



What carers say
about NSW
Mental Health
Services
2021-2022



Mental Health Carer Experience Survey

Acknowledgements

We gratefully acknowledge the members of the CES advisory committee and colleagues at Mental Health Carers NSW (MHCN) who supported the implementation and ongoing use of the CES. Thanks also to our colleagues at the NSW Ministry of Health Mental Health Branch and Bureau of Health Information for your support. Most importantly, thank you to the many carers who take the time and effort to complete a CES and the MHCN and NSW Health staff who have worked together to improve services using the CES feedback.

Report produced by:

InforMH
System Information and Analytics Branch
NSW Ministry of Health

Published November 2022

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

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SHPN (SIA) 220890
ISBN 978-1-76023-352-5



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Foreword from Mental Health Carers NSW

Mental Health Carers NSW (MHCN) is the peak body for families and carers of people who experience persistent mental distress in NSW. In partnership with InforMH (System Information & Analytics Branch, NSW Ministry of Health) MHCN has been proud to support the roll out of the Mental Health Carer Experience Survey (CES) across NSW Health's specialist mental health services. MHCN is keen to identify the range of carer experiences and the different issues and obstacles encountered by mental health carers with diverse needs in different settings. The CES offers a consistent, measurable method for collecting feedback from all mental health services operated by Local Health Districts and Specialty Health Networks across NSW.

Although families, kinship groups, partners, intimate communities, and friends are always important enablers of recovery when someone experiences any illness or disability, they are *particularly* important in the mental health recovery process. The relationships a person has and the way they are supported make a huge difference to wellbeing 'suffusing all aspects of recovery, including experiences such as hope, identity and empowerment'. The people that care for a person are one of the most potent sources of assistance for recovery that a clinician or service can engage. Informal caring relationships (or lack of them) will always affect the mental health of a person, often with far more opportunity for impact than formal mental health services could ever have.

The CES is a serious attempt to capture the experience of a broad cross-section of carers in being identified, recognised and supported by mental health services in their caring role. The CES is a step towards a broader and more consistent evaluation of health services by the people who use them, including families and carers. Understanding the experience of carers enhances the mental health literacy of services. It allows them to tailor service delivery to the needs of users, making them more accessible and more effective. Collecting data from carers also helps services to measure the effectiveness of actions they take to address problems that carers experience.

Thus, the CES is crucial for the implementation of a range of important mental health service reform initiatives, from the NSW Mental Health Commission's *Lived Experience Framework* to the Agency for Clinical Innovation's *Trauma-informed care in mental health services across NSW: A framework for change* as well as being a potentially important diagnostic tool for quality improvement projects under NSW Health's Mental Health Patient Safety Program.

NSW Health has mandated the CES for use state-wide, demonstrating its commitment to change. We again thank the Minister and Ministry for this decision and congratulate InforMH for its inclusive process in implementing this important tool. The CES has had significant success to date, as noted in this report, despite pandemic impacts, and MHCN looks forward to working with InforMH to explore ways that CES can continue to add value.

MHCN especially congratulates all the staff from NSW Health and Community Managed Organisations (CMOs) who offered the CES and all the carers who completed it. This collaborative model of carers and mental health staff working together with consumers is vital if we are to continuously improve our services. MHCN remains committed to the CES as part of its support for such collaboration. But it takes service staff and carers to make the CES happen! Without you, it can't work, so well done and thank you!



Glossary and acronyms

Glossary

Aboriginal	Within this report, the term 'Aboriginal' is used to represent Aboriginal and/or Torres Strait Islander people.
Carer	A family member, partner or friend of someone with a mental illness whose life is also affected by that person's illness. Carers provide support and assistance.
Consumer	Any person who identifies as having a current or past lived experience of psychological or emotional issues, distress or problems, irrespective of whether they have a diagnosed mental illness and/or have received treatment. Other ways people may choose to describe themselves include 'peer', 'survivor', 'person with a lived experience' and 'expert by experience'.
CES returns	The number of CES questionnaires completed in a period.

Services

Adult and general services	Services that provide mental health support to people aged 18 to 65 years.
Child and adolescent	Services that provide specialist mental health support to people aged under 18 years.
Forensic	Services that provide support to consumers that a court has found to be either: <ul style="list-style-type: none"> • unfit to be tried for an offence and ordered to be detained in a correctional centre, mental health facility or other place • not guilty by reason of mental illness or nominated a limiting term and ordered to be detained in a prison, hospital or other place • not guilty by reason of mental illness and released into the community subject to conditions.
Older people	Services that provide specialist mental health support to people aged 65 years and over.

Acronyms

Local Health Districts (LHDs)

CCLHD	Central Coast LHD
FWLHD	Far West LHD
HNELHD	Hunter New England LHD
ISLHD	Illawarra Shoalhaven LHD
MLHD	Murrumbidgee LHD
MNCLHD	Mid North Coast LHD
NBMLHD	Nepean Blue Mountains LHD
NNSWLHD	Northern NSW LHD
NSLHD	Northern Sydney LHD
SESLHD	South Eastern Sydney LHD
SLHD	Sydney LHD
SNSWLHD	Southern NSW LHD
SWSLHD	South Western Sydney LHD
WNSWLHD	Western NSW LHD
WSLHD	Western Sydney LHD

Specialty Health Networks (SHNs)

JH&FMHN	Justice Health and Forensic Mental Health Network
SCHN	Sydney Children's Hospitals Network
SVHN	St Vincent's Health Network
Other	
MH	Mental Health



Summary

The Mental Health Carer Experience Survey (CES) is a nationally developed survey designed to gather information from carers about their experience of Australian mental health services. This report summarises the feedback collected since the survey was first implemented in NSW public mental health services in 2018. As the survey has only been collected for a few years and the number of returns has been disrupted by the pandemic, this report avoids analysing trends over time. This is because any observed changes may reflect the fact that we are hearing from a different mix of carers, rather than an actual change.

Nearly 3000 CES surveys were returned in 2021–22

Around 50% of surveys were about hospital services and 50% were about community teams. More than two-thirds of the surveys received were completed by people caring for their child (across all age ranges) and the majority of carers reported that they had been in a caring role for over 10 years. Early CES results may represent carers who are better engaged with services as they are more likely to be offered (and to complete) the survey. More work is needed to ensure that all carers have an opportunity to provide feedback.

Carers reported a similar experience across hospital and community services

More than two-thirds of carers of consumers in both hospital and community settings rated their overall experience as excellent or very good (69% in community, 68% in hospital). Across both settings, Respect was the highest-rated domain; fewer carers rated the domains of Information and support and Making a difference as excellent or very good.

Carers in specialist, age-specific services reported a more positive experience

Some services provide specialist care to younger or older people. Carers reported a more positive experience in these services across hospital and community settings. Around three-quarters of carers in child and adolescent services reported an excellent or very good experience. Carers in older people's services reported a similarly positive experience (72% excellent or very good).

Carers in metropolitan areas report a more positive experience than in regional areas

There was a difference in experience reported by carers in metropolitan and regional areas. Overall experience in metropolitan services was 70% excellent or very good, compared to 68% for carers in regional services. This difference in experience was reported across all domains.

Regular communication and being involved have a big impact on carer experience

Communication was often mentioned as the best thing about a service, or as something that could be improved. Where there was regular communication, carers often reported a more positive experience. But many carers stated that they needed more communication and more information about the service, the care and treatment of their loved one, future planning and support services. Carers also reported a more positive experience when they felt listened to.

The experience of carers varied depending on who they were caring for

In community settings, people caring for a parent and those supported by a staff member or peer worker to complete the survey, reported a more positive experience. Carers older than 75 years reported a more negative experience. In hospital settings, people caring for siblings and carers aged 75 years and over reported a more positive experience. People who had been carers for 5–10 years reported a more negative experience. In both settings, those who had been engaged with services for more than five years reported a less positive experience.

Aboriginal carers reported a more positive experience of community services

Around 6% of community surveys and 7% of hospital surveys were from carers who identified as Aboriginal. Aboriginal carers were more likely to report an excellent or very good experience of community services (78%) than of hospital services (63%). Aboriginal carers reported a more positive experience of community services, when compared to non-Aboriginal carers. In hospital, Aboriginal carers reported a less positive experience than non-Aboriginal carers. The largest gaps were in the domains of Participation, Individuality and Respect.

The COVID-19 pandemic affected the experiences of carers

It is important to consider the possible impacts of COVID-19 when interpreting these results. The *Consumer and carer experience of NSW mental health services during the 2020 COVID-19 pandemic report* explores the impacts of COVID-19 in more detail.

The importance of gathering carer feedback

Carers are crucial to supporting the recovery and wellbeing of mental health consumers

Carers are the family members, partners or friends of someone with a mental illness. Their support often precedes and extends beyond the involvement of mental health services. The *Fifth National Mental Health and Suicide Prevention Plan (2017)* acknowledged the vital contribution of consumers and carers. It emphasised that consumers and carers should be at the centre of shaping how services are planned, delivered and evaluated. This is also a central theme in the NSW Mental Health Commission's *Lived Experience Framework* which mandates that lived experience is at the heart of reform.

Prior to the CES, carer experience was not collected in a systemic way

The CES provides an opportunity for carers to provide feedback about their experience. Understanding the experiences of family, friends and other carers is a vital part of ensuring they are fully supported throughout their time with the service. The survey asks for responses about the carer's own experience and recognises the unique perspectives carers bring to the care of the person they are supporting. The CES asks a small number of demographic questions to help identify if particular groups of carers are reporting a different experience.

The CES is a tool to help carers and services work together to improve services

As well as providing an opportunity for carers to provide anonymous feedback, the CES is a tool that can help support services and carers to work in partnership. As well as completing a CES, carers can help services to understand results, identify areas for improvement and co-design action and change initiatives. Gathering feedback is the important first step; doing something with that feedback is what will ensure NSW mental health services continue to improve.

Services should use information gathered with the CES alongside consumer experience data from the Your Experience of Service (YES) survey when implementing service improvement initiatives.

The best things about this service were...

Friendly, caring nature of staff – willingness to provide information or find out information when asked.



My experience would have been better if...

We were able to visit and interact with the patient.



The Mental Health Carer Experience Survey (CES)

The Mental Health Carer Experience Survey (CES) asks carers about their experience of mental health services. It was designed in partnership with carers throughout Australia.

NSW implemented the paper version of the CES in 2018 (see Appendix 1) and an electronic version was released in 2019.

For information about the development of the CES see Appendix 3.

Implementing CES is a joint project between the NSW Ministry of Health and Mental Health Carers NSW

Implementation and ongoing support of the CES is guided by an advisory committee with representatives from Mental Health Carers NSW, the NSW Ministry of Health, carers and consumers, and each NSW Local Health District (LHD) and Specialty Health Network (SHN).

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.

The challenge of identifying carers

Throughout the development and testing of the CES, identification of carers was highlighted as a vital but often challenging component of collecting carer feedback. The national guidance states:

It is important that services ensure that they are able to identify carers – both those that visit the service as well as those who do not (due to location, work, family life or other barriers). It is important from a statistical and advocacy point of view that all carers have an equal opportunity of being offered a survey. If the Carer Experience Survey is only offered to carers who visit a facility or who attended an appointment this will introduce systematic bias into the data and the results will not be representative of the population of carers.

In healthcare, it is usually very clear who the consumer is, but identifying carers is more complex. Individuals may draw on support from different family members, loved ones or friends at different times and so the idea of a person's primary or main carer may be complex and fluid. Mental health clinicians and services may not always have complete or up-to-date information on the consumers' support networks.

The potential for bias in carer feedback is more of a challenge than in consumer feedback because services are much more likely to offer a CES to carers who have contact with services. If carers have no physical contact or limited awareness of the healthcare being provided, they will likely be less aware of the opportunity to provide feedback.

Later in this report, we explore which carers have completed a CES and which groups may be under-represented in the feedback.

When and how is the CES offered?

Guidelines for NSW Health services encourage services to offer the CES to all carers of people accessing NSW Health hospital and community mental health services. If consumers have been engaged with more than one team, the CES should be offered by each of these teams. The CES is available to carers aged 11 years or older.

To help make the CES more accessible, it has been translated into 35 community languages and is available both on paper and online.

