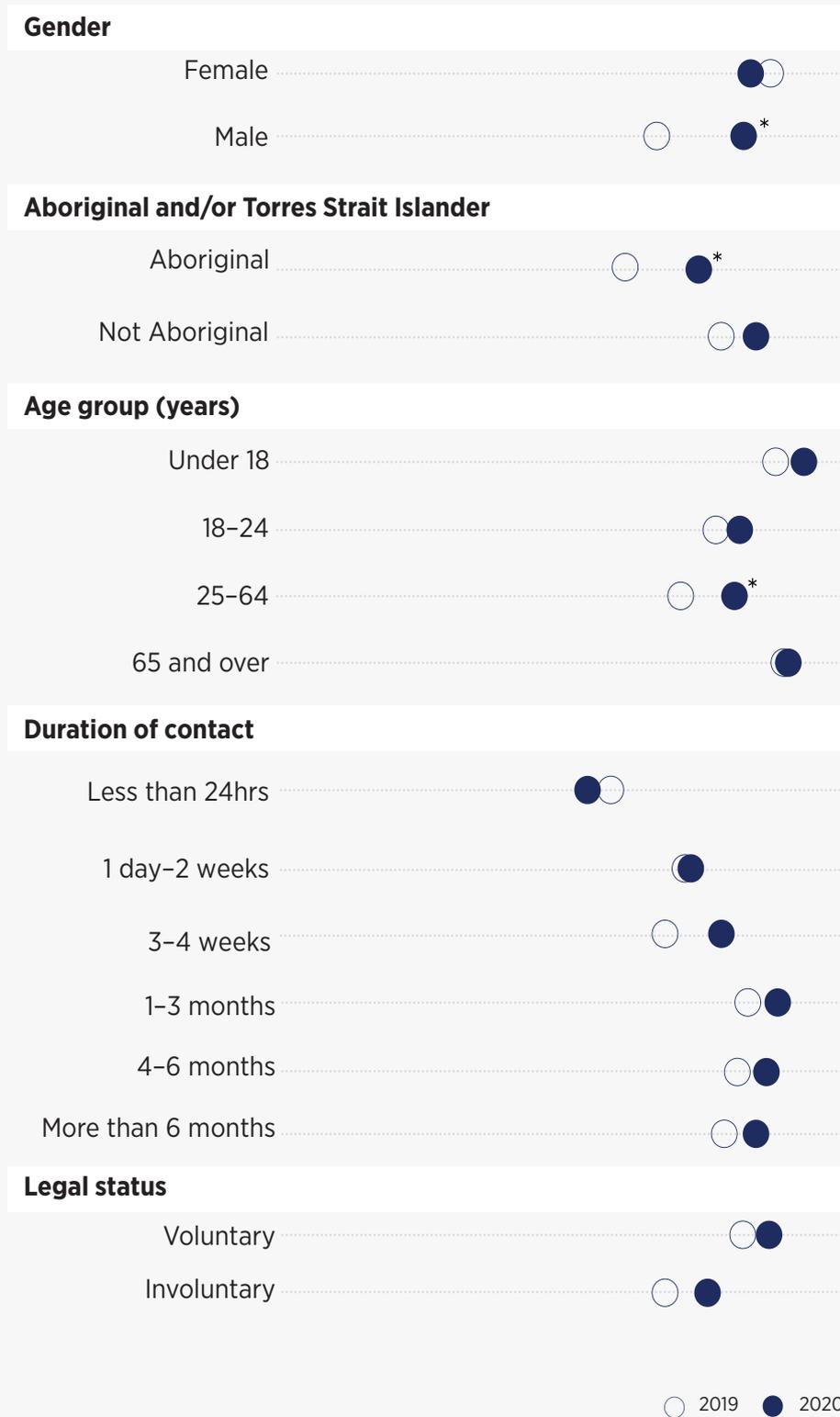
In the free-text comments, many people listed convenience and flexibility of access to services as things that made their experience better. Home visits were mentioned frequently, as was quick and convenient access to services via email and phone. As those aged 25 to 64 represent the majority of the workforce this could suggest that convenience and flexibility are particularly important to consumers who are employed.



#### My experience would have been better if...

It was difficult seeing the psychiatrist via video due to COVID-19. Having in person appointments would have been better

Figure 7. Percentage of consumers who rated their overall experience as excellent or very good in the community from April to June



\*Statistically significant difference.

Testing of significant differences was conducted using 95 per cent confidence intervals. For more information please see Appendix 1.

The best things about this service were...

Great follow up by my case manager and peer support worker. They've been really supportive during the corona virus



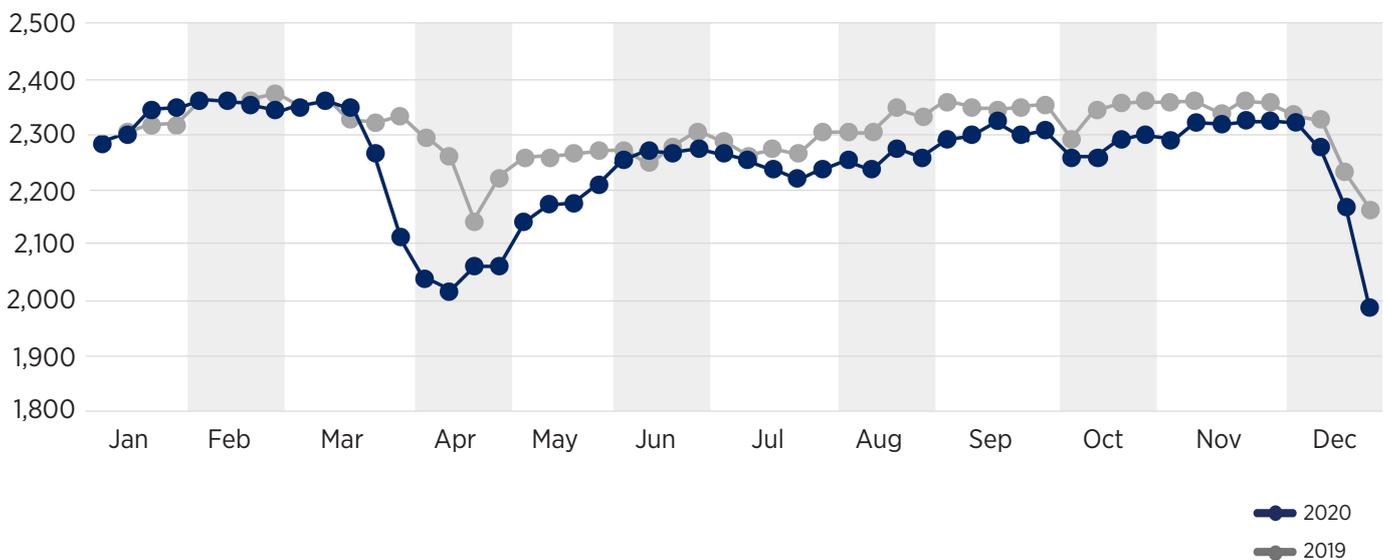
# 2: Consumer experience of hospital mental health care

## COVID-19 impact on hospital mental health service delivery

From late March 2020, changes were seen in the demand for hospital mental health services and how they were provided. Over a one-month period from late March to late April, admissions to acute units dropped (15%) and the number of people occupying mental health beds decreased (14%) (see Figure 8).

To prevent the introduction or spread of COVID-19, restrictions were placed on visitors and across many Local Health Districts and Specialty Health Networks, limitations were placed on consumers being able to leave the hospital. With these restrictions there were less opportunities for consumers to participate in groups, activities and social interaction.

Figure 8. Weekly average of occupied mental health beds in 2020 compared to 2019



**My experience would have been better if...**

A full explanation of all services, rules and activities on day one. COVID didn't help but that's no ones fault



## Responses to COVID-specific questions

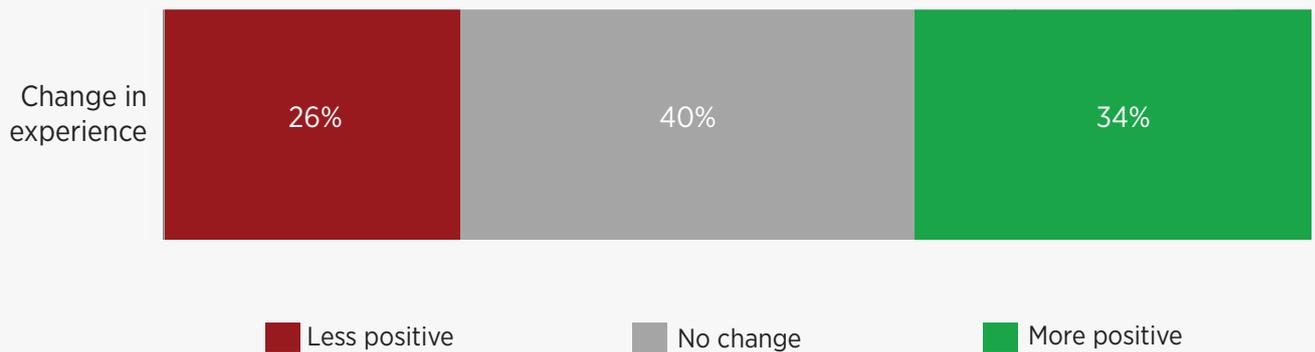
There were 262 responses to YES COVID-specific questions in hospital services from May to September 2020. Of these around 63 per cent were completed online. A broad range of consumers responded to the COVID-specific questions. Aboriginal and/or Torres Strait Islander consumers and people with brief contact (less than 24 hours) were slightly under represented.

