



What carers say
about NSW
Mental Health
Services
2020-2021



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.

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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 mental illness in NSW. We have been proud to participate in the rollout of the Mental Health Carer Experience Survey (CES) across NSW, in partnership with InforMH (System Information & Analytics Branch, NSW Ministry of Health). MHCN is keen to identify the range of experiences and, in particular, the different issues and obstacles encountered by mental health carers. The CES offers a consistent, measurable method for collecting feedback from all Local Health Districts and Specialty Health Networks across NSW.

Although families and carers are important when someone experiences any illness or disability, mental health carers and the families, kinship groups and communities of people experiencing mental illness are particularly important in the recovery process. This is because, with mental illness, interpersonal relationships can be seen as 'suffusing all aspects of recovery, including experiences such as hope, identity and empowerment'. Carers are one of the most potent sources of assistance for a person's recovery that a clinician or service can engage. Supporting and nurturing these caring relationships will impact upon the mental health of a person, often more consistently and for far longer than formal mental health services will.

The CES is the most serious attempt yet to capture the experience of a broad cross-section of carers in their routine experience of mental health services. Carers report high levels of recognition and respect for their role, in their engagement with services. This is a comforting counterweight to the many problems, complaints and areas for improvement that are the routine focus of a peak body. The CES does a great service when it helps to identify much that is right with our mental health and carer support systems, as well as the areas experienced less positively.

The CES is one of the first, vital steps towards a broader and more consistent evaluation and rating of health services by the people who use them, including carers. The CES will have as much to teach us about improving our methods of gathering feedback and obtaining specific, timely information to pinpoint problems, as it will about any specific issues currently being encountered.

As such, MHCN commends Mental Health Minister Bronnie Taylor, the NSW Government and NSW Health for courageously mandating the CES for use state-wide. We also congratulate all the services that have handed out Carer Experience Surveys and all the carers taking the time to complete them. By working together in this way, we can start to identify and fix the real problems facing our system, as well as finding the best ways of measuring these problems and the effectiveness of actions taken to remedy them. MHCN looks forward to continuing to support this work with InforMH and with the mental health carers of NSW, in every way it can.



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 implemented in NSW public mental health services in 2018.

7491 carer surveys have been returned

Around 51 per cent of surveys were about hospital services and 47 per cent were about community teams. More than half 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 over-represent carers who are better engaged with services as they would be 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

Around two-thirds of carers of consumers in both hospital and community settings rated their overall experience as excellent or very good (68% in community; 66% in hospital). Across both settings, respect was the highest-rated domain; fewer carers rated their access to information and support and the impact of the service as excellent or very good.

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.

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

In community settings, people caring for a parent or spouse and those supported by a staff member or peer worker to complete the survey reported a more positive experience. In hospital settings, people caring for siblings or friends and those who had been engaged with services for more than five years reported a less positive experience.

Aboriginal carers reported a less positive experience of hospital services

Around 4 per cent of community and 6 per cent of hospital surveys were from carers who identified themselves as Aboriginal. Aboriginal carers reported a slightly more positive experience of community services (65% excellent or very good) compared to hospital services (61% excellent or very good). In both hospital and community services, Aboriginal carers reported a significantly less positive experience in the domains of Respect and Participation compared to non-Aboriginal carers.

The COVID-19 pandemic has affected the experiences of carers

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

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



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 the way in which services are planned, delivered and evaluated.

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 using the CES alongside consumer experience data from the Your Experience of Service (YES) when implementing service improvement initiatives.

The best things about this service were...

A willingness to listen to our concerns and try to improve services



My experience would have been better if...

We had received more information at the beginning. We felt very overwhelmed leaving our daughter



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 – Survey) and an electronic version was released in 2019.

For information about the development of the CES see Appendix 2 – Technical information.

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

Implementation 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).

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 that in consumer feedback, because services are much more likely to be able to offer a CES survey to carers who have contact with services. If carers have no physical contact or limited awareness of the healthcare being provided, then they may be less likely to be aware of the opportunity to provide feedback.