See Appendix 2 for further information regarding CES distribution, collection and reporting in NSW.

Action and change

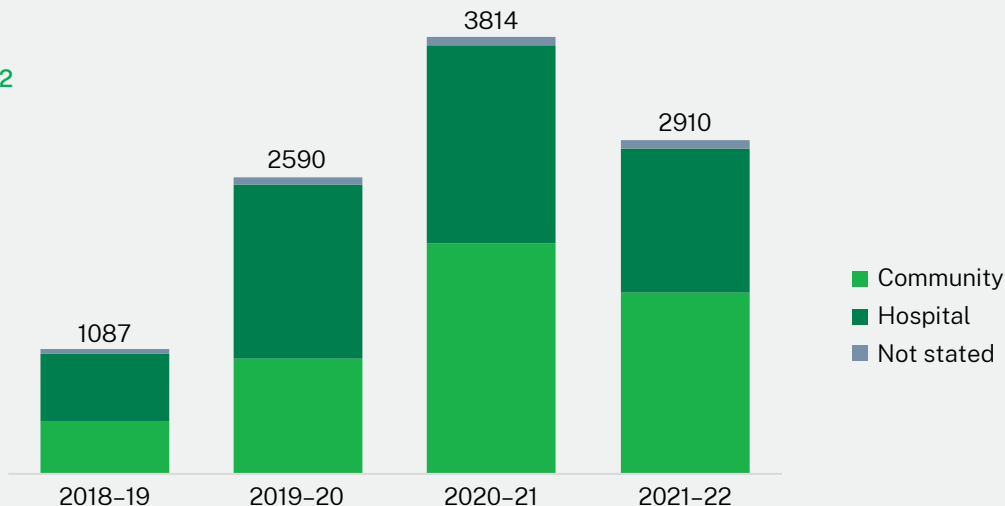
Feedback from the CES is used to support service improvement. The 'Action and Change Framework' is used as part of consumer and carer experience measurement in NSW. It helps NSW health services involve carers and consumers in planning and implementing service improvements. This process of co-design is an essential component of the CES.



How many carers completed a CES?

The number of surveys received each financial year

2910 surveys were received in 2021–2022



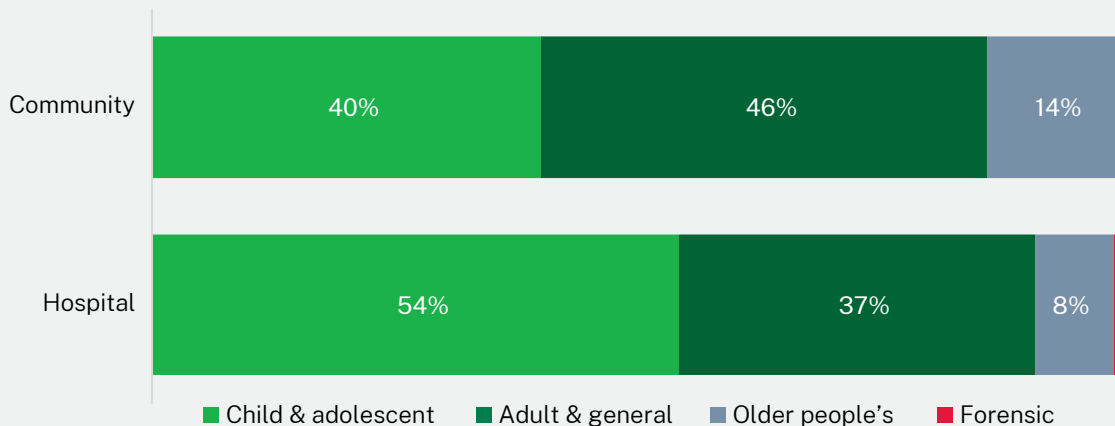
NSW aims to hear from as many carers as possible

Fewer surveys were completed in 2021–22 compared to the previous year. The CES is anonymous, and because there is no way of knowing how many carers were offered a survey, we cannot estimate a response or return rate. The number of returns is likely to have been impacted by the COVID-19 pandemic and ongoing pressures and restrictions on mental health services. There was a slight decrease in returns in July and December 2021, followed by a more substantial decrease in January–March 2022. The number of surveys returned improved in April–June 2022.

Two-hundred and seventy-seven services received feedback using the CES

There were 2910 CES returns in 2021–22. Two thirds (67%) were about community services (186 teams) and 33% were about hospital services (91 services). Most surveys were from child and adolescent services (46%) or adult and general services (42%).

Proportion of surveys received from different service types



Note: Due to rounding, some totals may not equal 100%.

Two-fifths of surveys for community services were completed online

The electronic version of CES was launched in August 2019. Uptake of the online survey has continued to increase, particularly in the community, since COVID-19 restrictions were first introduced in 2020. In 2021–22, 39% of community surveys were completed online, compared to 7% of hospital returns. The largest proportion of surveys returned online were from adult and general services, with 15% of online hospital returns and 55% of community returns. 31% of returns for community child and adolescent services were also online.

7% of CES surveys were completed by Aboriginal people

A total of 168 surveys were completed by Aboriginal people this year. Most of these were about community services (54%). Aboriginal carers were better represented in feedback about hospital adult and general services (8%). Aboriginal carers were slightly more likely than non-Aboriginal carers to complete the CES online for community services (55%), compared with non-Aboriginal carers (43%).

Approximately 4% of CES respondents speak a language other than English at home

Of the carers who have completed a CES in 2021–22, around 3% only speak a language other than English and a further 1% speak another language in addition to English. Despite this, only four translated surveys were completed. Fewer people who speak a language other than English completed a CES this year compared to previous years. The paper and online versions of the CES have been translated into 35 community languages. The low number of translated versions completed is mirrored in the returns of the YES survey completed by consumers. More work is needed to promote the availability of these translated versions.

My experience would have been better if...

I had more contact with the treating doctor to discuss concerns and strategies.



The best things about this service were...

The care from all staff towards my child was always above and beyond and I was treated exactly the same.



Which carers completed a CES?

A range of carers have completed the CES

It is important to know if some groups of carers are less likely to complete a CES. Since the CES was implemented, a broad range of carers have provided feedback, but more work is needed to reach as many carers as possible.

Most carers completing the CES are caring for their child

67% of community returns and 66% per cent of hospital CES returns were completed by parents caring for their child. Most carers were aged 35–64 years (72% in community, 79% in hospital) and caring for a consumer of child and adolescent or adult and general services.

The majority of carers identify as female and have been caring for a long time

More than 70% of CES responses were from people who identified as female (75% in community, 70% in hospital). Most carers who provided feedback using the CES have been caring for over 10 years (47% in community, 49% in hospital). In community services, most carers (89%) reported that the person they cared for had been receiving care from the service for more than one month. In hospital settings, many consumers (66%) had been engaged with the service for less than six months.

The proportion of CES surveys from Aboriginal carers has increased but this group is still likely to be under-represented

6% of community and 7% of hospital surveys were returned by Aboriginal carers, which is an increase from previous years. According to the YES data, in 2021–22, approximately 13% of community and 12% of hospital consumers identified as Aboriginal (Your Experience of Service: What consumers say about NSW mental health services 2021–22). When estimating how representative the CES results are, it is important to consider three things: not all consumers have a carer, not all carers of Aboriginal consumers are Aboriginal themselves, and some Aboriginal carers may be caring for non-Aboriginal consumers. While CES returns are likely to under-represent Aboriginal carers, this is difficult to estimate with the carer information currently available.

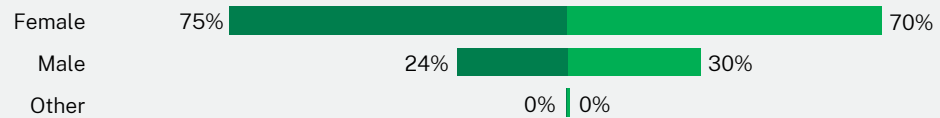
A small number of CES surveys were from young carers

Only 1% of community surveys and 4% of hospital surveys were from carers aged under 25 years. Young carers face unique challenges in their caring role which can also make it more difficult for services to identify them. Many young people may not use the term carer to describe themselves, which may reduce the likelihood of them completing a CES.

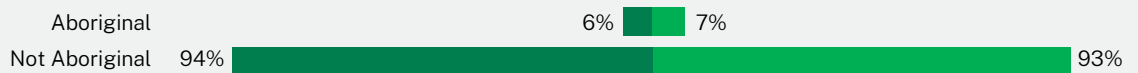
Proportion of CES returns across different groups

■ Community ■ Hospital

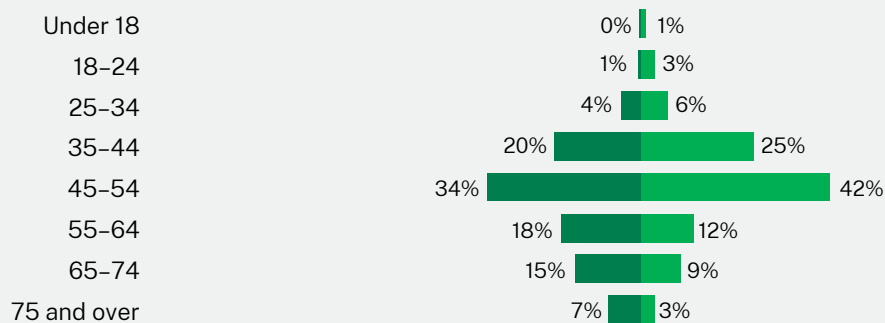
Gender



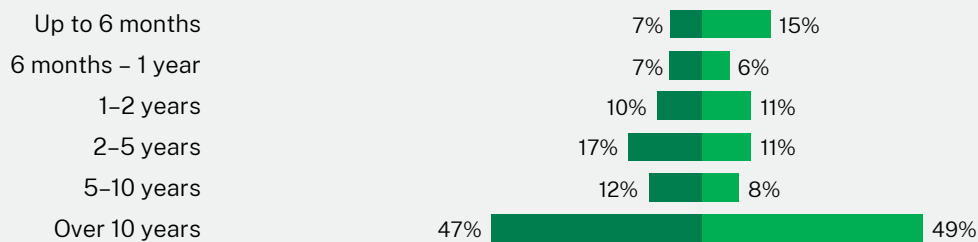
Aboriginal and/or Torres Strait Islander



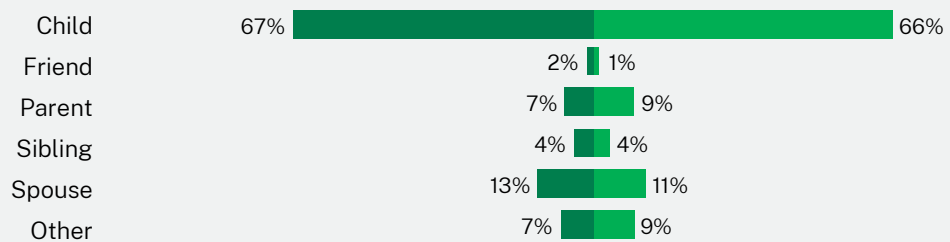
Age group (years)



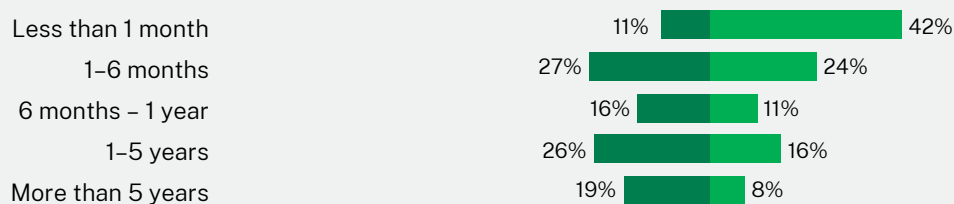
Duration as a carer



Relationship (the person I care for is my...)



Duration with service



What did carers say about their experience?

Using an overall experience score

Overall experience was summarised by combining the scores of questions 1–24 (excluding Q15 and Q19). This ensures that different areas of experience are included in the overall score. This score was then used to calculate the percentage of carers reporting an excellent or very good experience. Using this method, 69% of carers reported an excellent or very good overall experience. The percentage of carers reporting an excellent or very good experience was similar across hospital and community settings (69% community, 68% hospital).