### There were a range of experiences in hospital during COVID-19

Of the consumers who responded to the COVID-specific questions, 34 per cent reported a more positive experience and 26 per cent had a less positive experience. This emphasises that COVID-19 may have had diverse impacts on consumers of hospital services.

The COVID-specific questions related to the amount of care provided online and consumers' contact with the service, so were less applicable for hospital consumers. Therefore, to understand why some consumers had a more or less positive experience in hospital we focused on feedback from the core YES questionnaire and free-text comments.

Figure 9. How has your experience of care with this service changed during COVID-19, hospital consumers



## Responses to core YES questions

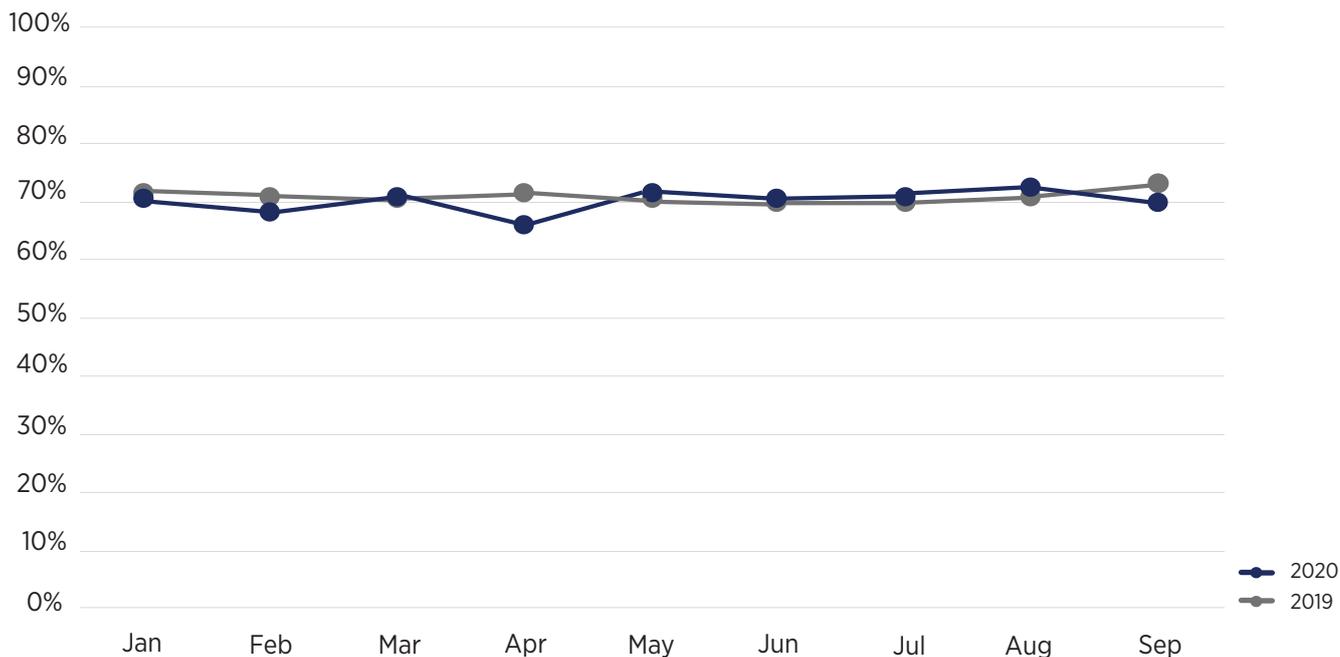
### Overall experience in hospital has not changed significantly during COVID-19

In April 2020, there was a slight decrease in the proportion of consumers reporting an excellent or very good experience. Otherwise, the overall experience each month has remained similar to that of 2019.

The decline in reported experience in April 2020 was not the result of a drop in returns (1,181 returns in April 2019, 1,240 returns in April 2020) or a different mix of consumers. The proportion of consumers responding was compared across the two time periods and is available in Appendix 1.

To align with the analysis of community mental health services and explore the possible changes in hospital experience, April to June 2020 was compared with the same period in 2019. There were 3,308 YES questionnaires returned from April to June 2020 and 4,199 for the same period in 2019.

Figure 10. Percentage of consumers reporting an excellent or very good experience in hospital



#### My experience would have been better if...

There was a video chat system for personal connection during COVID-19

#### The best things about this service were...

The true compassion of all the staff (especially during this time of strain on the hospital sector to assist with COVID-19)





## What changed most in hospital experiences?

Although overall experience did not change significantly during COVID-19 it is still important to explore if any particular areas of experience were impacted.

Figure 11 shows the average rating of each YES question throughout the first three quarters of the year and compared this to the same period in 2019. This highlights that there was very little change when comparing 2019 to 2020 across all three quarters.

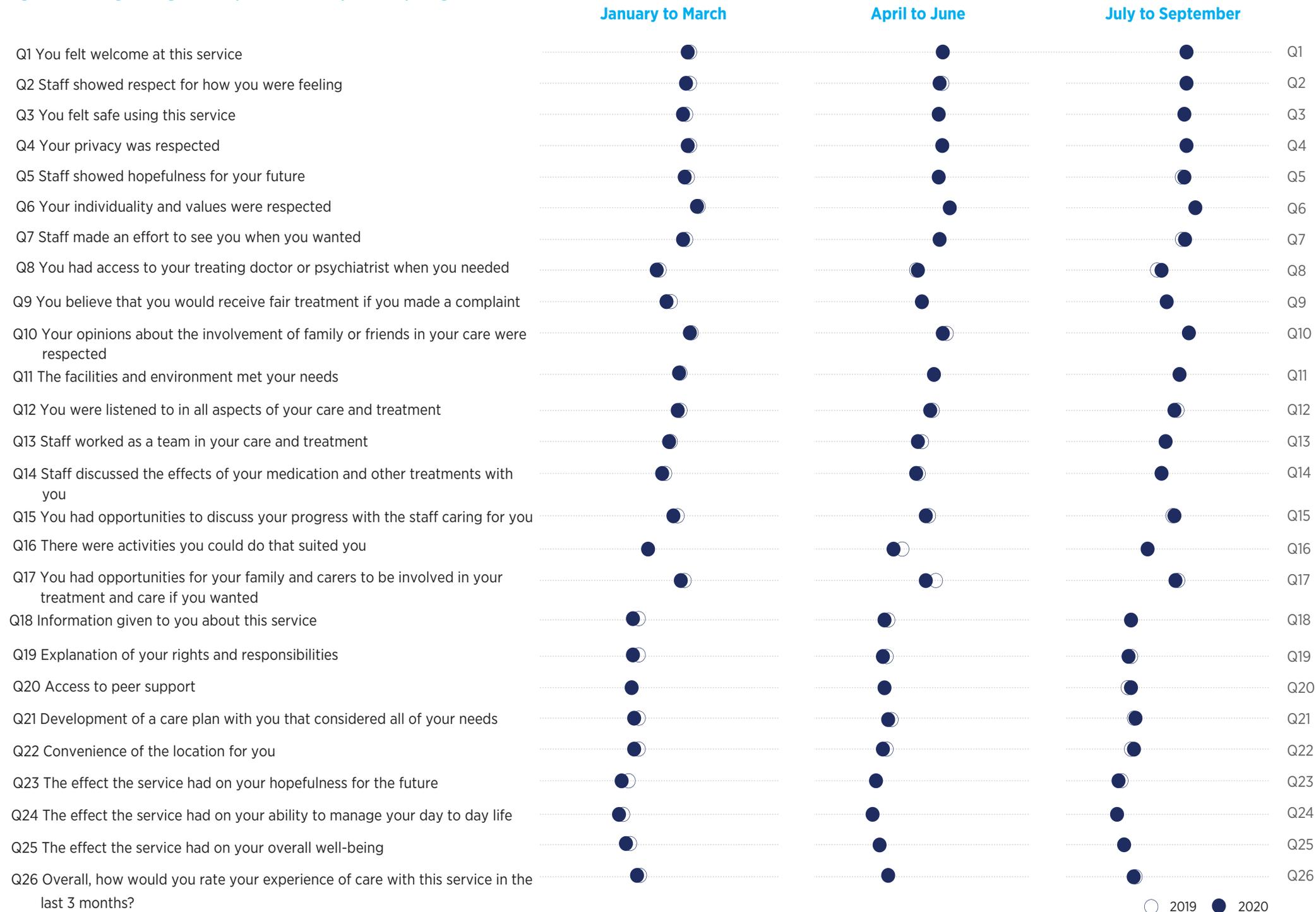
### **There were fewer opportunities for family and carers to be involved**

Within the April–June quarter, there were two questions that stood out as having a less positive experience. While differences were small, questions related to the involvement of family and carers (Q10, Q17) were rated slightly lower than in 2019. In the free-text comments, consumers frequently mentioned that their experience would have been better if their family members were able to visit more and if communication between staff and family was clearer and more consistent.

### **There were fewer activities for consumers to engage in**

Consumers rated Q16 (There were activities you could do that suited you) lower than in 2019. In the free-text comments, consumers stated that COVID-19 impacted on their freedom, ability to leave or have visitors and opportunities to participate in activities. Prior to COVID-19 people would often state that the best thing about the service was the range of activities available and opportunities to engage with other consumers and staff socially.

Figure 11. Average rating of YES questions in hospital comparing 2019 to 2020



○ 2019 ● 2020

## Which groups reported the biggest change in experience in hospital?

While overall experience for all hospital consumers did not change significantly during COVID-19, it is important to know whether some groups of consumers reported a better or worse experience.

To test for change we looked at the percentage of consumers reporting an excellent or very good experience from April to June 2020 and compared this to the same period in 2019 (see Figure 12).