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

When and how is the CES offered?

Guidelines for NSW Health services encourage that the CES should be offered 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.



The stages of CES distribution, collection and reporting in NSW are:

Distribution to services: LHDs/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 2.

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/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 completed paper CES forms 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 CES online are asked to submit their responses at the end of the survey. These are sent directly to the secure database.

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

Data:

- Scanned data from paper forms are 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 SQL (structured query language) 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/SHNs
- services are also provided each quarter with all raw data and free-text responses to support further local analysis and improvement projects.

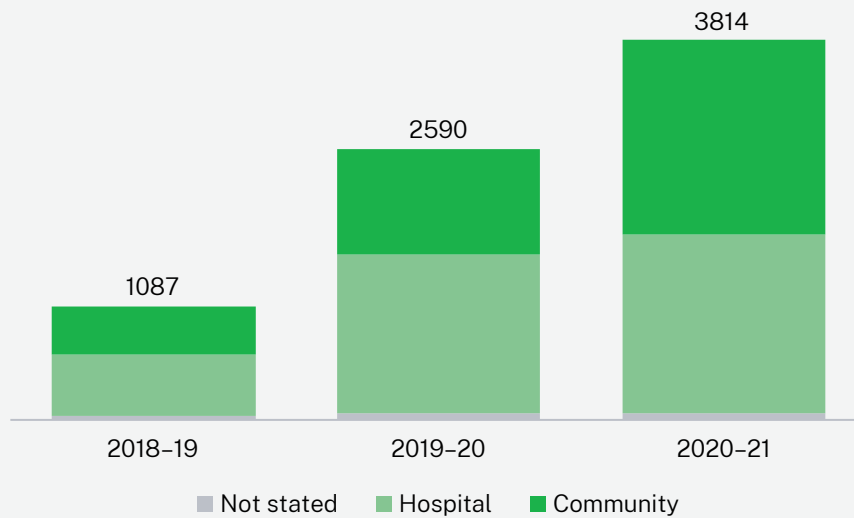
Action and change

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?

7491 surveys received



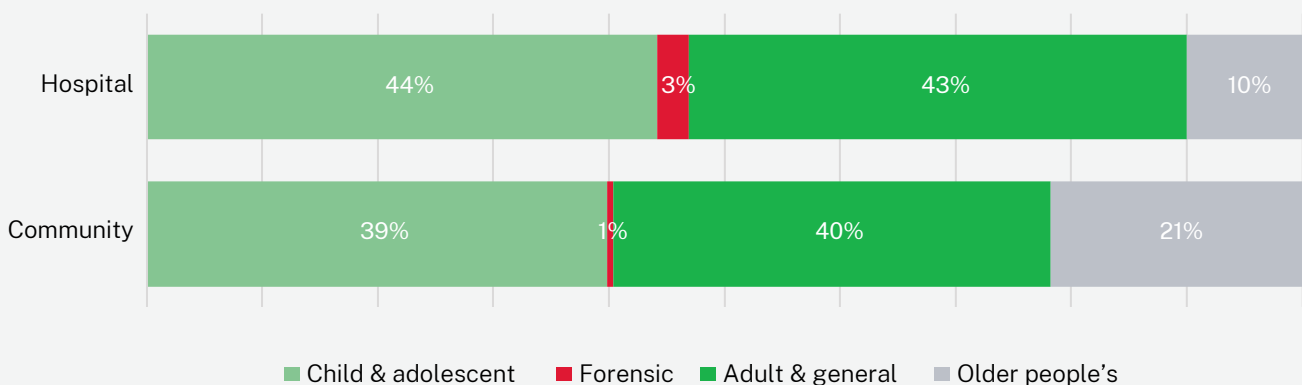
NSW aims to hear from as many carers as possible

The number of surveys completed has increased each year. The CES is anonymous, and there is no way of knowing how many carers were offered a survey or estimating a response or return rate.