The survey also contains a question that allows a carer to rate their own overall experience: Q28. *Overall, how would you rate your experience as a carer with this mental health service over the last three months?* When compared to the overall experience score, carers' rated question 28 about the same in community settings (70% excellent or very good) but lower in hospital (58%).

Respect, Participation and Individuality were the highest-rated domains

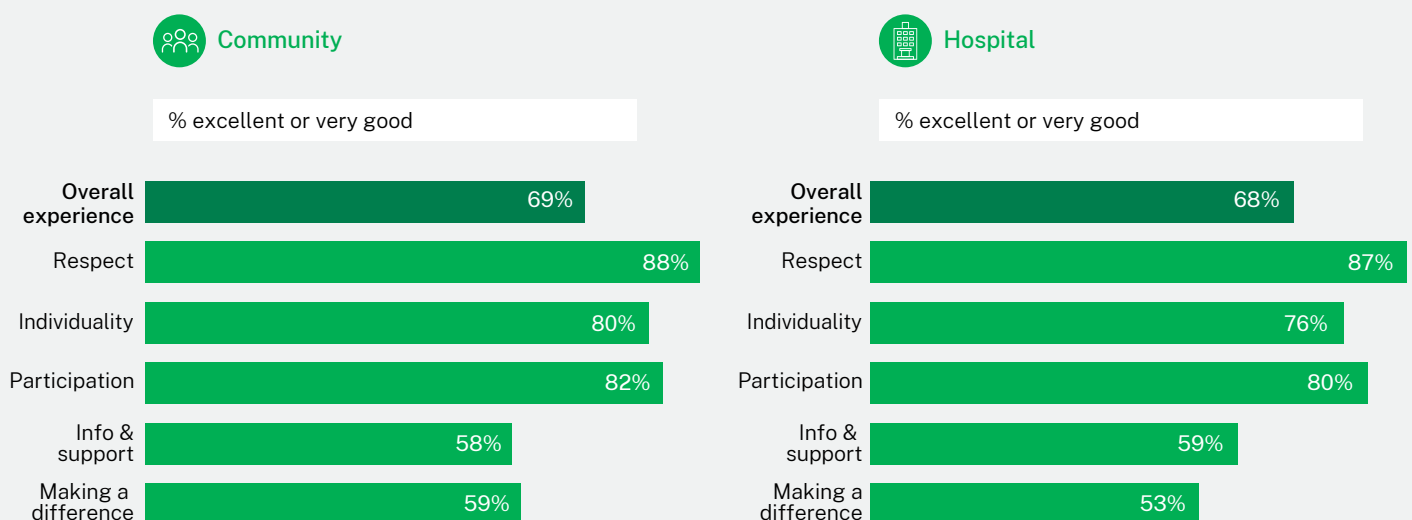
CES questions are grouped into five domains, consistent with those used in the YES questionnaire. The most positive experiences were reported for the domains of Respect, Participation and Individuality. Overall, fewer carers rated the Information and support and Making a difference domains as excellent or very good.

Carers' experience throughout the COVID-19 pandemic

It is important to acknowledge the ongoing impact of the COVID-19 pandemic on carer and consumer experience throughout 2021–22. While we are unable to reliably compare CES feedback with pre-COVID-19 experience, we can use the free-text responses and information collected from certain CES questions to understand some of the impacts. Overall, carers had a mixed experience of telehealth. When carers had more contact with services (face-to-face or telehealth), they reported a more positive experience. For many carers, particularly in the community, regular communication and being involved had a positive impact on experience.

In hospital services, carers commented that one of the most challenging aspects of COVID-19 was visiting restrictions. Many commented that their experience would have been better if information about restrictions was more clearly communicated. With continued restrictions across mental health services in 2021–22, many carers reported that they needed more contact than they had previously received to remain connected and involved in their loved one's care.

Overall experience score and domains



My experience would have been better if...

"Information was consistent. The brochure is out of date and has conflicting information to what is on the ward."

"We had known that weekends operated differently from the beginning."

"Doctors were more available to speak."

"More information about what to expect."

"They were caring, positive and there were follow up phone calls."

The best things about this service were...

"All the information I was told about the plans and progress made me feel better."

"I was treated with respect and advised every step of the way."



Do some groups of carers report a different experience?

It is important to know whether some groups of carers have a different experience of services. This can help services identify how they can better meet the needs of all carers. Knowing which groups of carers report a different experience also helps when interpreting other data in this report. Some apparent differences between services may be simply because they support different groups of people. For this analysis we compared the overall experience of different groups of carers with the average experience of all carers. For more information about how this was calculated, and the significance testing methods, see Appendix 3.

Most groups of carers did not have a significantly different experience to the average

While there are differences in experience across different carer groups, whether these are significant or not is influenced by the average score and the number of responses. In 2021–22 there was a small number of carer groups that reported a significant difference when compared to the average for all carers.

In community services, people who were assisted to complete the survey reported a significantly more positive experience

Carers who were assisted by staff members, including peer workers, to complete the survey reported the most positive experience of any group (86% excellent or very good). In the free-text comments, these carers frequently stated that they felt supported and understood by staff.

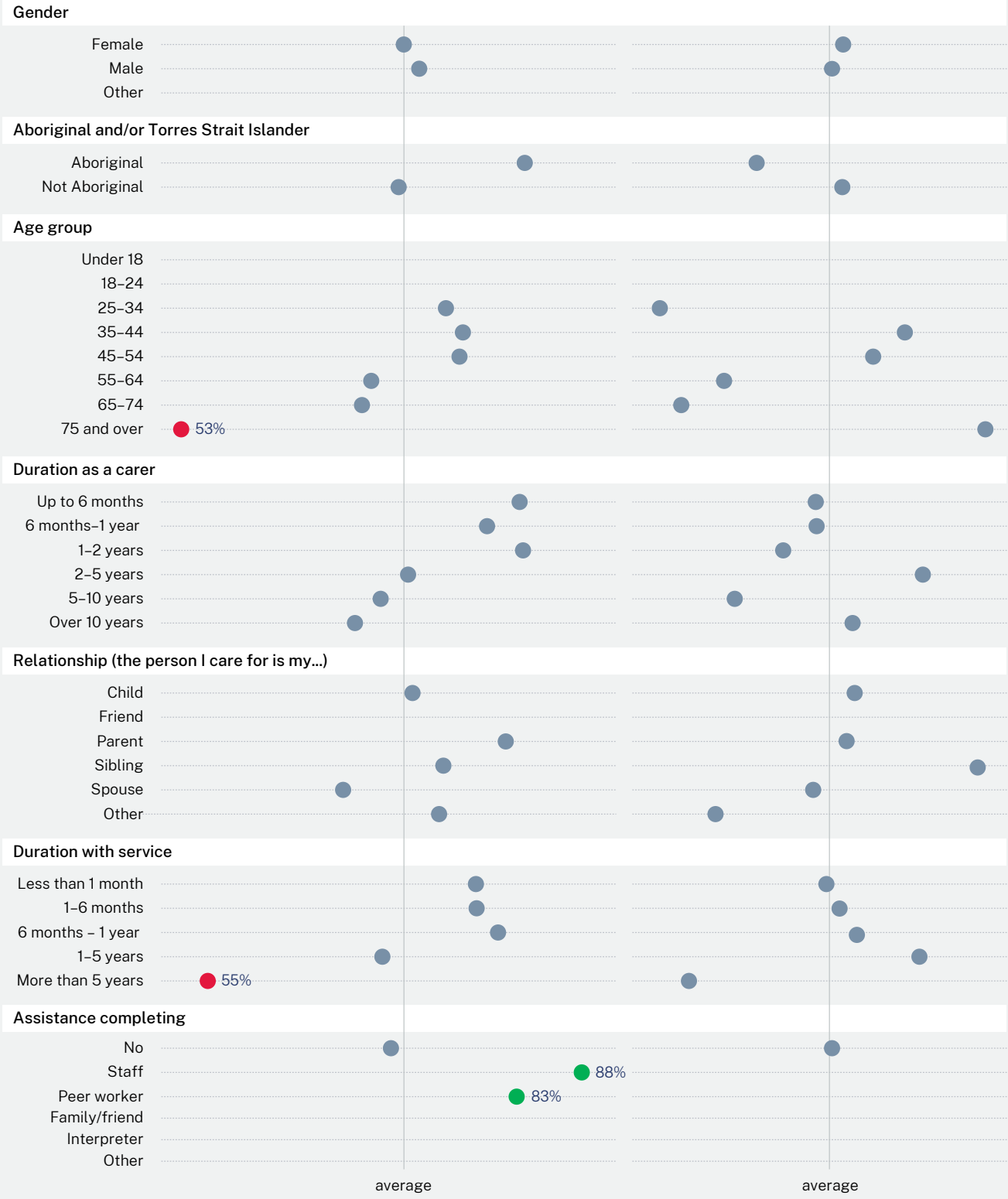
When consumers had a long duration of care with community services, carers reported a significantly less positive experience

Where the consumer had been engaged with a community service for more than five years, carers reported a less positive experience. As in previous years, these carers often commented that they needed more information and better communication from the service.

In community settings, carers aged 75 years or over reported the least positive experiences

Of carers aged 75 years and over, only 53% reported an excellent or very good overall experience. The highest scoring domain for this group was Respect, and the lowest was Information and support, which had a score of 44% excellent or very good. In the free-text responses, carers said that their experience would have been better if more information was given and if they had felt listened to.

The overall experience of different groups of consumers



Legend:
 Compared to NSW average:
 ● Significantly higher
 ● Significantly lower
 ● No difference

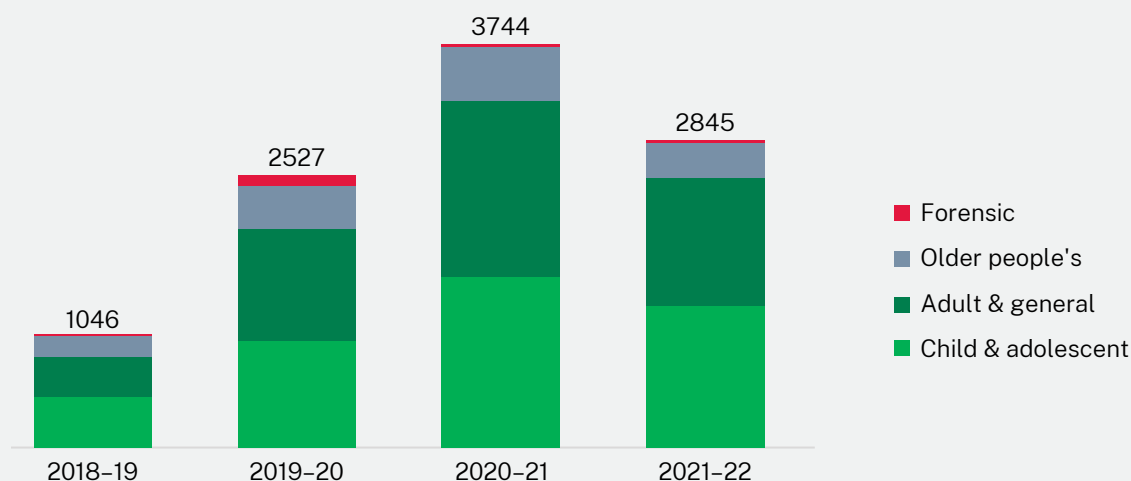
Note: Groups with less than 30 surveys returned are not displayed. Whether a difference is significant is influenced by the average score and the number of responses. Groups may have the same score but not the same significance rating, due to rounding or because of smaller numbers of returns.

A focus on carers in age-specific services

Carers in child and adolescent services returned the highest number of surveys

Since CES was implemented, the highest number of surveys have been returned for child and adolescent services. In 2021-22, 1318 surveys were received for those services, followed by 1191 for adult and general services. It is generally easier to identify a carer for a young person, and this may partly explain the higher number of surveys for child and adolescent services.

The number of surveys received each financial year



The best overall experience was for carers in child and adolescent services and older people's services

Child and adolescent services received the highest rating of overall experience in community settings and in combined hospital and community scores (74% excellent or very good). In hospital care, older people's services reported the most positive experiences with 78% rating their experience as excellent or very good. Carers of people accessing adult and general services rated their experience lower (65% in community, 54% in hospital) compared to age-specific services.