In hospital settings there were no statistically significant changes for different groups of consumers. Differences were assessed as statistically significant where the 95 per cent confidence intervals for proportions did not overlap. Whether a difference is significant is influenced by the average score and the number of responses.

### People under 18 years old in hospital have been more impacted by COVID-19 than other age groups

How young people accessed services changed throughout this period. From April 2020 there was an increase in the number of young people presenting to emergency departments for mental health and self-harm or suicidal ideation. This upward trend has continued throughout the remainder of 2020 and is greater than any other age group. There was an increase in the number of acute admissions for young people which has also continued to increase throughout the second half of 2020.

On average, 64 per cent of people aged less than 18 years reported their experience as excellent or very good from April to June 2020. This was a drop of 11 per cent from the same period in 2019. Throughout COVID-19, young people have accessed mental health services more than ever before. However, due to restrictions put in place to protect consumers from the virus, many of the things young people find most positive about services have been limited.

In the free-text comments, young people often mentioned that their experience would have been better if there was more leave, activities and social interaction. Prior to COVID-19, young people would often comment that the best thing about the service was making friends and participating in groups and activities.

#### The best things about this service were...

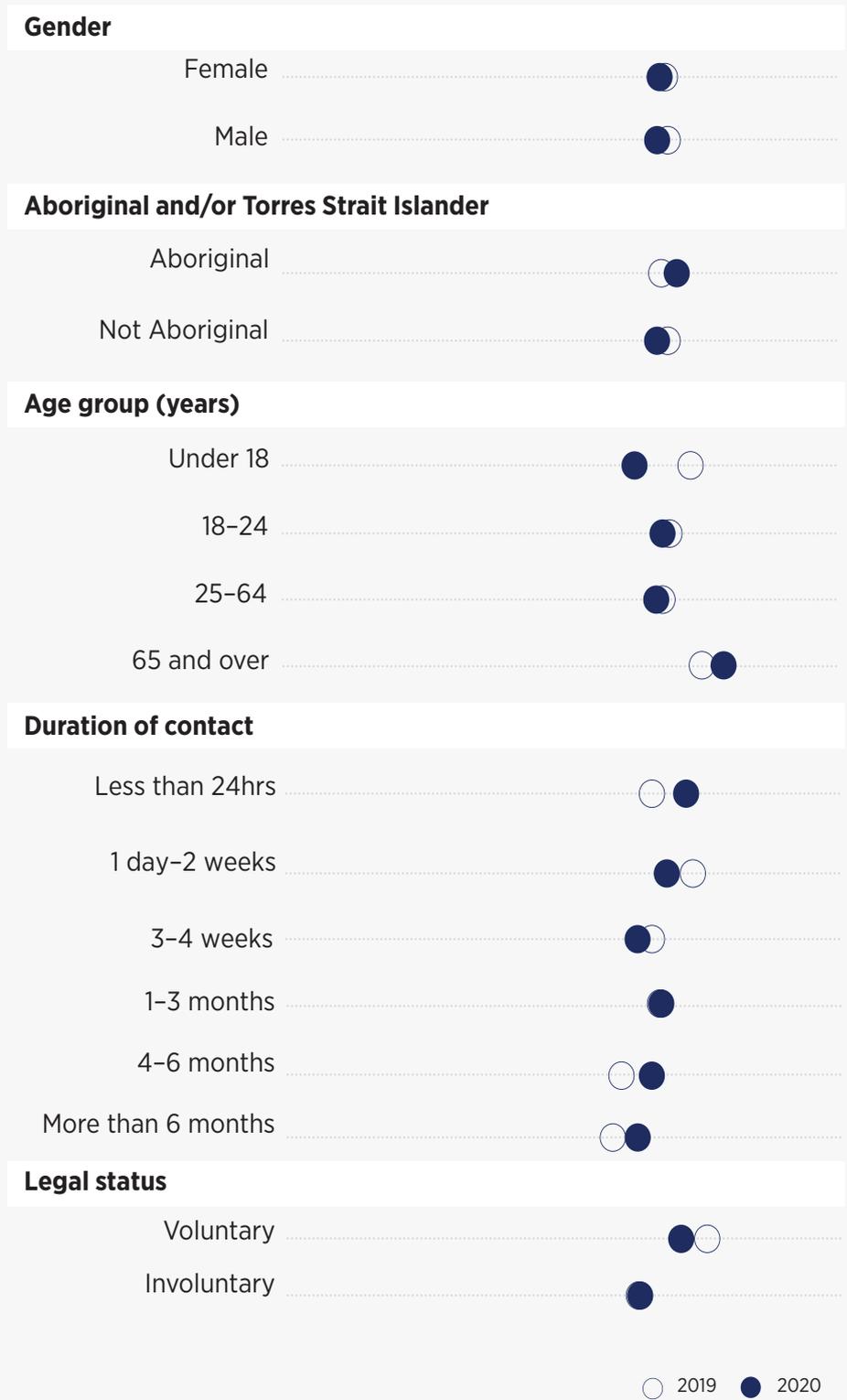
The staff are amazing and do their best within the COVID guidelines

#### My experience would have been better if...

COVID-19 wasn't happening  
i.e. Group work, talking, socialising, walking, physical activities



Figure 12. Percentage of consumers who rated their overall experience as excellent or very good in hospital from April to June



\*Statistically significant difference. Testing of significant differences was conducted using 95 per cent confidence intervals. For more information please see Appendix 1.

**The best things about this service were...**  
 The staff. Isolation and protection during the corona virus



# 3: Carer experience of community mental health care

## COVID-19 impacts on community mental health service delivery

Earlier in this report we explored some of the changes that occurred in community mental health services as a result of COVID-19 (page 6). While the data available can provide some insight into how consumers accessed services throughout this time, it is less clear how COVID-19 impacted family members and carers. The CES survey provides a perspective that is often missing in other data sources and can help provide some information about carer experience during COVID-19. The full text of the CES is in Appendix 4.

The CES was implemented in NSW public mental health services in July 2018. As the CES is at a much earlier stage in its use in NSW compared to YES, we must be cautious when interpreting the feedback.

Due to the low number of carer surveys returned in early 2019, a meaningful comparison with 2020 data is difficult, and any changes are unlikely to reflect the true impacts of the pandemic.

For this reason, this section will focus primarily on the COVID-specific CES questions and the free-text responses. Using this method, we can be confident that the carer experiences reflected are related to COVID-19 and not the result of change in survey returns or a different mix of carers.

## Responses to COVID-specific questions

There were 191 responses to the CES COVID-specific questions in the community from May to September 2020. Of these, most were completed online (84%) and can be linked to full CES surveys. Although we do not have accurate data about the family members and carers of people accessing community mental health services, the CES can provide some insight into which carers are providing feedback.

More feedback was received from female carers (73%), people aged 35 to 74 years (90%) and people who have been caring for over 10 years (37%). Despite 10 per cent of consumers in the community identifying as Aboriginal and/or Torres Strait Islander people, only 3 per cent of CES COVID-specific

returns were from Aboriginal and/or Torres Strait Islander carers. Overall, most people reported that they were caring for their child (64%) or spouse (14%) and had been engaged with the service for over one month (93%). While this tells us that a range of carers are providing feedback, it is not known if this is a representative sample of the carers of people accessing mental health services.

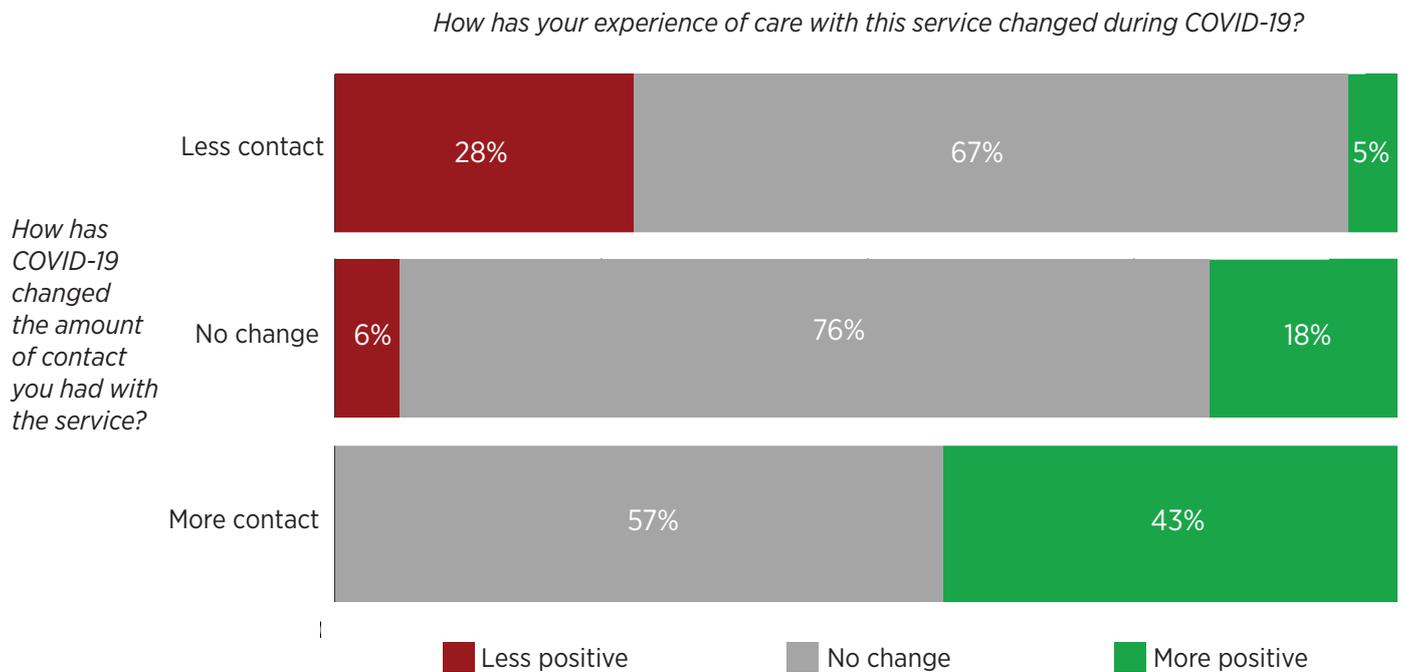
### More than half of carers had less contact with the service

As with consumers, we might expect that disruptions to services may have resulted in carers having less contact with services. In the community, 61 per cent of carers stated that they had less contact with services throughout COVID-19 (see Figure 13). Around 19 per cent of carers continued with only face-to-face contact in the community whereas over 80 per cent reported that between a little and all of their contact was by phone or online. While many carers reported a change in how much contact and the method of contact with the service, 68 per cent reported no change in their overall experience as a result of COVID-19. Where carer experience did change, it was more likely to be less positive (18%).