Around 526 services have received feedback using the CES

There were 7491 CES returns from September 2018 to June 2021. Around half (51%) were about hospital services (198 services) and 47 per cent were about community teams (336 teams). The remaining 2 per cent were not able to be linked to a specific service due to a missing or invalid service code. Most surveys were from child and adolescent services (41%) or adult and general services (42%). COVID-19 resulted in a temporary decrease in the number of surveys returned in April-June 2020. Following this drop, returns increased quickly, with July-September CES returns being the highest in a quarter so far.

Proportion of surveys received from different service types



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

Almost one-fifth of surveys for community services were completed online

The electronic version of CES was launched in August 2019. Since then 27 per cent of community returns and 7 per cent of hospital returns have been completed online. Uptake of the online survey has continued to increase, particularly since COVID-19 restrictions commenced in 2020. The largest proportion of surveys returned online were from adult and general services (23%).

Around 5 per cent of CES surveys were completed by Aboriginal people

Since the CES was made available, 375 surveys have been completed by Aboriginal people. Most of these were about hospital services (57%). Aboriginal carers were better represented in feedback about hospital adult and general services (8%) and community forensic services (11%). Aboriginal carers were equally as likely as non-Aboriginal carers to complete the CES online, with 23% of community and 8% of hospital returns completed via eCES.

Approximately 8 per cent of people who completed the CES speak a language other than English at home

Of the carers who have completed a CES, around 5 per cent only speak a language other than English and a further 3 per cent speak another language along with English. Despite this, only two translated surveys have been completed. The paper and online versions of the CES have been translated into 35 community languages. More work is needed to promote the availability of these translated versions.



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

Sixty-one per cent of community returns and 62 per cent of hospital CES returns were completed by parents caring for their child. Most carers were between 35 and 64 years old (69% in community; 75% in hospital) and caring for a consumer of child and adolescent or adult services.

The majority of carers have been caring for a long time

Most carers who provided feedback using the CES have been caring for over 10 years (44% in community; 50% in hospital). In community services, most carers (91%) reported that the person they cared for had been receiving care for more than one month. In hospital settings, many consumers (66%) had been engaged with the service for less than six months.

Aboriginal and/or Torres Strait Islander carers are likely to be under-represented

Since the CES was implemented, 4 per cent of community and 6 per cent of hospital surveys have been returned by Aboriginal and/or Torres Strait Islander carers. In 2020–21, approximately 11 per cent of community and 12 per cent of hospital consumers identified as Aboriginal and/or Torres Strait Islander (Your Experience of Service: What consumers say about NSW mental health services 2020–21). When estimating how representative the CES results are, it is important to consider three things: not all consumers may have a carer, not all carers of Aboriginal consumers may be 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.

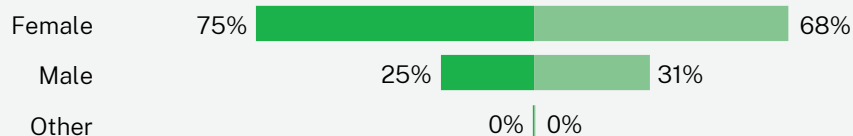
A small number of CES surveys were from young carers

Only 1 per cent of community surveys and 3 per cent of hospital surveys were from carers aged less than 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 also impact their likelihood of completing a CES.