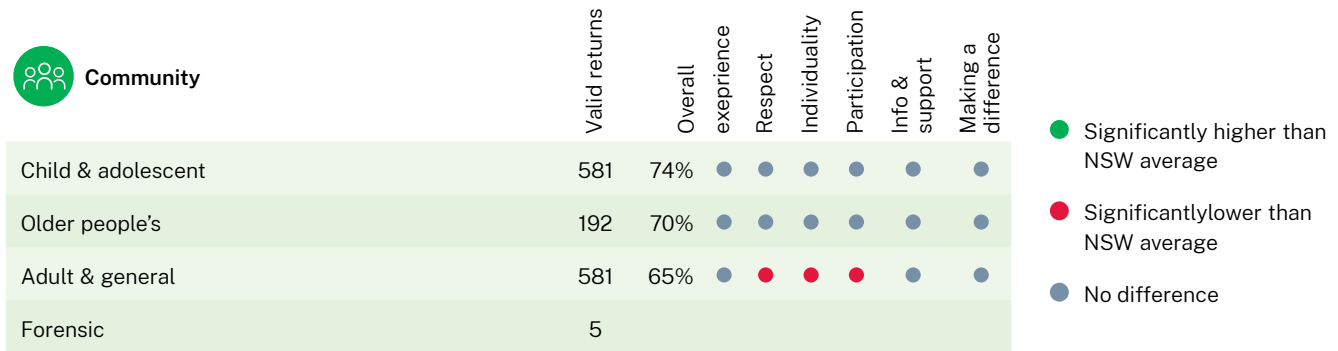
Child and adolescent services scored significantly higher on the Respect, Individuality and Participation domains

Scores varied across the five domains, with carers in child and adolescent and older people's services consistently rating their experience more positively than adult and general services. In child and adolescent services, carers reported a significantly more positive experience overall, and in the domains of Respect, Individuality and Participation. In contrast, carers in adult and general services reported a significantly less positive experience overall and in those same domains as well as the Information and support domain.

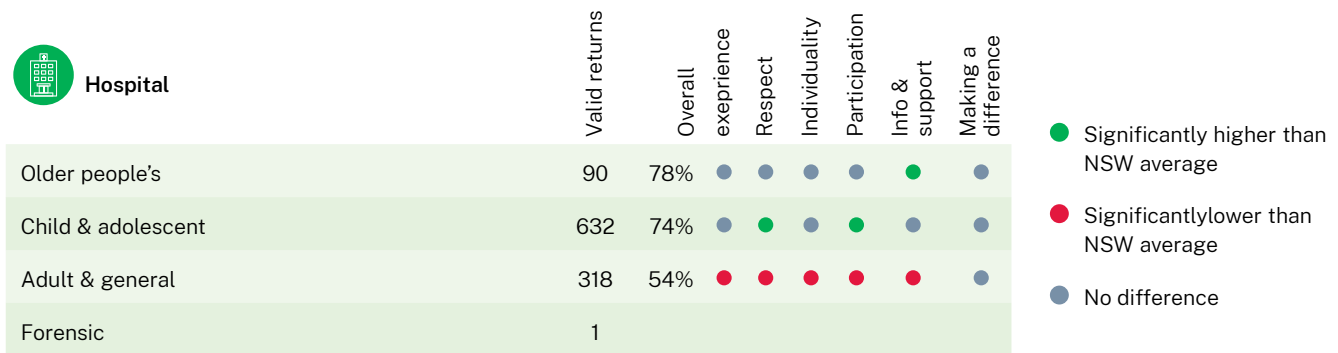
Carers in age-specific services reported a more positive overall experience

Overall	Valid returns	Overall experience	Respect	Individuality	Participation	Info & support	Making a difference	Comparison to NSW average	
								Significantly higher	Significantly lower
Child & adolescent	1213	74%	●	●	●	●	●	●	●
Older people's	282	73%	●	●	●	●	●	●	●
Adult & general	899	61%	●	●	●	●	●	●	●
Forensic	6								

In the community, carers in adult and general services reported a significantly less positive experience in the domains of Respect, Individuality and Participation.



In the hospital, carers in older people's services reported the most positive overall experience and a significantly more positive experience in the domain of Information and support. Carers in adult and general services reported a significantly less positive overall experience and in all domains except for Making a difference.



Identifying carers in adult and general services may be more difficult than in age-specific services. This may mean that carers for people receiving adult and general care are under-represented in the feedback, but also feel less recognised by the service and less included in care.

Staff characteristics and communication had the most impact on positive experience

Carers in child and adolescent and older people's services often commented on communication and staff attributes such as caring and friendliness as some of the best things about the service. Carers in adult and general services often commented that their experience would have been better with improved communication and easier access to services.



Is there a regional difference in carer experience?

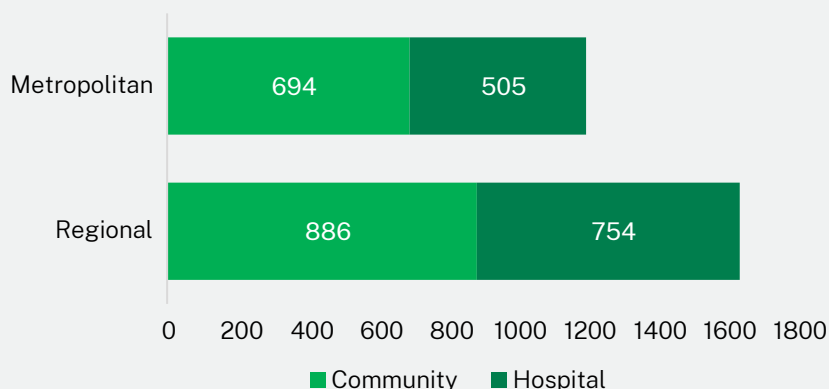
Services in metropolitan and regional areas see different populations of consumers and carers. There may also be different obstacles to care delivery and communication due to service location and geographical differences. This section looks at the experience of regional and metropolitan services across NSW. Local Health Districts (LHDs) and Specialty Health Networks (SHNs) have been grouped as follows:

Regional	Metropolitan
CCLHD	NBMLHD
FWLHD	NSLHD
HNELHD	SCHN*
ISLHD	SESLHD
MLHD	SLHD
MNCLHD	SVHN*
NNSWLHD	SWSLHD
SNSWLHD	WSLHD
WNSWLHD	

Notes: * These SHNs have been included in the metropolitan group based on geographical location. The Justice and Forensic Mental Health Network has been excluded from this analysis.

Carers in regional services returned 58% of all surveys for 2021–22 and 55% of surveys since 2018.

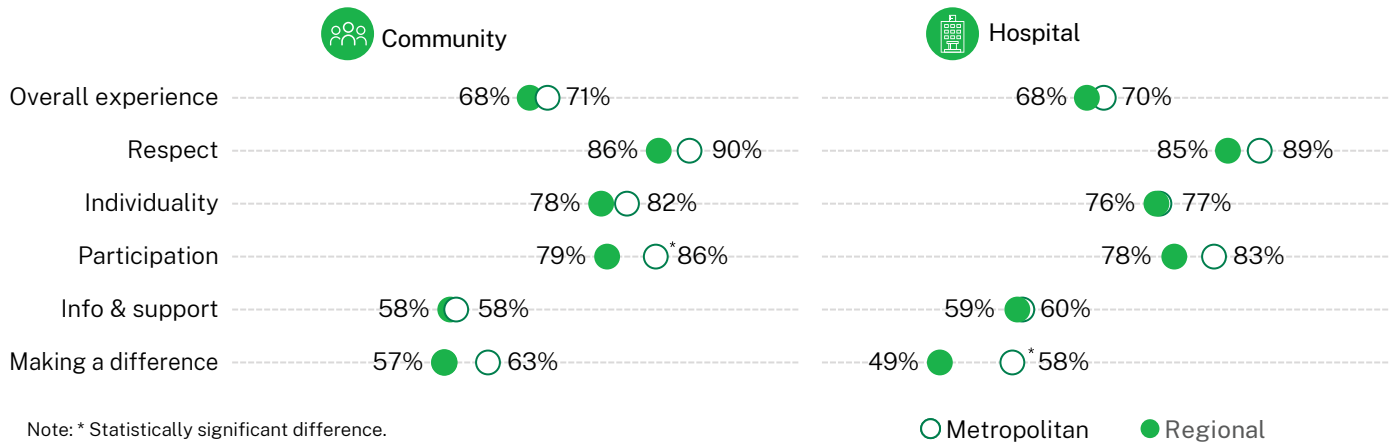
The number of surveys from regional and metropolitan locations in 2021–22



Carers in metropolitan services report a more positive experience overall and across all domains

In community settings, carers in metropolitan areas reported a more positive experience (71% excellent or very good) than carers in regional areas (68% excellent or very good). In both regional and metropolitan areas, the most positive experience was for the domains of Respect, Individuality and Participation, but these were rated higher in metropolitan areas. While the largest gaps were in the domains of Participation (community) and Making a difference (hospital), Information and support was rated similarly across regional and metropolitan services in both settings. In the free-text comments, feedback was broadly similar for metropolitan and regional districts, although in regional districts, location and travel to the service was mentioned as one of the things that could have been better.

Excellent or very good experience across regional and metropolitan locations



In community settings, 10 questions were rated as significantly more positive in metropolitan services. The three questions with the greatest difference were:

Q17. *You had opportunities to communicate confidentially with the treating doctor if you needed*

Q25. *Your relationship with the person for whom you care*

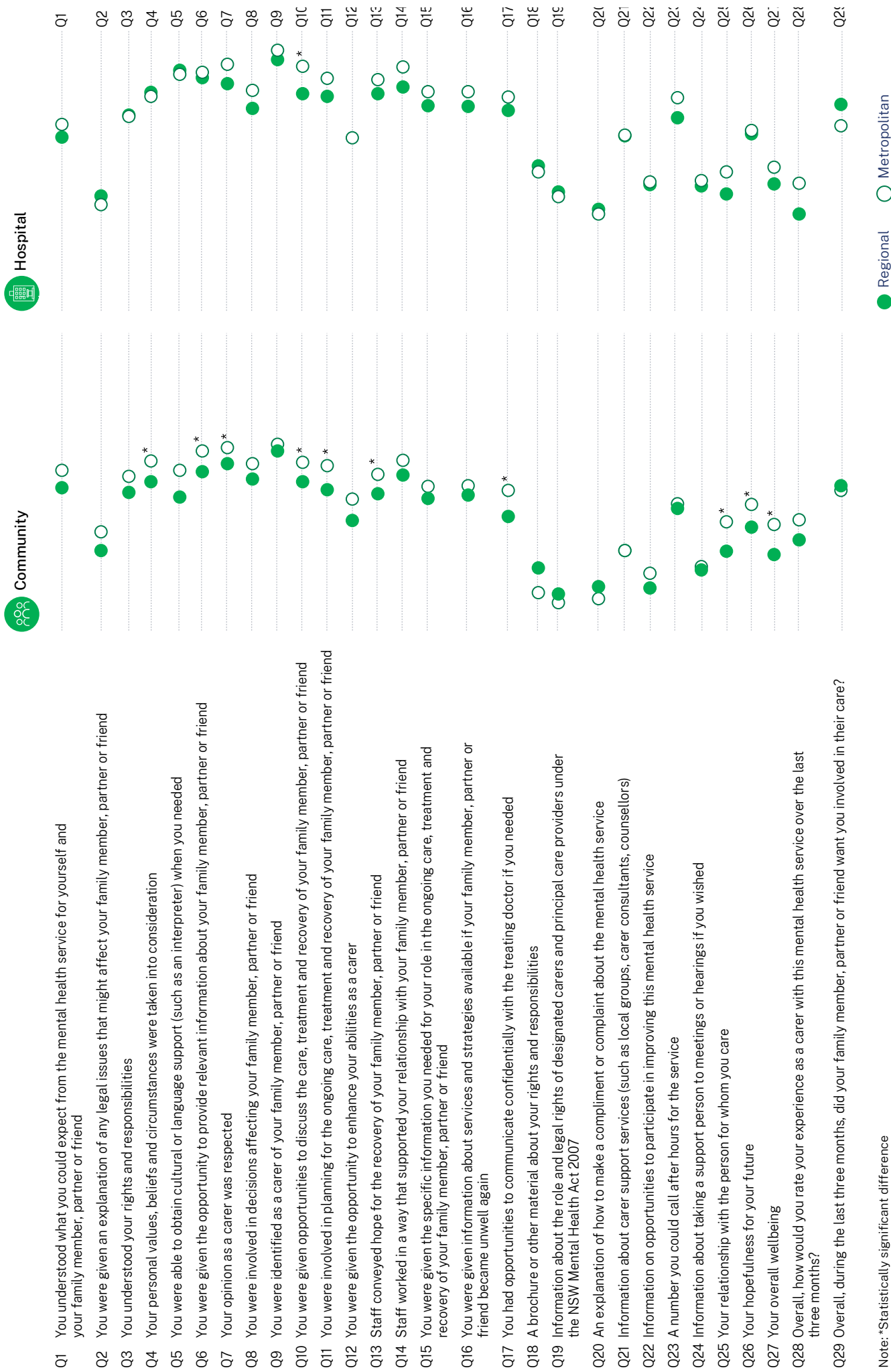
Q27 *Your overall wellbeing*

One question was rated as significantly more positive in hospital settings:

Q10. *You were given opportunities to discuss the care, treatment and recovery of your family member...*



CES items rated as excellent or very good, comparing regional and metropolitan services



Note: *Statistically significant difference

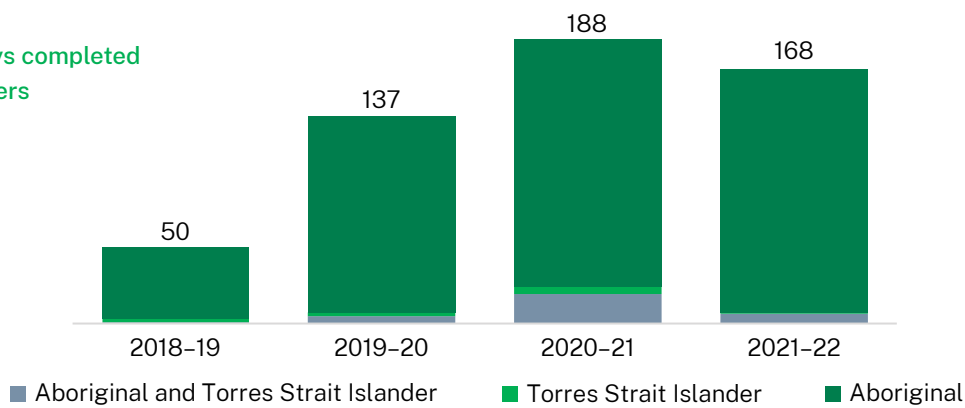
What was the experience of Aboriginal carers?



It is important to acknowledge different factors that can affect the experience of Aboriginal people, including the historical aspects and impacts of colonisation. Health is strongly affected by broader social and community factors, including transgenerational trauma and disadvantage. NSW Health is committed to delivering holistic and culturally safe services to make a positive difference to Aboriginal people, families and communities. This commitment is outlined in the NSW Aboriginal Mental Health and Wellbeing Strategy 2020–2025. In this report the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander.

In 2021–22, 12% of all people accessing hospital and community mental health services in NSW identified as Aboriginal. 168 surveys were completed by Aboriginal carers (6% of community returns, 7% of hospital returns). The proportion of all responses completed by Aboriginal people has increased slightly compared to previous years.

Number of surveys completed by Aboriginal carers

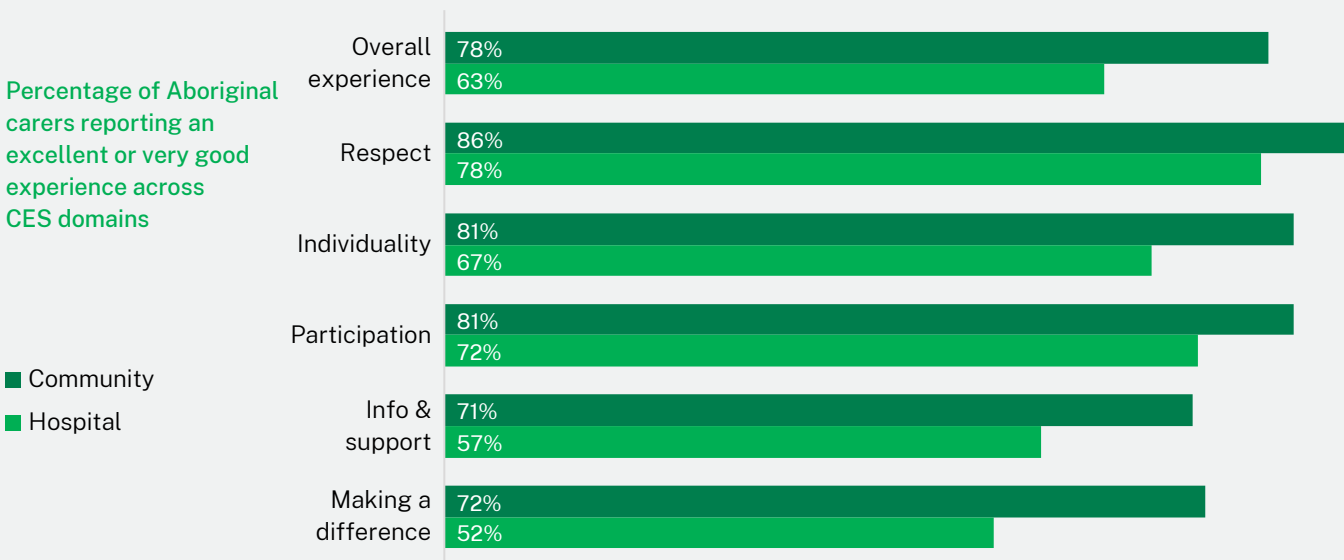


Aboriginal carers reported a more positive experience of community services than hospital services

Around 78% of Aboriginal carers in the community and 63% in hospitals reported an excellent or very good overall experience. This more positive experience in the community was reported across all domains, with the biggest difference seen in the domains of Individuality and Information and support.

Compared with 2020–21, the experience of Aboriginal carers in the community has improved by over 10% across all domains. The percentage of Aboriginal carers returning the survey also increased slightly, from 4% to 7%. It is possible that the increase in proportion of surveys from Aboriginal carers provides a more representative view of the experience of Aboriginal carers, rather than showing an actual change in how services are being provided.

Percentage of Aboriginal carers reporting an excellent or very good experience across CES domains

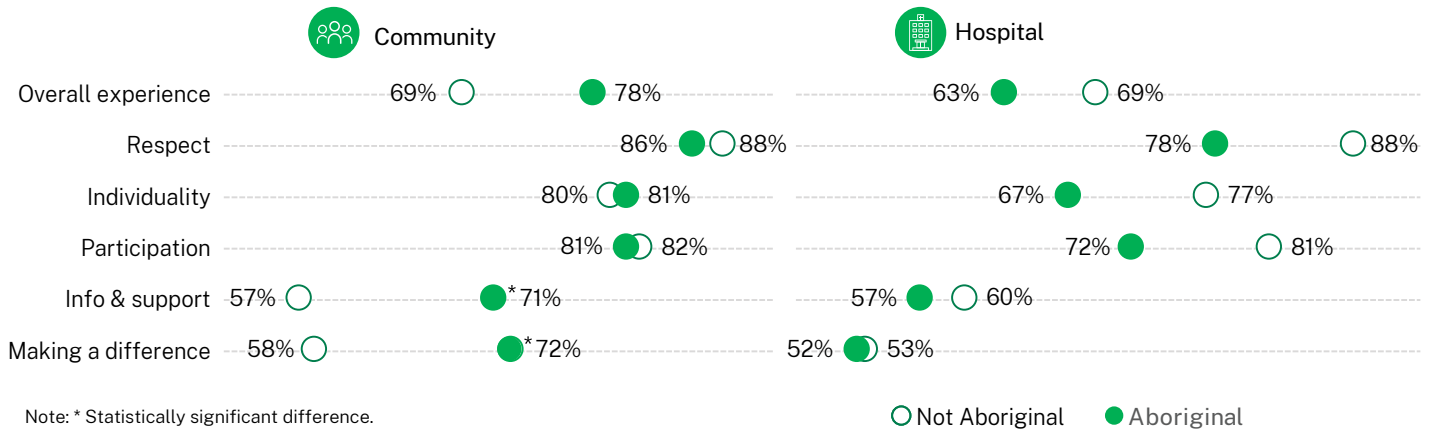


Aboriginal carers in community settings reported a significantly more positive experience in the Information and support and Making a difference domains

When comparing the experience of Aboriginal and non-Aboriginal carers, the overall experience of Aboriginal carers in the community was rated higher than for non-Aboriginal carers. Aboriginal carers in the community also reported a significantly more positive experience in the Information and support and Making a difference domains compared to non-Aboriginal carers.

In hospital, overall experience was less positive for Aboriginal carers. This was observed across all domains, with the largest differences in Respect, Individuality and Participation (although these were not statistically significant).

Percentage of Aboriginal carers reporting an excellent or very good experience across CES domains



In community settings, three questions were rated by Aboriginal carers as significantly more positive:

Q16. You were given information about services and strategies available if your family member, partner or friend became unwell again

Q19. Information about the role and legal rights of designated carers and principal care providers under the NSW Mental Health Act 2007

Q24. Information about taking a support person to meetings or hearings if you wished

Q27. Your overall wellbeing



CES items rated as excellent or very good by Aboriginal and non-Aboriginal carers



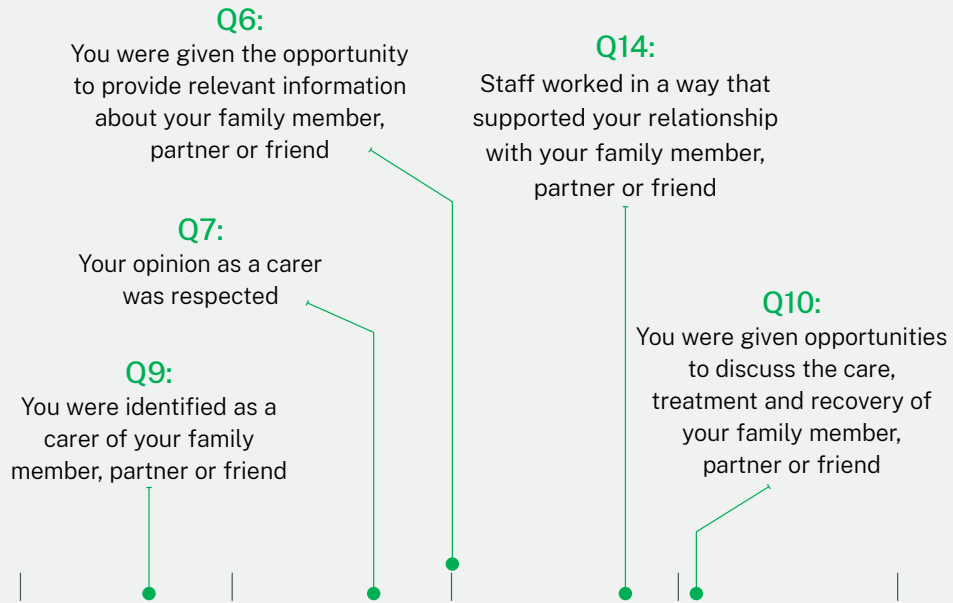
Note: *Statistically significant difference