Figure 13. Responses to supplementary COVID questions, community carers



Figure 14. How the frequency of contact impacted overall carer experience, community carers



**The more contact with the service, the more positive the carer's experience**

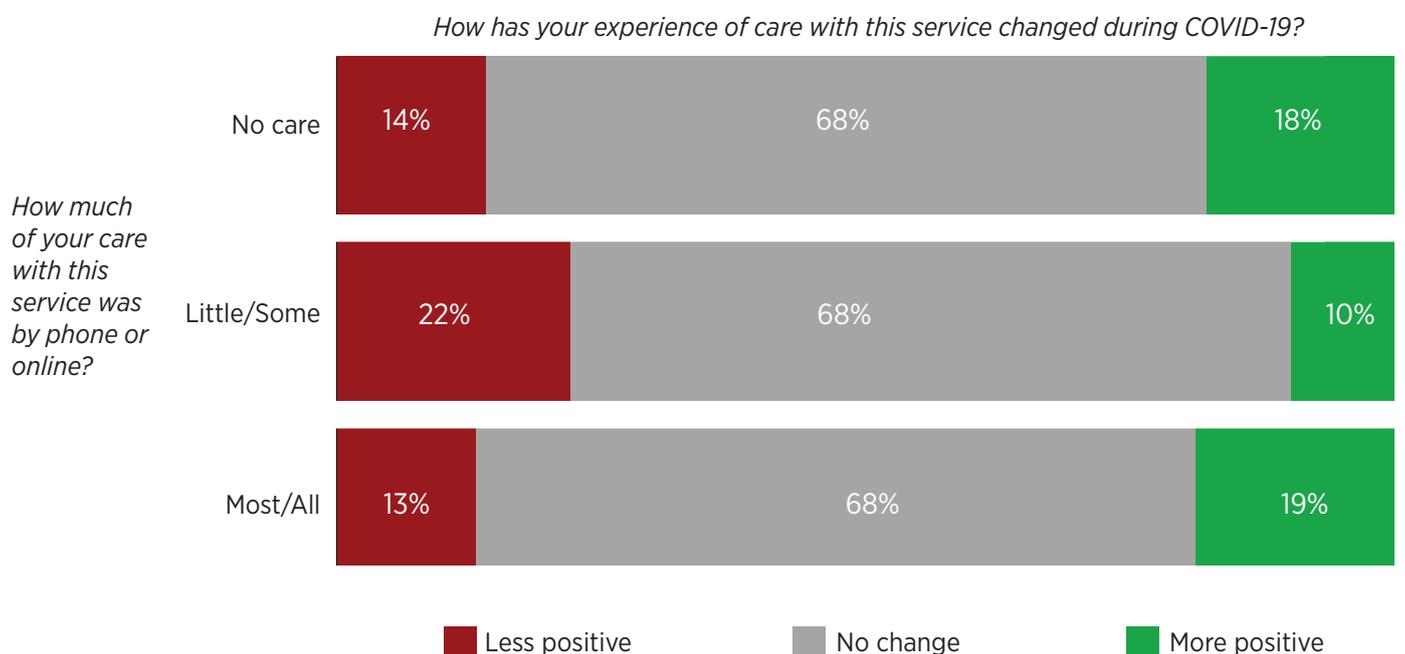
Where carers had more contact with the service during COVID-19 they were more likely to report a more positive experience (43%) compared to those who had less contact or no change (see Figure 14). There were no carers who reported a less positive experience where there was increased contact. For those carers who had less contact with the services, 28 per cent stated that their experience was less positive. Interestingly, where there was no change in the amount of contact around 18 per cent of carers reported a more positive experience.

With many people reporting increased feelings of social isolation throughout COVID-19, it is possible that contact with services may have been more impactful for carers, even where there was a reduction in the amount of contact. In the free-text comments, many carers mentioned that the best thing about the service was the regular contact and feeling informed and involved in the care of their family member, partner or friend.

**How often carers were contacted mattered more than how they were contacted**

The method with which services connect with carers (face-to-face, phone or online) did not significantly impact the carers experience of the service. Figure 15 shows that carers who had a little or some of their carer provided by phone or online were slightly more likely to state that their experience was less positive. Otherwise, there were similar experiences for carers who had contact with the service either face-to-face only, phone or online, or both. Again, this suggests that the amount of contact with the service had a larger impact on carer experience than the method of contact.

Figure 15. How the frequency of contact impacted overall carer experience



## Responses to core CES questions

Next, we examined responses to the core CES questions, comparing January to September 2019 with the same period in 2020. Throughout 2020 there have been significant increases in the number of CES surveys completed. From April to June 2020, 235 CES surveys were returned from community services. This was an increase of 35 per cent from the same period in 2019 (175 CES surveys returned April–June 2019).

Between July and September 2020, the number of returns more than doubled from 2019 (219 returns from July to September 2019, 578 returns from July to September 2020). Although this increase in returns is positive, it makes it difficult to compare experience across the two years.

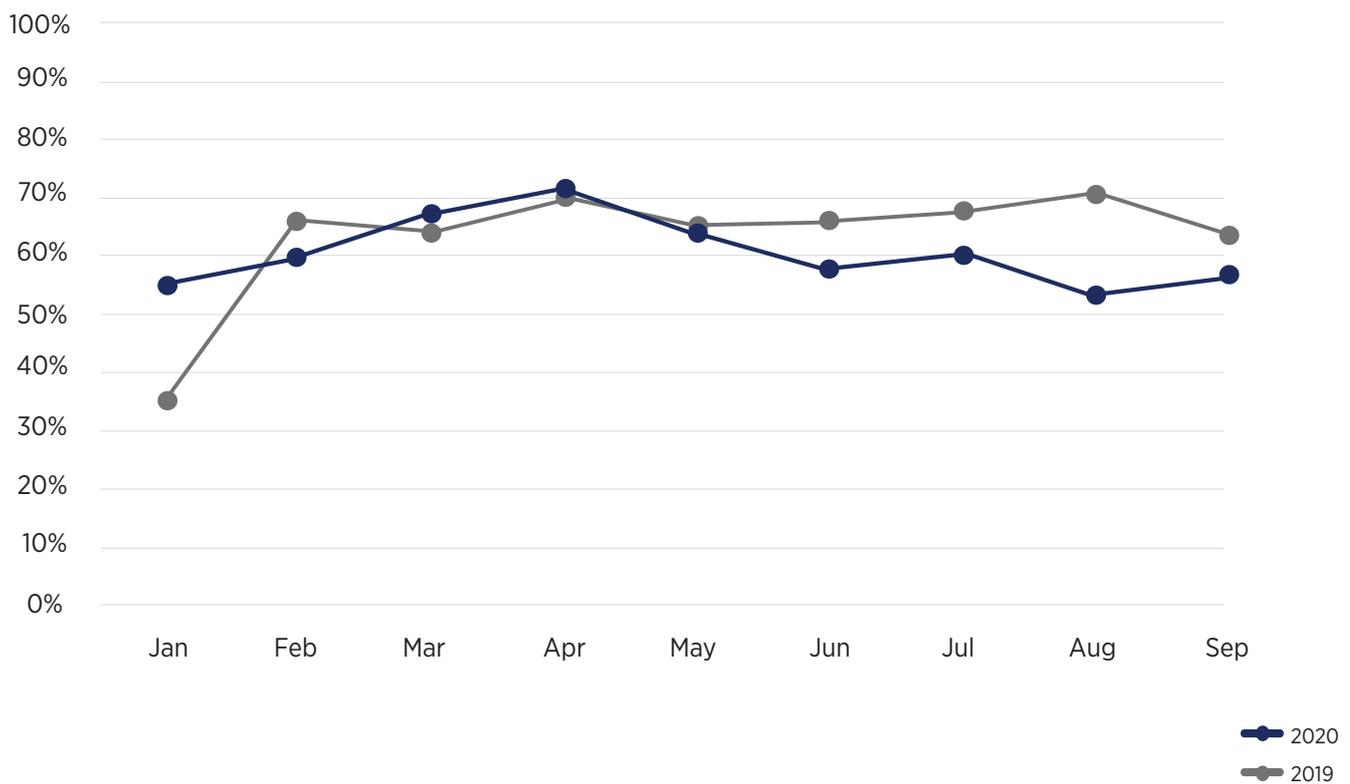
### Overall carer experience was less positive during early stages of the pandemic

Figure 16 shows that from April to June 2020 there was a decrease in the percentage of carers reporting an excellent or very good overall experience. Most of this drop occurred in June and continued into the later months of the year.