Proportion of CES returns across different groups

■ Community ■ Hospital

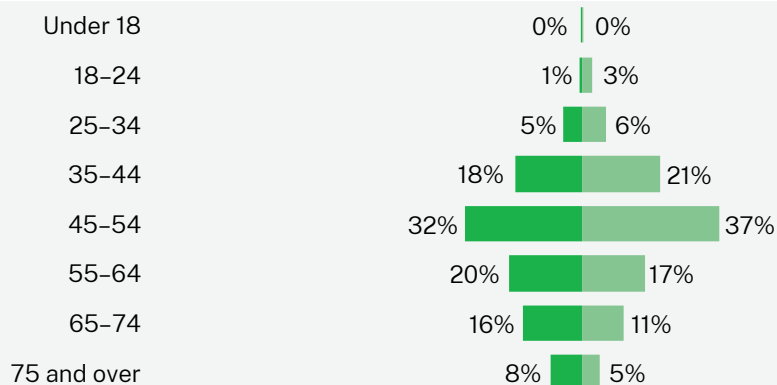
Gender



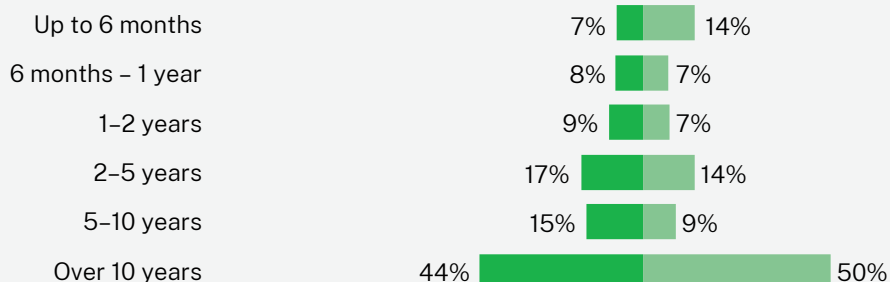
Aboriginal and/or Torres Strait Islander



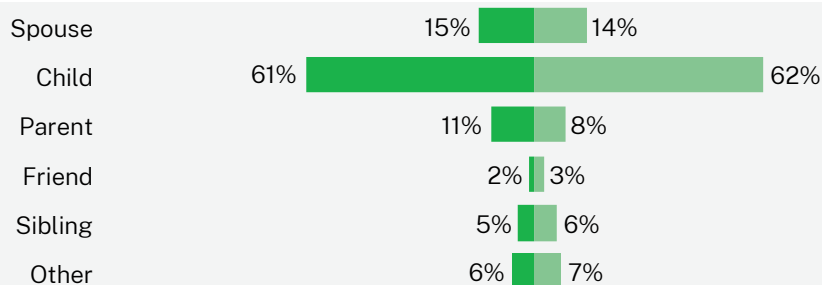
Age group (years)



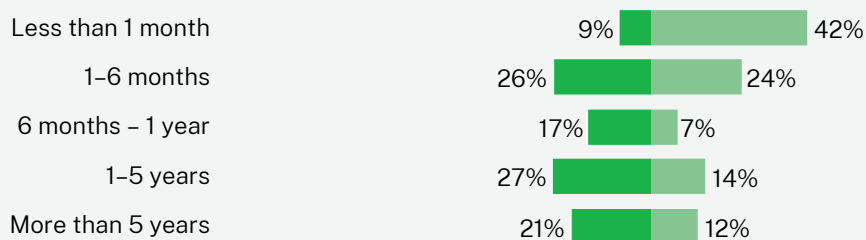
Duration as a carer



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



Duration with service



What did carers say about their experience?