Aboriginal Not Aboriginal



Highest and lowest scoring questions

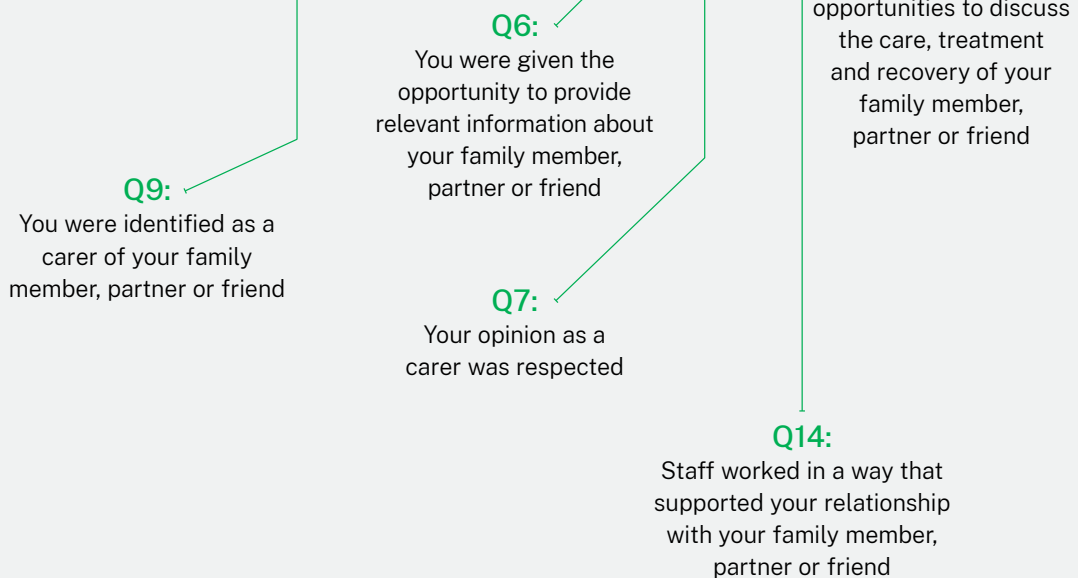
Community

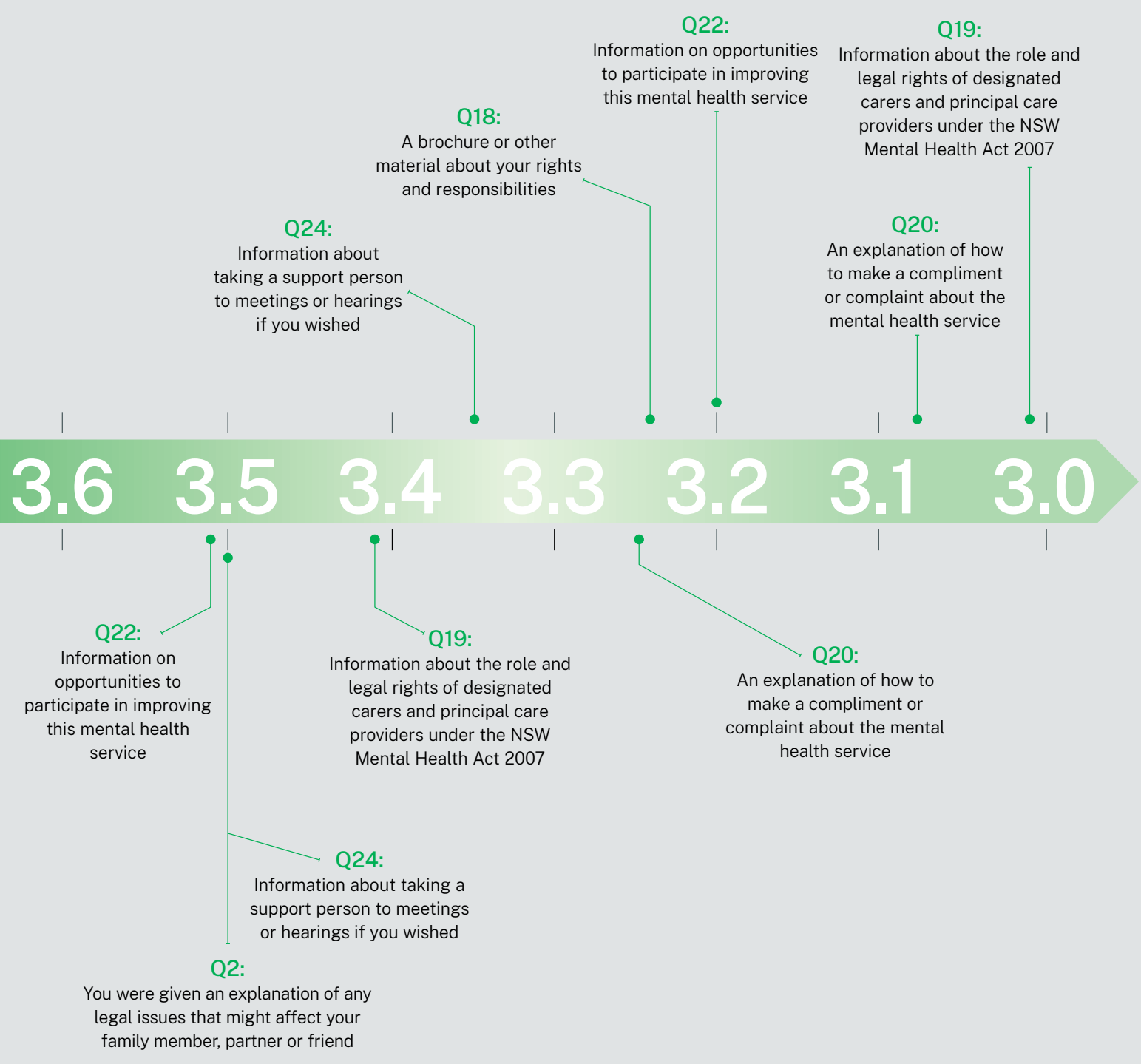


5.0

4.8 4.7 4.6 4.5 4.4

Hospital





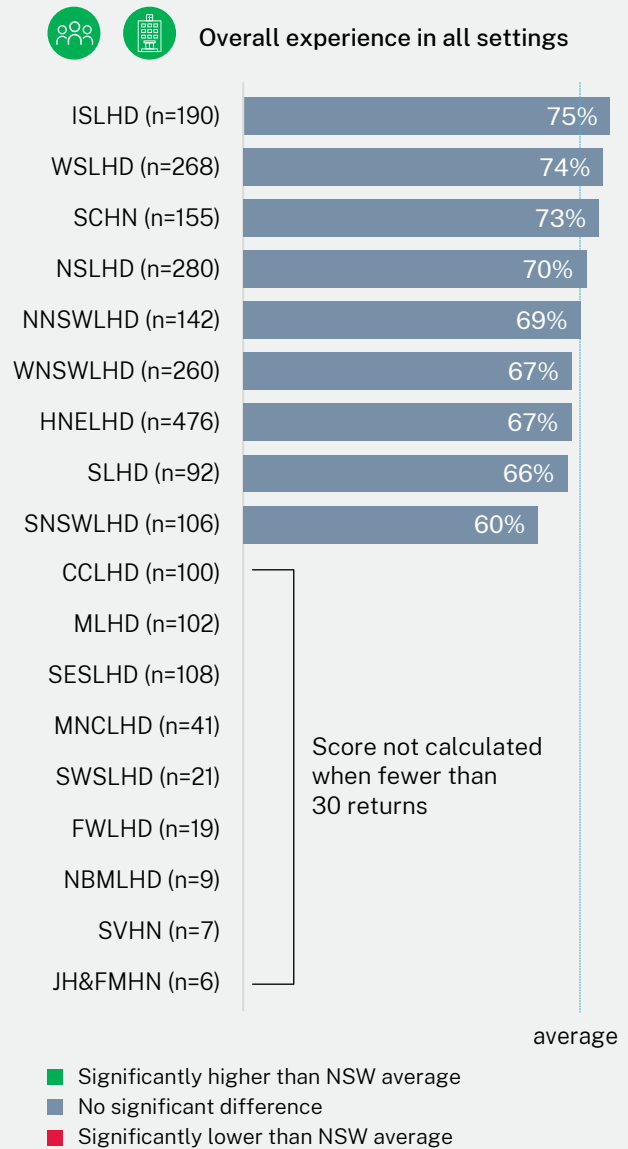
How do LHDs and SHNs compare in 2021–22?

This section looks at the percentage of carers reporting an excellent or very good experience across LHDs and SHNs using the overall experience index (the average of questions 1–24, excluding Q15 and Q19). Hospital and community data need to be combined into a single performance measure that is not altered by a different mix of hospital and community responses between LHDs and SHNs. The simplest method for this is to calculate hospital and community scores separately and then combine them in a simple unweighted average.

In this report, we only present differences where there are 30 or more responses for an individual LHD or SHN.

At this stage a target has not been developed for CES performance. The following graphs compare LHD and SHN scores to the NSW average. Significance testing was used to identify the districts that were rated significantly above or below the NSW average.

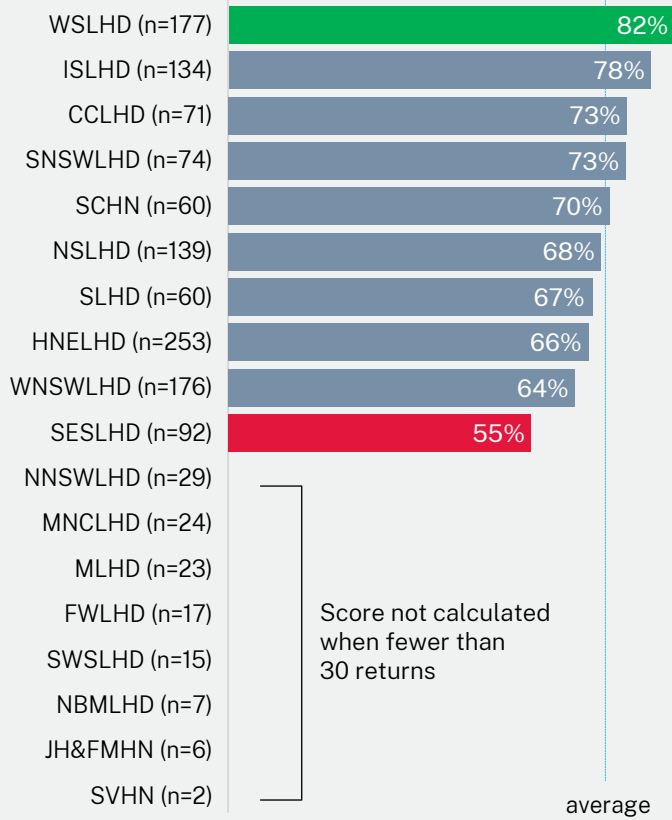
In 2021–22, 13 districts/networks submitted enough returns to calculate the overall experience. No districts/networks scored significantly above the NSW average and one scored below.



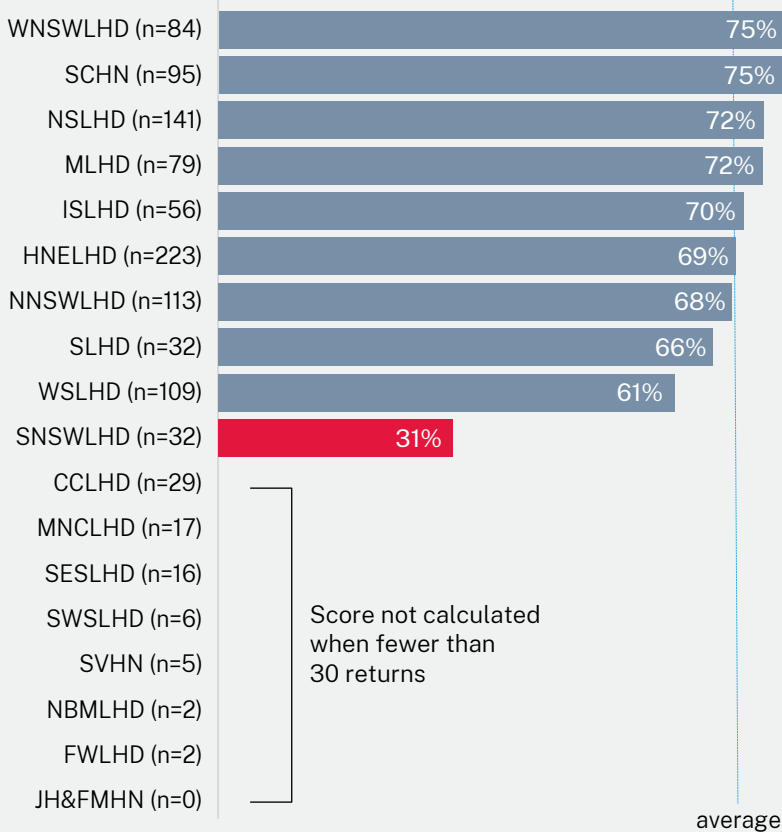
Notes: Whether a difference is significant is influenced by the average score and the number of responses. LHDs and SHNs may have the same score but not the same level of significance, due to rounding or because of a smaller number of returns. Due to rounding, some bars on the graph may have the same number even though they differ slightly in length.