While it is difficult to compare with the previous year, we can see that until April 2020 experience was improving and from May to September 2020 there was a downward trend.

The free-text comments were used to further explore what impacted carer experience throughout COVID-19. This is outlined in the next section.

Figure 16. Percentage of carers reporting an excellent or very good experience in the community



### COVID-19 was mentioned by community carers in the free text comments

The CES offers carers the option to provide additional information about their experience using two free-text questions:

*Q30. My experience with this service would have been better if...*

*Q31. The best things about this service were...*

These comments were used to help further understand how COVID-19 impacted carer experience. Terms related to COVID-19 such as COVID, corona, pandemic and virus were mentioned more frequently in response to Q30 (My experience with this service would have been better if). Over 7 per cent of responses to this question included these key words whereas less than 1 per cent of responses to Q31 (The best things about this service were) included them.

The following themes were mentioned frequently through the free-text comments in relation to COVID-19.

### Many carers would have preferred some face to face contact with the service

Using the CES COVID-specific questions we found that the amount of contact with the service had a greater impact on experience than the method of that contact. However, many carers still commented in the free-text responses that their experience would have been better if there was some face-to-face contact.

For some carers whose contact with the service began during COVID-19 they found initial appointments and discussions more challenging over the phone or online. Many carers who had contact with the service prior to COVID-19 commented that they preferred face-to-face appointments.

### Regular communication and being involved had a big impact on carer experience

Regular contact with carers, and when carers reported that they felt included in discussions and care planning were often mentioned as the best things about a service. While this feedback is not specific to COVID-19, carers commented that having frequent contact and access by phone, email or text for updates and appointments made a difference to them during the pandemic.

Some carers commented that regular updates were especially helpful during COVID-19, as it provided reassurance and kept them involved in the care of their family member, partner or friend. A number of carers commented that family meetings and support groups were not provided due to COVID-19 and that this impacted their opportunities to be involved and link in with support. While many carers acknowledged that this was not the fault of the service, it did have an impact on their experience.

When carers felt that they could contact the service at any time, many mentioned feeling safe and supported throughout the challenges of COVID-19. Carer experience was varied throughout this time, but the benefit of regular communication and involvement was a common theme.

#### The best things about this service were...

The services ability to adapt to changes being implemented due to COVID

#### My experience would have been better if...

We hadn't needed services during COVID-19. Online appointments were challenging

#### The best things about this service were...

Feeling safe during COVID-19 and excellent, professional, supportive and friendly service always

#### My experience would have been better if...

If not for the virus which resulted in lock down & social distancing my experience with the service would have been a lot better

# 4: Carer experience of hospital mental health care

## COVID-19 impacts on hospital mental health service delivery

Earlier in this report we explored some of the changes that occurred in hospital mental health services as a result of COVID-19 (page 14). With restrictions on visitors to hospital units and limitations on consumers being able to leave, COVID-19 appeared to have a larger impact on carers in the hospital setting. As with earlier sections, we will focus on the feedback provided by carers throughout the first few months of the COVID-19 pandemic in NSW.

## Responses to COVID-specific questions

There were 68 responses to the CES COVID-specific questions in hospital from May to September 2020. Of these, around half were completed online (53%) and can be linked to full CES surveys. Similar to the carer feedback in the community, a range of carers provided feedback about hospital services.

Female carers (69%) and people who have been caring for less than 6 months (22%) or over 5 years (61%) provided more feedback. Aboriginal and/or Torres Strait Islander carers are likely to be under-represented with 11 per cent of consumers in hospital identifying as Aboriginal and/or Torres Strait Islanders and only 6 per cent of CES COVID-specific returns from Aboriginal and/or Torres Strait Islander carers.

Most people reported that they were caring for their child (34%) or sibling (26%) and had been engaged with the service for less than 6 months (56%). While this tells us that a range of carers are providing feedback, it is not known if this is a representative sample of the carers of people accessing mental health services.

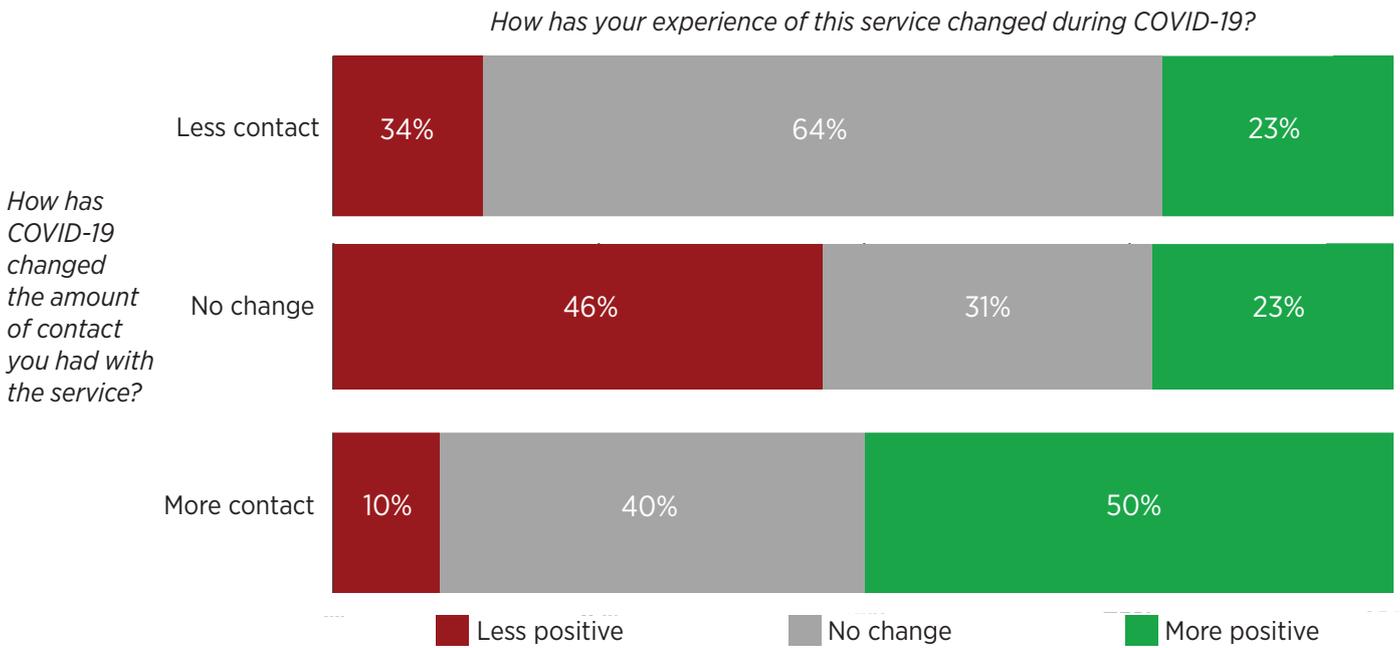
## Carers in hospital service reported more change in experience due to COVID-19

As shown in Figure 17, just over half of the carers (52%) who completed the supplementary COVID-19 questions reported a change in experience. For many carers this was a positive change (30%) but for around 1 in 5 the experience was less positive (22%). Similarly, just over half of carers reported less contact with the service (52%) and the amount of contact provided by phone or online was varied.

Figure 17. Responses to supplementary COVID questions, hospital carers



Figure 18. How the frequency of contact impacted overall carer experience, hospital carers



**Many carers needed more frequent contact with services throughout COVID-19**

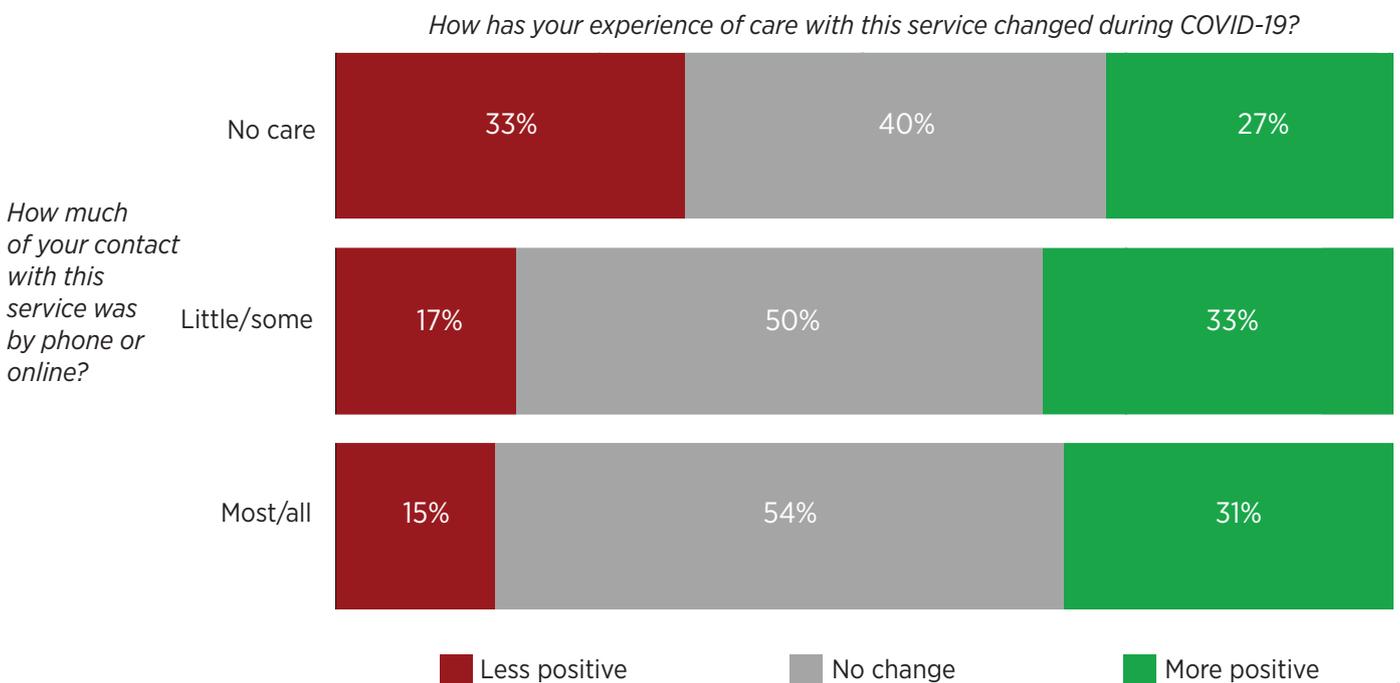
Almost half (46%) of the carers who had no change in the amount of contact with the service reported a less positive experience (see Figure 18). With hospital restrictions on visitors and leave, keeping carers connected with consumers and services was more challenging throughout COVID-19. Those carers who had more contact with the service often reported a more positive experience.