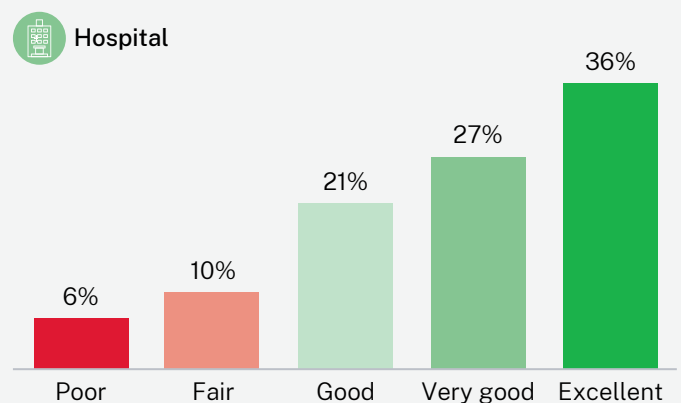
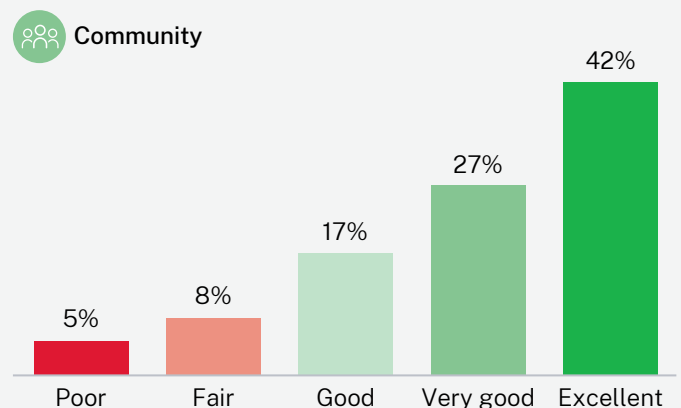
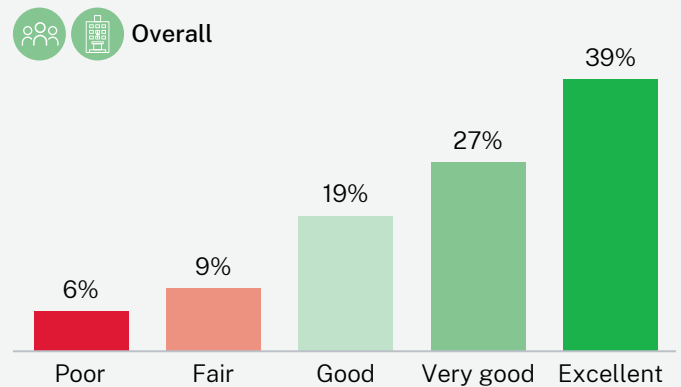
Overall experience can be summarised in two ways: by using a single summary question (Q28), or by calculating an overall experience score.

Using results from question 28

Question 28 asks people to summarise their experience in a single question. Around two-thirds of carers described their overall experience as excellent (39%) or very good (27%). Carers in community services reported a more positive experience than carers in hospital settings. On this single question, around 69 per cent of carers rated their experience of community mental health services as excellent or very good, compared with 63 per cent in hospital settings.