Overall experience in community



Overall experience in hospital



- Significantly higher than NSW average
- No significant difference
- Significantly lower than NSW average

My experience would have been better if... There was better communication about leave for the patient.

The best things about this service were... Getting the tools to help our son deal with his anxieties.



Themes from the free-text responses – what do carers want from our services?

Questions 30 and 31 asked carers to provide detailed comments about areas for improvement (Q30. *My experience with this service would have been better if...*) and things that went well (Q31. *The best things about this service were...*). Carers were slightly more likely to comment on the best things about the service (1425 responses) compared to the things that could be improved (933 responses).

Responses to these questions revealed very clear key themes. In fact, the responses to both questions often raised the same issue because it was both the thing that was best about a service, or what could be better about a service.

Carers told us many of the things they need from a service to make their experience a positive one.

★★★★★ The recipe for ★★★★★ **SUCCESS** What carers want!

- ✓ Staff are kind, empathetic and responsive
- ✓ I can contact staff when I need to
- ✓ Appointments are regular and consistent
- ✓ It is quick and easy to access carer
- ✓ Staff listen to and respect my contribution
- ✓ Staff provide me with feedback and information
- ✓ The same staff member provides care over time
- ✓ Care is offered face to face and virtually

COVID-19 was raised frequently in the feedback

There were regular comments about the impact of COVID-19 on carers' experiences. In hospital services, carers most frequently commented on visiting restrictions having a negative impact. In both community and hospital settings, COVID-19 was mentioned as affecting access to clinicians to share information and be involved in care planning.

Regular communication and being involved remain the most common themes in carer feedback

Communication was often mentioned by carers in response to both free-text questions. When highlighted as something that could be improved, carers often mentioned that they needed more contact with services and detailed the importance of frequent communication and consistent information from staff. Carers often mentioned their need to be listened to and recognised as making an important contribution in care planning for the person in their care.

When carers had a more positive experience, they often commented that this was because of the clear and regular two-way communication with staff. This contact helped carers to feel informed, involved and supported.

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

'More consistent and clearer communication. Better feedback on how the person I care for is progressing.'

'They listened to my concerns. They took time to understand our situation.'

The best things about this service were...

'The case manager communication and the access to a psychiatrist. Lovely staff, understanding.'

'Effective communication – consulted by team – my daughter was respected and safe.'

Information is a key ingredient for positive carer experiences

In their comments, many carers highlighted their need for more information about the service, the care and treatment of their loved one, future planning and support services.

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

'I had more information about what to expect.'

'I had been told what was expected to be achieved and what period of time the service was to be involved.'

The best things about this service were...

'We felt well supported and informed of all the information and services we can access.'

'Regular visits giving good information – overall great support.'

'Being able to access support and information via email and Zoom meetings regularly and consistency of support for our son. Kindness care for the whole family.'

Staff qualities are often the best things about a service, but access to staff and changes in staff can be challenging

When staff were mentioned as the best thing about a service, comments frequently described personal qualities such as 'kindness', 'compassion', 'caring', 'professional' and 'patient'. When mentioned as something that could be improved, carers often mentioned that they needed more frequent and easier access to staff and consistency in the staff involved in care.

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

My family member has had in the last 18 months, five different case workers...It doesn't give [them] the time to develop a close bond with the case worker.'

'I had contact numbers [instead of an] unlisted, blocked telephone number.'

The best things about this service were...

'Supportive, caring staff, always providing suggestions to help make the process less stressful and make each day easier to get through with solutions along the way.'

'The friendly staff. The way your service helped to make my role as carer more easy to manage. The information you provided me with, both written and verbal, that helped me to become a better carer.'

My experience would have been better if...

They had listened to me and admitted him sooner. I have been caring for 26 years and know when he needs to be admitted.



The best things about this service were...

Being a part of my mum's treatment plan.



What's next in measuring carer experience?

Continuing to hear from more carers

The first few years of CES feedback has helped fill an important gap in understanding peoples' experience of mental health services in NSW. While the number of surveys completed since the CES was implemented is very encouraging, more work is needed to ensure all carers have an opportunity to provide feedback. Promotion of the survey is vital to ensure we reach all carers, especially those who are often missed by services.

Action and change

Collecting carer experience is only the first step of the CES. Most important is how this feedback is used to improve how services work together with and support carers. The action and change cycle describes a process of continually collecting feedback, analysing and reporting that information and developing processes for services to work together with carers to make real change. Many services across NSW are already using CES data and working in partnership with carers to co-design and implement service-improvement initiatives. As more feedback continues to be received using the CES, this process can become part of all NSW mental health services.

Mental Health Carers NSW capacity development

MHCN is developing resources and supports to assist carers and carer peer workers across NSW. One aspect of this will be helping carers and peer workers understand the CES results for their services. However, developing the ability to interpret CES and YES results and their implications for service improvement is a key capacity development objective for all levels of service delivery, review design and management in NSW Health services, not only for peer workers. MHCN will work with InforMH and NSW Health quality improvement frameworks and processes to refine the capacity to analyse CES results against issue specific improvement frameworks (e.g. the Agency for Clinical Innovation's Framework for Implementing trauma-informed care), and more general concepts of mental health literacy. This will help carers and peer workers identify key areas for action. These resources and supports will be promoted by MHCN through its planned Carer Peer Worker Community of Practice under the MHCN Mental Health Carer Advocacy Network.

Getting carer experience on the agenda

As with consumer experience, carer experience needs to be a part of all conversations about service improvement. From the individual team up to the executive level, this valuable information should be included as part of ongoing discussions. Through the benchmarking program, the NSW Ministry of Health will continue to support services to understand and use their CES feedback.

Appendix 1 – Survey

Service:



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 last three months , how often did the following occur?	As a carer with a family member, partner or friend who had contact with this mental health service in the last three months, 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 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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. You were identified as a carer of your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. You were given the opportunity to enhance your abilities as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Staff conveyed hope for the recovery of your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Staff worked in a way that supported your relationship with your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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"/>	<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> 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"/>

As a result of your experience with this mental health service in the *last three months*, has your life changed in the following areas?

A lot worse	A little worse	No change	A little better	A lot better	Not Needed
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

28. Overall, how would you rate your experience as a carer with this mental health service over the *last three months*?

Poor	Fair	Good	Very Good	Excellent	Don't Know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. Overall, during the *last three months*, did your family member, partner or friend want you involved in their care?

Never	Rarely	Sometimes	Usually	Always	Not Needed
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30. My experience with this service would have been better if...

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

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Please turn over →



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? Less than 18 years 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**

Appendix 2 – CES reporting process

Distribution to services

LHDs and SHNs order blank CES forms and pre-addressed envelopes using the same online ordering process as for other NSW Health forms. Services can also order promotional materials for the electronic CES (eCES) to encourage carers to complete the survey online.

Identifying services

Before distributing the CES to carers, services enter a unique four-digit service code in the service identification box on page 1 of the survey. If completing the CES online, this code must be entered by the carer before the survey can be completed. Using this code, carer feedback can be provided to specific services, while still allowing the carer and consumer to remain anonymous. More information about how services are identified is available in Appendix 3.

Sampling periods

NSW Health recommends that the CES is offered to all carers on a continuous basis, either at a consumer's discharge or at regular intervals if there is ongoing contact with services. LHDs and SHNs differ in their approach, and different service types may adopt methods of offering the survey that best fit their model of care.

Promotion

Services are encouraged to promote the availability of the CES through posters and the display of collection boxes. The CES can be made available in waiting rooms, but it is important that staff also regularly offer the survey to carers and explain its importance.

Returning

Carers place their completed CES form in a sealed, reply-paid envelope. This can be placed in collection boxes at the service or posted directly by the carer. Carers who complete the eCES are asked to submit their responses at the end of the survey. These are sent directly to the secure database.

Data processing

Completed paper surveys are collated and scanned by a commercial scanning organisation under contract to NSW Health.

The scanned data are then provided to InforMH, System Information and Analytics Branch, NSW Ministry of Health, within two weeks of the end of each month. Data are checked, validated and stored in a secure purpose-built structured query language (SQL) database on password-protected NSW Health servers.

Reporting on the CES

InforMH analyses CES data and reports to NSW mental health services regularly, including:

- monthly reports on the number of returns and overall experience
- quarterly reports summarising results for individual questions, the number of returns over time and the percentage of consumers reporting an excellent or very good experience across LHDs and SHNs
- quarterly reports containing all raw data and free-text responses to support further local analysis and improvement projects.

Appendix 3 – Technical information

CES development and validation

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

<https://www.amhocn.org/mental-health-carer-experience-survey-0>

Identification of NSW services

The CES is anonymous and contains no identifying information. Therefore, in order to report on services, all services must be accurately identified on the survey.

All NSW mental health services are registered in a central database, the Mental Health Service Entity Register (MH-SER) and have a unique four-digit numerical code. This four-digit code is used in CES reporting because:

- it can be more accurately scanned than a handwritten service name
- it allows CES feedback to be accurately compared to other data on the same service (e.g. consumer feedback).

If service codes are missing or invalid, the response cannot be attributed to an individual LHD/SHN or service.

Of the 2910 surveys completed, 2845 (98%) had a valid four-digit service code.

Analysis

Initial data manipulation for this report was conducted using SAS software and statistical analyses were conducted using Stata SE v15. Missing, invalid or duplicate answers were recoded as null. CES returns with fewer than 12 of the first 24 questions completed were excluded from analysis. Overall scores and domain scores were calculated following the methods prepared during the national CES development and align with the methods used in the YES reporting. Testing of significant differences between groups and across LHDs and SHNs was conducted using 95% confidence intervals. These were calculated using Wald's formula for proportions. LHD and SHN totals were calculated across both hospital and community settings. Setting-specific averages and confidence intervals were also calculated separately for hospital and community services. Testing of significant differences was conducted by comparing the average and 95% confidence intervals for an LHD or SHN against the NSW average, or the average for a service against the average for other services of the same setting (hospital or community). Non-overlapping 95% confidence intervals were used to define statistically significant differences.

We did not undertake standardisation or weighting of items when comparing services, but this approach will be examined for future reporting.

CES questions use four scoring scales



Frequency scale	Performance scale	Change scale	Performance information	Numerical score
Always	Excellent	A lot better	Yes	5
Usually	Very good	A little better		4
Sometimes	Good	No change		3
Rarely	Fair	A little worse		2
Never	Poor	A lot worse	No	1

A 'Not needed' response option is available for each question.