Where there was no change in the amount of contact almost half (46%) reported a less positive experience. This feedback suggests that throughout COVID-19 in 2020, carers needed more contact than they were previously provided to remain connected and involved in their loved one’s care.

**Carers who had no contact with the service by phone or online reported a less positive experience**

With restrictions on visitors to hospitals occurring throughout this time, carers who did not have contact with the service by phone or online would have had limited opportunities to engage with the staff supporting their family member, partner or friend. Carers who had between some and all of their contact by phone or online were more likely to rate their experience as more positive (see Figure 19).

Figure 19. How the method of contact impacted overall carer experience, hospital carers



## Responses to core CES questions

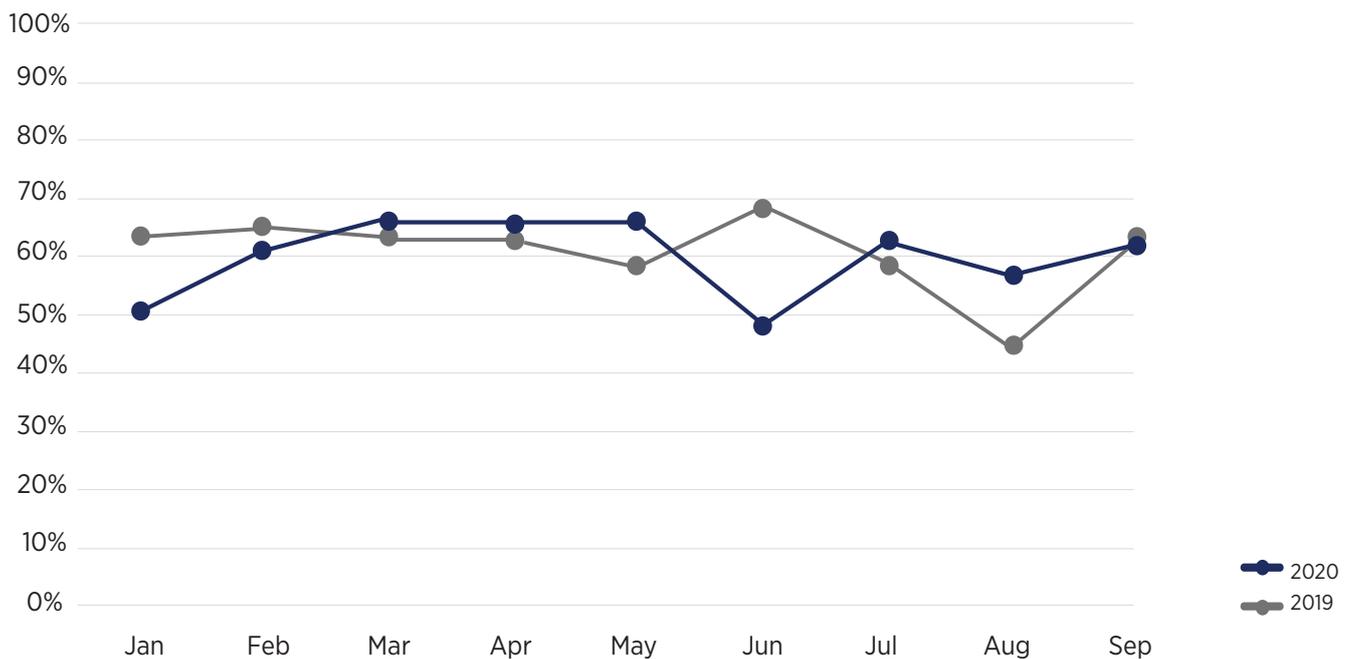
Responses to the core CES questions from January to September 2019 were compared with the same period in 2020. Throughout 2020 the number of CES surveys completed increased. From April to June 2020, 311 CES surveys were returned from hospital services. This was an increase of 16 per cent from the same period in 2019 (268 CES surveys returned April to June 2019). Between July and September 2020, the number of returns increased by almost half (336 returns from July to September 2019, 498 returns from July to September 2020). Although this increase in returns is positive, it makes it difficult to compare experience across the two years.

### Overall carer experience decreased in June 2020

Figure 20 shows that from March to May 2020 carer experience appeared stable, with 66 per cent of carers reporting an excellent or very good experience across these months. In June 2020 this dropped by 17 per cent with 48% of carers reporting an excellent or very good experience. It is important to note that there was a decrease in returns in June with around 30% less than the average number of returns from January to May 2020. This reduced sample size makes it difficult to compare experience over time.

From July onwards, the number of CES surveys returned to pre-COVID levels and although we saw an increase in carers reporting a positive experience, this remained slightly lower than the March–May 2020 period. To understand possible causes for a change in experience, the free-text comments were explored.

Figure 20. Percentage of carers reporting an excellent or very good experience of hospital services



### COVID-19 was mentioned by hospital carers in the free text comments

As with the community analysis, terms related to COVID-19 such as *COVID*, *corona*, *pandemic* and *virus* were searched for in the CES free-text comments. Over 9 per cent of responses to Q30 (*My experience with this service would have been better if*) included these key words, whereas less than 1 per cent of responses to Q31 (*The best things about this service were*) included them. The following themes were mentioned frequently through the free-text comments in relation to COVID-19.

### Visiting restrictions had a big impact on carer experience of hospital services

Most of the free-text comments that related to COVID-19 mentioned visiting restrictions. Many carers commented that this was one of the most difficult aspects of COVID-19. Although many carers commented that they understood the need for these restrictions, carers felt less connected with their loved one and reported less opportunities to be involved.

Several carers also commented that this increased their own feelings of isolation. Despite the challenges caused by the restrictions, some carers stated that they appreciated the increased precautions as this meant their family member, partner or friend was kept safe during the pandemic.

### The experience of carers will continue to be explored as more data becomes available

Although this report only used the COVID-specific questions, overall experience and free-text analysis has provided some insight into the experience of carers throughout the first few months of the pandemic. As more feedback is received from carers over time, we will conduct further in-depth analysis of individual CES questions and domains.

#### The best things about this service were...

The strict hygiene regulations around COVID. That my son was cared for and he was kept safe during his stay

#### My experience would have been better if...

There was no COVID-19 pandemic. I felt left out as my visiting rights were removed and this made me feel isolated

#### The best things about this service were...

They did the best they could with COVID-19

#### My experience would have been better if...

Visiting hours were not so restricted because of COVID. This has been challenging

# Appendix 1. Technical information

## YES and CES development and validation

The development, validation and psychometric properties of the YES and CES questionnaires are described in detail at:

<https://www.amhocn.org/measures>

The following supplementary questions were added to the YES and CES questionnaires. These were added to the electronic versions and available for services to print as a separate A4 sheet to be offered along with the questionnaires .

## Analysis

Initial data manipulation for this report was conducted using SAS, with statistical analyses conducted using Stata SE v15. Missing, invalid or duplicate answers were recoded as null. YES returns with less than 12 of the first 22 questions completed were excluded from analysis. CES returns with less than 12 of the first 24 questions (excluding questions 15 and 19) were excluded from analysis.

Overall scores and domain scores were constructed following the methods used in the national YES and CES development. All qualitative comments were included even if the rest of the questionnaire was not completed.

Testing of significant differences between groups or over time was conducted using 95 per cent confidence intervals. These were calculated using the Wald formula for proportions. Non-overlapping confidence intervals were used to identify significant differences.

Table 2. Supplementary questions added to YES and CES questionnaires

<p><b>How much of your care/contact with this service was by phone or online (e.g. videoconferencing such as Skype/Pexip)?</b></p> <p>None of my care A little of my care Some of my care Most of my care All of my care</p>
<p><b>How has COVID-19 changed the amount of contact you have had with the mental health service (including face to face and phone/online)?</b></p> <p>No contact A lot less contact A little less contact No change in contact A little more contact A lot more contact N/A (started with service during COVID-19)</p>
<p><b>How has your experience of care with this service changed during COVID-19?</b></p> <p><b>My experience has been...</b></p> <p>A lot worse A little worse No change A little better A lot better N/A (started with service during COVID-19)</p>

## Analysis of change

The table below summarises the average rating out of 5 across each of the YES questions from April to June 2019 and April to June 2020.