Overall experience using Q28

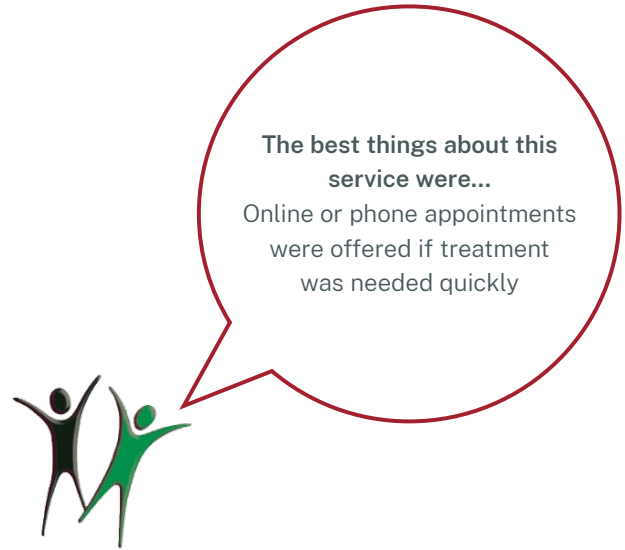


Using the overall experience score

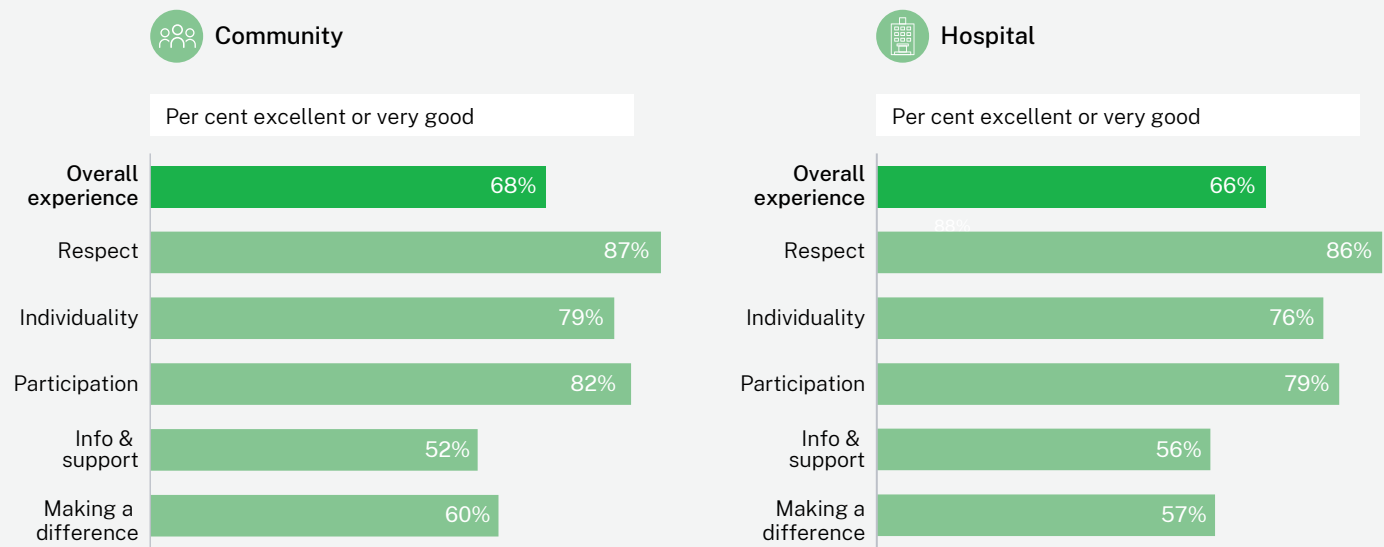
An overall experience index is calculated by combining the scores of questions 1–24 (excluding Q15 and Q19). This ensures that different areas of experience are included in the overall score. This score was then used to calculate the percentage of carers reporting an excellent or very good experience. Using this method, 67 per cent 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 (68% community; 66% hospital).

Respect was the highest-rated domain

CES questions are grouped into five domains, consistent with those used in the Your Experience of Service (YES) questionnaire. The most positive experiences were reported for the domains of Respect, Participation and Individuality. Overall, fewer carers rated their access to information and support and the impact of the service as excellent or very good.



Overall experience score and domains



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 2.

In community services, some groups reported a significantly more positive experience

Carers who were assisted by staff members to complete the survey reported the most positive experience of any group (91% excellent or very good). In the free-text comments, these carers frequently stated that they were involved, kept informed and felt supported and listened to by staff. People caring for a parent or spouse also reported a more positive experience and highlighted trust in the staff, communication from the team and personal qualities of the staff as the most positive things about the service.

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

Where the consumer had been engaged with the hospital or community service for more than five years, carers reported a significantly less positive experience. These carers often commented that their experience of community services would have been better with more frequent communication to keep them informed. In hospital settings, carers often commented that they needed more information, that they noticed the turnover of staff and had more concerns for the wellbeing of the consumer.