Comparison of subgroups

	Community			Hospital		
	Valid N	Excellent or very good %	95% confidence interval	Valid N	Excellent or very good %	95% confidence interval
Gender						
Female	1004	69.2%	66.4–72.1	683	69.3%	65.8–72.7
Male	321	70.4%	65.4–75.4	291	68.4%	63.0–73.7
Other	4			4		
Aboriginal status						
Aboriginal	83	78.3%	69.4–87.2	67	62.7%	51.1–74.3
Not Aboriginal	1249	68.9%	66.3–71.4	914	69.1%	66.2–72.1
Age group (years)						
Under 18	6			10		
18–24	10			24		
25–34	58	72.4%	60.9–83.9	56	55.4%	42.3–68.4
35–44	266	73.7%	68.4–79.0	249	73.9%	68.4–79.4
45–54	470	73.4%	69.4–77.4	414	71.5%	67.1–75.8
55–64	244	66.8%	60.9–83.9	113	60.2%	51.2–69.2
65–74	183	66.1%	59.3–73.0	86	57.0%	46.5–67.4
75 and over	95	52.6%	42.6–62.7	30	80.0%	65.7–94.3
Duration as a carer						
Up to 6 months	95	77.9%	69.6–86.2	143	67.1%	59.4–74.8
6 months –1 year	102	75.5%	67.1–83.8	58	67.2%	55.2–79.3
1–2 years	133	78.2%	71.2–85.2	102	64.7%	55.4–74.0
2–5 years	217	69.6%	63.5–75.7	101	75.2%	66.8–83.7
5–10 years	157	67.5%	60.2–74.8	77	61.0%	50.1–71.9
Over 10 years	610	65.6%	61.8–69.3	469	69.9%	65.8–74.1
Relationship						
Child	891	69.9%	66.9–72.9	642	70.1%	66.6–73.6
Friend	18			10		
Parent	95	76.8%	68.4–85.3	82	69.5%	59.5–79.5
Sibling	54	72.2%	60.3–84.2	34	79.4%	65.8–93.0
Spouse	170	64.7%	57.5–71.9	109	67.0%	58.1–75.8
Other	96	71.9%	62.9–80.9	84	59.5%	49.0–70.0
Duration with service						
Less than 1 month	150	74.7%	67.7–81.6	409	68.0%	63.4–72.5
1–6 months	363	74.7%	70.2–79.1	229	69.0%	63.0–75.0
6 months –1 year	219	76.3%	70.6–81.9	101	70.3%	61.4–79.2
1–5 years	337	67.7%	62.7–72.7	152	75.0%	68.1–81.9
More than 5 years	249	54.6%	48.4–60.8	73	57.5%	46.2–68.9
Assistance completing						
No	1207	68.3%	65.6–70.9	924	68.4%	65.4–71.4
Staff	51	88.2%	79.4–97.1	8		
Peer worker	48	83.3%	72.8–93.9	19		
Family or friend	18			17		
Interpreter	1			1		
Other assistance	7			3		

The experience of Aboriginal people (% scored excellent/very good)

	 Community				 Hospital			
	Aboriginal		Not Aboriginal		Aboriginal		Not Aboriginal	
	Excellent or very good %	95% confidence interval	Excellent or very good %	95% confidence interval	Excellent or very good %	95% confidence interval	Excellent or very good %	95% confidence interval
Q1	88.5%	81.8–95.2	84.7%	82.8–86.7	66.7%	55.8–77.6	75.9%	73.2–78.7
Q2	63.5%	51.6–75.4	66.9%	63.8–70.0	51.6%	39.2–64.1	60.3%	56.8–63.8
Q3	86.7%	79.5–94.0	83.0%	80.8–85.1	76.1%	66.1–86.0	79.2%	76.6–81.9
Q4	79.1%	70.5–87.7	87.6%	85.8–89.5	76.1%	66.1–86.0	83.6%	81.1–86.0
Q5	81.4%	69.8–93.0	85.7%	81.7–89.7	71.1%	56.6–85.5	80.5%	75.5–85.5
Q6	84.7%	77.1–92.4	90.3%	88.7–92.0	76.8%	66.9–86.8	89.3%	87.3–91.3
Q7	87.4%	80.4–94.3	92.1%	90.7–93.6	79.2%	69.8–88.5	89.0%	87.0–91.0
Q8	88.2%	81.4–95.1	87.2%	85.4–89.1	79.7%	69.8–89.5	83.0%	80.6–85.5
Q9	94.1%	89.1–99.1	94.5%	93.3–95.8	90.6%	83.5–97.8	93.3%	91.7–94.9
Q10	85.5%	78.0–93.1	87.0%	85.2–88.9	75.8%	65.4–86.1	87.5%	85.3–89.6
Q11	85.7%	78.2–93.2	85.0%	83.0–87.0	78.8%	68.9–88.7	85.5%	83.2–87.8
Q12	83.1%	74.7–91.5	75.2%	72.7–77.7	66.7%	54.4–78.9	73.4%	70.4–76.4
Q13	82.7%	74.5–91.0	83.3%	81.2–85.4	75.8%	65.4–86.1	85.9%	83.6–88.2
Q14	87.8%	80.7–94.9	88.4%	86.6–90.1	79.1%	69.4–88.8	88.3%	86.2–88.2
Q15	84.1%	76.2–92.1	80.8%	78.6–83.0	67.7%	56.3–79.1	83.6%	81.1–86.0
Q16	90.1%	83.6–96.6	81.2%	79.0–83.4	75.4%	64.9–85.9	82.7%	80.3–85.2
Q17	82.7%	74.5–91.0	76.9%	74.5–79.4	75.8%	65.4–86.1	81.9%	79.3–84.4
Q18	62.9%	50.9–74.9	55.5%	52.2–58.8	66.7%	54.4–78.9	66.0%	62.5–69.5
Q19	65.5%	52.9–78.0	49.0%	45.5–52.5	70.0%	58.4–81.6	59.5%	55.8–63.2
Q20	62.5%	50.6–74.4	51.0%	47.6–54.4	57.1%	44.2–70.1	56.2%	52.4–60.0
Q21	75.7%	65.9–85.5	63.1%	60.1–66.1	74.6%	63.5–85.7	74.2%	71.1–77.2
Q22	68.3%	56.6–80.1	53.8%	50.6–57.0	66.1%	53.7–78.5	62.3%	58.7–65.8
Q23	84.4%	76.3–92.5	76.5%	74.0–79.0	69.8%	58.5–81.2	81.0%	78.3–83.7
Q24	76.7%	66.0–87.4	57.4%	54.0–60.9	64.8%	52.1–77.6	62.6%	58.8–66.4
Q25	76.3%	66.8–85.9	66.8%	64.1–69.4	70.2%	58.3–82.1	61.8%	58.5–66.4
Q26	81.3%	72.7–89.8	73.2%	70.7–75.7	75.0%	64.0–86.0	74.5%	71.6–77.4
Q27	82.3%	73.9–90.7	65.6%	62.9–68.3	63.9%	51.9–76.0	63.4%	60.2–66.6
Q28	78.3%	69.4–87.2	69.2%	66.7–71.8	49.2%	37.1–61.4	58.8%	55.5–62.0
Q29	82.5%	74.2–90.8	82.8%	80.6–84.9	77.8%	67.5–88.0	79.4%	76.7–82.0

The experience of people in regional and metropolitan services

	 Community				 Hospital			
	Excellent or very good %	95% confidence interval	Excellent or very good %	95% confidence interval	Excellent or very good %	95% confidence interval	Excellent or very good %	95% confidence interval
Q1	82.5%	79.9-85.2	87.7%	84.9-90.4	73.6%	84.9-90.4	76.6%	72.6-80.7
Q2	64.1%	60.1-68.1	69.5%	65.0-73.9	59.8%	65.0-73.9	57.7%	52.4-63.0
Q3	81.3%	78.5-84.0	85.9%	82.9-88.8	78.9%	82.9-88.8	78.6%	74.6-82.6
Q4	84.3%	81.8-86.9	90.6%	88.1-93.0	84.3%	88.1-93.0	83.3%	79.6-86.9
Q5	79.9%	73.5-86.2	87.8%	83.2-92.5	89.5%	83.2-92.5	88.5%	85.6-91.3
Q6	87.3%	85.0-89.6	93.4%	91.3-95.4	87.8%	91.3-95.4	89.0%	86.0-92.0
Q7	89.8%	87.7-91.9	94.4%	92.5-96.3	86.3%	92.5-96.3	90.8%	88.1-93.6
Q8	85.1%	82.6-87.6	89.8%	87.3-92.3	80.4%	87.3-92.3	84.7%	81.2-88.2
Q9	93.4%	91.7-95.1	95.5%	93.8-97.2	92.0%	93.8-97.2	94.3%	92.0-96.5
Q10	84.5%	81.9-87.0	90.1%	87.6-92.5	84.0%	87.6-92.5	90.4%	87.6-93.3
Q11	82.1%	79.4-84.7	89.2%	86.6-91.8	83.3%	86.6-91.8	87.5%	84.3-90.8
Q12	72.9%	69.7-76.1	79.3%	75.8-82.9	73.5%	75.8-82.9	73.5%	69.0-77.9
Q13	80.8%	78.0-83.6	86.5%	83.7-89.4	83.9%	83.7-89.4	87.2%	83.9-90.5
Q14	86.4%	84.0-88.7	90.7%	88.3-93.1	85.5%	88.3-93.1	90.3%	87.4-93.2
Q15	79.4%	76.6-82.3	83.1%	79.9-86.2	81.0%	79.9-86.2	84.5%	80.9-88.1
Q16	80.4%	77.6-83.2	83.1%	80.0-86.3	80.9%	80.0-86.3	84.5%	80.9-88.1
Q17	74.1%	71.0-77.3	81.8%	78.5-85.1	80.0%	78.5-85.1	83.2%	79.5-86.8
Q18	58.9%	54.9-63.0	51.5%	46.4-56.5	66.9%	46.4-56.5	65.4%	60.0-70.8
Q19	51.2%	46.9-55.5	48.5%	43.2-53.8	60.8%	43.2-53.8	59.6%	53.9-65.3
Q20	53.3%	49.2-57.4	49.7%	44.5-55.0	56.6%	44.5-55.0	55.4%	49.7-61.2
Q21	64.0%	60.3-67.6	63.9%	59.4-68.5	73.9%	59.4-68.5	74.1%	69.5-78.8
Q22	52.9%	48.9-57.0	57.2%	52.5-62.0	62.5%	52.5-62.0	63.0%	57.6-68.5
Q23	76.4%	73.3-79.6	77.8%	74.1-81.6	78.2%	74.1-81.6	83.0%	79.0-87.0
Q24	58.2%	54.0-62.5	59.3%	54.3-64.4	62.1%	54.3-64.4	63.4%	57.5-69.3
Q25	63.9%	60.5-67.3	72.4%	68.7-76.2	60.2%	68.7-76.2	65.5%	60.7-70.3
Q26	70.9%	67.7-74.0	77.6%	74.1-81.1	74.4%	74.1-81.1	75.3%	70.9-79.6
Q27	62.8%	59.4-66.2	71.8%	68.0-75.6	62.7%	68.0-75.6	66.6%	61.8-71.3
Q28	67.2%	64.0-70.4	73.1%	69.5-76.8	55.5%	69.5-76.8	62.7%	57.9-67.5
Q29	83.2%	80.6-85.8	81.8%	78.6-85.0	81.4%	78.6-85.0	76.3%	72.1-80.5



Appendix 4 – CES domains

Making a difference (in this report, referred to as ‘Making a difference’ or ‘Impact’)	
Q25	Your relationship with the person for whom you care
Q26	Your hopefulness for your future
Q27	Your overall wellbeing
Q28	Overall, how would you rate your experience as a carer with this mental health service over the <i>last three months</i> ?
Providing information and support (in this report, referred to as ‘Info & support’)	
Q1	You understood what you could expect from the mental health service for yourself and your family member, partner or friend
Q2	You were given an explanation of any legal issues that might affect your family member, partner or friend
Q3	You understood your rights and responsibilities
Q16	You were given information about services and strategies available if your family member, partner or friend became unwell again
Q18	A brochure or other material about your rights and responsibilities
Q20	An explanation of how to make a compliment or complaint about the mental health service
Q21	Information about carer support services (such as local groups, carer consultants, counsellors)
Q22	Information on opportunities to participate in improving this mental health service
Q23	A number you could call after hours for the service
Q24	Information about taking a support person to meetings or hearings if you wished
Valuing individuality (in this report, referred to as ‘Individuality’)	
Q4	Your personal values, beliefs and circumstances were taken into consideration
Q5	You were able to obtain cultural or language support (such as an interpreter) when you needed
Q12	You were given the opportunity to enhance your abilities as a carer
Q14	Staff worked in a way that supported your relationship with your family member, partner or friend
Supporting active participation (in this report, referred to as ‘Participation’)	
Q6	You were given the opportunity to provide relevant information about your family member, partner or friend
Q8	You were involved in decisions affecting your family member, partner or friend
Q10	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)
Q11	You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend
Q17	You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)
Showing respect (in this report, referred to as ‘Respect’)	
Q7	Your opinion as a carer was respected
Q9	You were identified as a carer of your family member, partner or friend
Q13	Staff conveyed hope for the recovery of your family member, partner or friend
Additional NSW questions	
Q15	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
Q19	Information about the role and legal rights of designated carers and principal care providers under the NSW Mental Health Act 2007

Notes: Question 29 (Overall, during the last three months, did your family member, partner or friend want you involved in their care?) is not included in the domain structure. The additional NSW questions do not contribute to the overall score.