Table 3. Average YES question rating (out of 5)

	Community		Hospital	
	April–June 2019	April–June 2020	April–June 2019	April–June 2020
Q1 You felt welcome at this service	4.53	4.67	4.48	4.47
Q2 Staff showed respect for how you were feeling	4.51	4.67	4.47	4.44
Q3 You felt safe using this service	4.48	4.61	4.42	4.42
Q4 Your privacy was respected	4.55	4.69	4.47	4.45
Q5 Staff showed hopefulness for your future	4.40	4.52	4.43	4.42
Q6 Your individuality and values were respected	4.56	4.67	4.56	4.55
Q7 Staff made an effort to see you when you wanted	4.42	4.57	4.44	4.42
Q8 You had access to your treating doctor or psychiatrist when you needed	4.21	4.43	4.15	4.17
Q9 You believe that you would receive fair treatment if you made a complaint	4.27	4.38	4.25	4.23
Q10 Your opinions about the involvement of family or friends in your care were respected	4.48	4.63	4.52	4.49
Q11 The facilities and environment met your needs	4.48	4.66	4.37	4.37
Q12 You were listened to in all aspects of your care and treatment	4.41	4.53	4.36	4.34
Q13 Staff worked as a team in your care and treatment	4.32	4.48	4.23	4.20
Q14 Staff discussed the effects of your medication and other treatments with you	4.25	4.42	4.20	4.17
Q15 You had opportunities to discuss your progress with the staff caring for you	4.37	4.52	4.31	4.28
Q16 There were activities you could do that suited you	4.02	4.22	4.00	3.92
Q17 You had opportunities for your family and carers to be involved in your treatment and care if you wanted	4.30	4.52	4.38	4.27
Q18 Information given to you about this service	3.93	4.13	3.83	3.79
Q19 Explanation of your rights and responsibilities	3.90	4.05	3.83	3.78
Q20 Access to peer support	3.79	3.91	3.80	3.80
Q21 Development of a care plan with you that considered all of your needs	3.91	4.09	3.88	3.86
Q22 Convenience of the location for you	3.99	4.18	3.82	3.81
Q23 The effect the service had on your hopefulness for the future	3.74	3.91	3.70	3.71
Q24 The effect the service had on your ability to manage your day to day life	3.74	3.92	3.67	3.66
Q25 The effect the service had on your overall well-being	3.79	3.96	3.74	3.74
Q26 Overall, how would you rate your experience of care with this service in the last 3 months?	3.97	4.17	3.85	3.86

## The experience of different consumer groups

Testing of significant differences between groups or over time was conducted using 95 per cent confidence intervals. These were calculated using the Wald formula for proportions. Non-overlapping confidence intervals were used to identify significant differences (Table 4, Table 5, Table 6). Note that demographic data is only available for the COVID-specific questions completed online. This equates to 93 per cent of community returns (770 of 829 COVID-specific returns) and 63 per cent of hospital returns (165 of 262 COVID-specific returns).

Table 4. Overall experience for difference consumer groups

Characteristic	Community				Hospital			
	April–June 2019		April–June 2020		April–June 2019		April–June 2020	
	% Excellent/ Very Good	95% Confidence Intervals						
<b>GENDER</b>								
Female	86%	(83.4–87.7)	83%	(80.3–86.5)	71%	(68.6–72.8)	69%	(67.1–71.8)
Male	67%	(63.6–69.5)	81%	(77.8–84.8)	72%	(69.7–73.7)	69%	(67.1–71.8)
<b>ABORIGINAL AND/ OR TORRES STRAIT ISLANDER</b>								
Aboriginal	61%	(53.6–68.3)	73%	(63.6–82.8)	70%	(65.2–74.2)	72%	(67.1–76.7)
Not Aboriginal	77%	(75.6–79.4)	83%	(80.9–85.6)	71%	(69.5–72.7)	69%	(67.6–71.2)
<b>AGE GROUP (YEARS)</b>								
Under 18	87%	(83.0–91.5)	91%	(84.9–96.9)	75%	(69.9–79.9)	64%	(58.1–70.2)
18–24	77%	(71.5–82.8)	80%	(71.0–89.5)	71%	(67.4–75.0)	70%	(65.6–74.6)
25–64	71%	(68.1–73.2)	79%	(76.4–82.5)	70%	(67.9–71.5)	69%	(67.0–71.1)
65 and over	88%	(84.7–91.6)	89%	(84.6–92.9)	78%	(72.4–82.8)	80%	(74.7–85.3)
<b>DURATION OF CONTACT</b>								
Less than 24 hours	57%	(47.5–67.4)	54%	(34.2–74.1)	68%	(62.2–73.9)	74%	(67.0–80.5)
1 day–2 weeks	71%	(63.4–78.6)	72%	(60.8–82.4)	75%	(72.6–76.7)	71%	(69.2–73.7)
3–4 weeks	68%	(60.6–74.8)	77%	(68.5–86.0)	67%	(63.8–71.2)	66%	(61.4–69.9)
1–3 months	82%	(78.4–86.5)	87%	(82.3–92.4)	69%	(65.1–73.6)	69%	(64.4–74.0)
4–6 months	81%	(75.8–85.7)	85%	(79.0–91.3)	63%	(54.1–71.2)	68%	(58.4–77.1)
More than 6 months	78%	(75.5–80.5)	83%	(80.3–86.5)	61%	(56.1–66.2)	64%	(57.3–71.2)
<b>LEGAL STATUS</b>								
Voluntary	82%	(79.8–83.9)	85%	(82.6–87.9)	77%	(75.2–79.4)	74%	(71.6–76.7)
Involuntary	68%	(62.5–72.7)	75%	(68.8–80.9)	66%	(63.4–68.5)	65%	(62.7–68.3)

Table 5. Demographic and service characteristics of consumers who completed YES questionnaires from April-June

Characteristic	Community		Hospital	
	April-June 2019	April-June 2020	April-June 2019	April-June 2020
<b>GENDER</b>				
Female	51%	54%	48%	49%
Male	48%	45%	51%	50%
Other	1%	1%	1%	1%
<b>ABORIGINAL AND/ OR TORRES STRAIT ISLANDER</b>				
Aboriginal	8%	8%	11%	12%
Not Aboriginal	92%	92%	89%	88%
<b>AGE GROUP (YEARS)</b>				
Under 18	12%	8%	8%	8%
18-24	10%	7%	15%	14%
25-64	61%	64%	70%	70%
65 and over	17%	21%	7%	8%
<b>DURATION OF CONTACT</b>				
Less than 24 hours	5%	2%	7%	6%
1 day-2 weeks	8%	8%	50%	54%
3-4 weeks	8%	8%	17%	17%
1-3 months	17%	16%	13%	13%
4-6 months	12%	12%	3%	3%
More than 6 months	50%	54%	10%	6%
<b>LEGAL STATUS</b>				
Voluntary	81%	77%	54%	52%
Involuntary	19%	23%	46%	48%

Please note, due to rounding, each category may not add up to 100%

Table 6. Demographic and service characteristics of consumers who completed YES questionnaires and COVID-specific questions from May to September 2020

Characteristic	Community		Hospital	
	YES questionnaire	COVID questions	YES questionnaire	COVID questions
GENDER				
Female	53%	57%	49%	55%
Male	45%	41%	50%	45%
Other	1%	2%	1%	0%
ABORIGINAL AND/OR TORRES STRAIT ISLANDER				
Aboriginal	9%	11%	12%	5%
Not Aboriginal	91%	89%	88%	95%
AGE GROUP (YEARS)				
Under 18	11%	11%	10%	7%
18-24	8%	15%	16%	12%
25-64	61%	66%	66%	61%
65 and over	19%	8%	8%	20%
DURATION OF CONTACT				
Less than 24 hours	3%	7%	6%	5%
1 day-2 weeks	9%	12%	54%	42%
3-4 weeks	7%	6%	17%	17%
1-3 months	16%	19%	12%	20%
4-6 months	12%	12%	3%	8%
More than 6 months	51%	43%	7%	9%
LEGAL STATUS				
Voluntary	79%	77%	53%	42%
Involuntary	21%	23%	47%	58%

Please note, due to rounding, each category may not add up to 100%



## Your Experience of Service

Service:

Your feedback is important. This questionnaire was developed with mental health consumers. It is based on the Recovery Principles of the Australian National Standards for Mental Health Services. It aims to help mental health services and consumers to work together to build better services. If you would like to know more about the survey please ask for an information sheet.

Completion of the questionnaire is voluntary. All information collected in this questionnaire is anonymous. None of the information collected will be used to identify you. It would be helpful if you could answer all questions, but please leave any question blank if you don't want to answer it.

Please put a cross in just one box for each question, like this ...

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	X	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	---	--------------------------	--------------------------

These questions ask how often we did the following things ...

Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:	Never	Rarely	Sometimes	Usually	Always	Not Applicable
1. You felt welcome at this service	<input type="checkbox"/>					
2. Staff showed respect for how you were feeling	<input type="checkbox"/>					
3. You felt safe using this service	<input type="checkbox"/>					
4. Your privacy was respected	<input type="checkbox"/>					
5. Staff showed hopefulness for your future	<input type="checkbox"/>					
6. Your individuality and values were respected (such as your culture, faith or gender identity, etc.)	<input type="checkbox"/>					
7. Staff made an effort to see you when you wanted	<input type="checkbox"/>					
8. You had access to your treating doctor or psychiatrist when you needed	<input type="checkbox"/>					
9. You believe that you would receive fair treatment if you made a complaint	<input type="checkbox"/>					
10. Your opinions about the involvement of family or friends in your care were respected	<input type="checkbox"/>					
11. The facilities and environment met your needs (such as cleanliness, private space, reception area, furniture, common areas, etc.)	<input type="checkbox"/>					

As a result of your experience with the service in the last 3 months or less please rate the following:	Poor	Fair	Good	Very Good	Excellent
23. The effect the service had on your hopefulness for the future	<input type="checkbox"/>				
24. The effect the service had on your ability to manage your day to day life	<input type="checkbox"/>				
25. The effect the service had on your overall well-being	<input type="checkbox"/>				
26. Overall, how would you rate your experience of care with this service in the last 3 months?	<input type="checkbox"/>				

These questions ask if we did the following things ...

In the last 3 months, has the service advised you about the following:	Yes	No	Not sure	Not Applicable
27. Healthy eating and diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Alcohol and drug use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Sexual health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Exercise and physical activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Possible physical side effects of some medications (such as weight gain, diabetes or heart disease)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. My experience would have been better if ...

.....

.....

.....

34. The best things about this service were ...

.....

.....

.....

These questions ask how often we did the following things ...

Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:	Never	Rarely	Sometimes	Usually	Always	Not Applicable
12. You were listened to in all aspects of your care and treatment	<input type="checkbox"/>					
13. Staff worked as a team in your care and treatment (for example, you got consistent information and didn't have to repeat yourself to different staff)	<input type="checkbox"/>					
14. Staff discussed the effects of your medication and other treatments with you	<input type="checkbox"/>					
15. You had opportunities to discuss your progress with the staff caring for you	<input type="checkbox"/>					
16. There were activities you could do that suited you	<input type="checkbox"/>					
17. You had opportunities for your family and carers to be involved in your treatment and care if you wanted	<input type="checkbox"/>					

These questions ask how well we did the following things ...

Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:	Poor	Fair	Good	Very Good	Excellent	Not Applicable
18. Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc.)	<input type="checkbox"/>					
19. Explanation of your rights and responsibilities	<input type="checkbox"/>					
20. Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc.)	<input type="checkbox"/>					
21. Development of a care plan with you that considered all of your needs (such as health, living situation, age, etc.)	<input type="checkbox"/>					
22. Convenience of the location for you (such as close to family and friends, transport, parking, community services you use, etc.)	<input type="checkbox"/>					

This information helps to show whether some groups of people are missing out on giving their feedback. It also shows if some groups of people have a better or worse experience than others. Knowing this helps to focus efforts to build better services. No information collected in this section will be used to identify you.

What is your gender?

Male     Female     Other

What is the main language you speak at home?

English    Other

Are you of Aboriginal or Torres Strait Island origin?

No  
 Yes - Aboriginal  
 Yes - Torres Strait Islander  
 Yes - Aboriginal and Torres Strait Islander

What is your age?

Under 18 years     18 to 24 years  
 25 to 34 years     35 to 44 years  
 45 to 54 years     55 to 64 years  
 65 years and over

How long have you been receiving care from this service on this occasion?

Less than 24 hours     1 day to 2 weeks  
 3 to 4 weeks     1 to 3 months  
 4 to 6 months     More than 6 months

At any point during the last 3 months were you receiving involuntary treatment (such as an involuntary patient or on a community treatment order) under Mental Health Legislation?

Yes, involuntary patient/on a community treatment order  
 No, I was always a voluntary patient  
 Not Sure

Did someone help you complete this survey?

No  
 Yes - family or friend  
 Yes - language or cultural interpreter  
 Yes - consumer worker or peer worker  
 Yes - another staff member from the service  
 Yes - someone else

Thank you for your time and comments  
 Please place the completed questionnaire  
 in the envelope provided and return by mail

InforMH  
 Reply Paid 3975  
 Sydney NSW 2001

© 2013 The Secretary to the Department of Health (Vic) developed with funding from the Australian Government Department of Health



# Appendix 3. YES domains

<b>Making a difference</b>	
Q23	The effect the service had on your hopefulness for the future
Q24	The effect the service had on your ability to manage your day to day life
Q25	The effect the service had on your overall wellbeing
Q26	Overall, how would you rate your experience of care within this service in the last 3 months
<b>Providing information and support</b>	
Q18	Information given to you about this service
Q19	Explanation of your rights and responsibilities
Q20	Access to peer support
Q21	Development of a care plan with you that considered all of your needs
<b>Valuing individuality</b>	
Q6	Your individuality and values were respected
Q16	There were activities you could do that suited you
<b>Supporting active participation</b>	
Q8	You had access to your treating doctor or psychiatrist when you needed
Q10	Your opinions about the involvement of family or friends in your care were respected
Q13	Staff worked as a team in your care and treatment
Q14	Staff discussed the effects of your medication and other treatments with you
Q15	You had opportunities to discuss your progress with the staff caring for you
Q17	You had opportunities for your family and carers to be involved in your treatment and care if you wanted
<b>Showing respect</b>	
Q1	You felt welcome at this service
Q2	Staff showed respect for how you were feeling
Q4	Your privacy was respected
Q5	Staff showed hopefulness for the future
Q7	Staff made an effort to see you when you wanted
Q12	You were listened to in all aspects of your care and treatment
<b>Ensuring safety and fairness</b>	
Q3	You felt safe using this service
Q9	You believe that you would receive fair treatment if you made a complaint
Q11	The facilities and environment met your needs



# Mental Health Carer Experience Survey

This survey is about your experiences, as a carer **over the last three months**. By completing this survey, you will help the service better understand how to work with carers towards the recovery of mental health consumers. If you care for more than one person, just think of one of these people when completing the questionnaire.

## WHO IS A CARER?

Carers can come from many different backgrounds but many never think of themselves as carers. Many feel they are doing what anyone else would in the same situation; looking after their family member, partner or friend. Carers are the family member, partner or friend of someone with a mental illness whose lives are also affected by that illness. Carers provide support and assistance to the person with a mental illness.

## GETTING STARTED

Your responses to this questionnaire are anonymous. Your experiences are very important to us so we would like you to provide an answer to each question. But you can leave a question blank if you wish. There is space at the end of the survey for you to provide additional feedback about your experiences.

Please put a cross in just one box for each question, like this ...

<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	-------------------------------------	--------------------------	--------------------------	--------------------------

As a carer with a family member, partner or friend who had contact with this mental health service in the <b>last three months</b> , how often did the following occur?		Never	Rarely	Sometimes	Usually	Always	Not Needed
1.	You understood what you could expect from the mental health service for yourself and your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	You were given an explanation of any legal issues that might affect your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	You understood your rights and responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Your personal values, beliefs and circumstances were taken into consideration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	You were able to obtain cultural or language support (such as an interpreter) when you needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	You were given the opportunity to provide relevant information about your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Your opinion as a carer was respected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

As a carer with a family member, partner or friend who had contact with this mental health service in the <i>last three months</i> , how often did the following occur?						
	Never	Rarely	Sometimes	Usually	Always	Not Needed
8. You were involved in decisions affecting your family member, partner or friend	<input type="checkbox"/>					
9. You were identified as a carer of your family member, partner or friend	<input type="checkbox"/>					
10. You were given opportunities to discuss the care, treatment and recovery of your family member, partner or friend (even, if for reasons of confidentiality, you could not be told specific information)	<input type="checkbox"/>					
11. You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend	<input type="checkbox"/>					
12. You were given the opportunity to enhance your abilities as a carer	<input type="checkbox"/>					
13. Staff conveyed hope for the recovery of your family member, partner or friend	<input type="checkbox"/>					
14. Staff worked in a way that supported your relationship with your family member, partner or friend	<input type="checkbox"/>					
15. You were given the specific information you needed for your role in the ongoing care, treatment and recovery of your family member, partner or friend	<input type="checkbox"/>					
16. You were given information about services and strategies available if your family member, partner or friend became unwell again	<input type="checkbox"/>					
17. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)	<input type="checkbox"/>					

As a carer with a family member, partner or friend who had contact with this mental health service, in the <i>last three months</i> have you been given the following?				
	Yes	No	Don't know	Not Needed
18. A brochure or other material about your rights and responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Information about the role and legal rights of designated carers and principal care providers under the NSW Mental Health Act 2007	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. An explanation of how to make a compliment or complaint about the mental health service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Information about carer support services (such as local groups, carer consultants, counsellors)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Information on opportunities to participate in improving this mental health service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. A number you could call after hours for the service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Information about taking a support person to meetings or hearings if you wished	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



# DEMOGRAPHICS

Please tick one box for each question

32. What is your gender?  Male  Female  Other

33. What is the main language you speak at home?  English Other

34. What is your age?  18 to 24 years  25 to 34 years  35 to 44 years  
 45 to 54 years  55 to 64 years  65 to 74 years  
 75 years and over

35. Are you of Aboriginal or Torres Strait Islander descent?  Yes, Aboriginal  
 Yes, Torres Strait Islander  
 Yes, both Aboriginal and Torres Strait Islander  
 No

36. How long have you been a carer of your family member, partner or friend with a mental illness?  Up to 6 months  6 months to 1 year  1 to 2 years  
 2 to 5 years  5 to 10 years  Over 10 years

37. What is your relationship to the family member, partner or friend for whom you are a carer? The person I care for is:  
 My spouse / partner (including married, defacto)  
 My son or daughter (including step and in-law)  
 My mother or father (including step and in-law)  
 A friend  
 My brother or sister (including step and in-law)  
 Other

38. How long has your family member, partner or friend been a client of this mental health service?  Less than 1 month  1 to 6 months  6 months - 1 year  
 1 to 5 years  More than 5 years

39. Did someone help you complete this survey?  No  
 Yes - carer or consumer worker/ peer worker  
 Yes - family member, partner or friend  
 Yes - another staff member from the service  
 Yes - language or cultural interpreter  
 Yes - someone else

**Thank you for completing this Survey.**

Please place the completed survey in the prepaid envelope provided and return by mail or local collection box

**InforMH**  
**Reply Paid 3975**  
**Sydney NSW 2001**