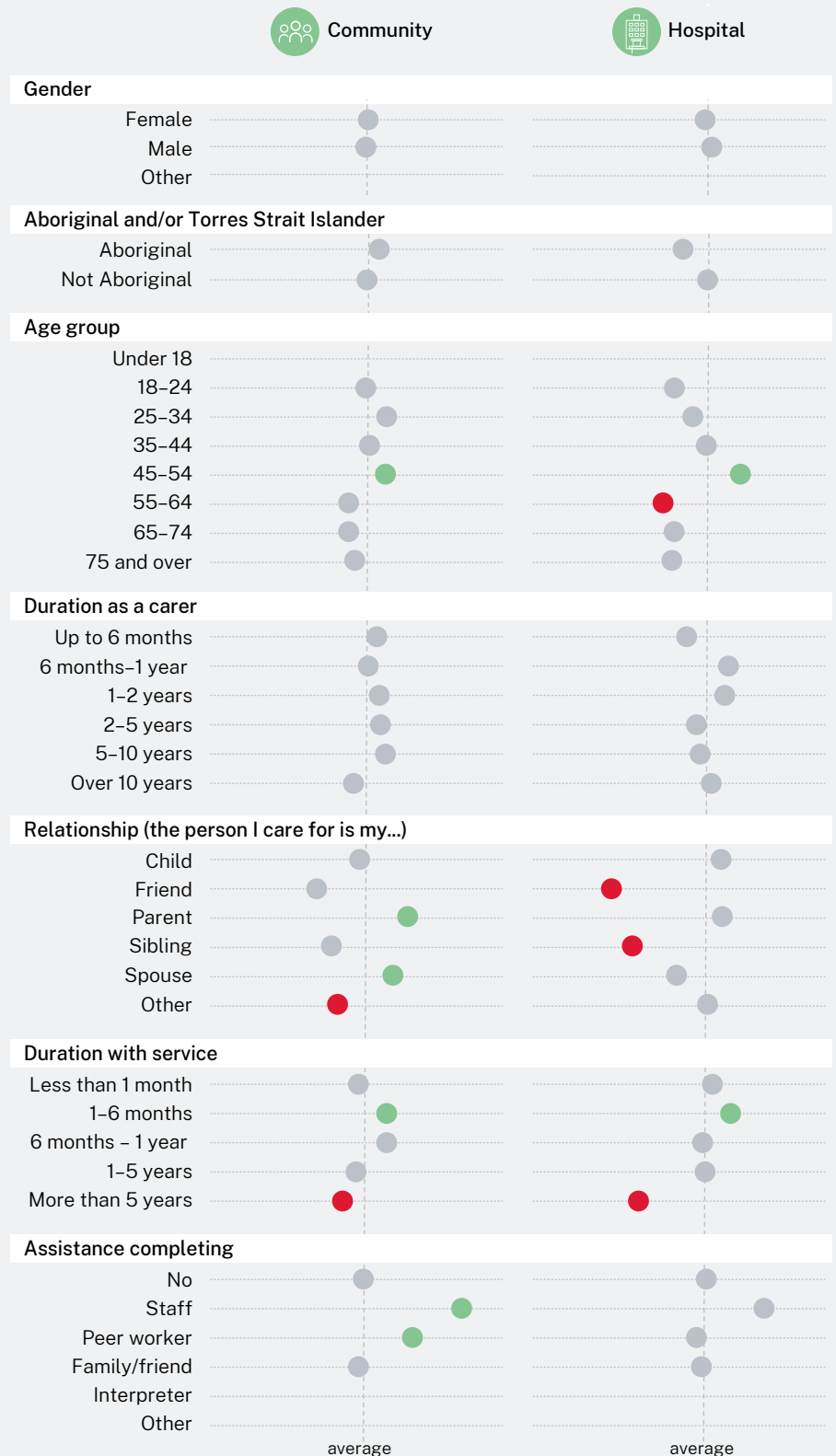
In hospital settings, people caring for a friend reported the least positive experiences

Only 46 per cent of people caring for a friend in hospital reported an excellent or very good experience. Siblings also reported a significantly less positive experience, compared to other groups. These carers often commented that they did not feel included, and that they needed more communication and information, and more opportunities to connect with other carers.

Carers aged 45–54 and those engaged with the hospital service for 1–6 months reported a more positive experience

Most carers aged 45–54 were caring for their child (76%) and had been caring for over 10 years (50%). These carers often described staff qualities when commenting on the best things about the service, stating that staff were ‘caring’, ‘supportive’, ‘knowledgeable’ and ‘professional’. Where consumers had been engaged with the service for 1–6 months, 71 per cent reported an excellent or very good experience.

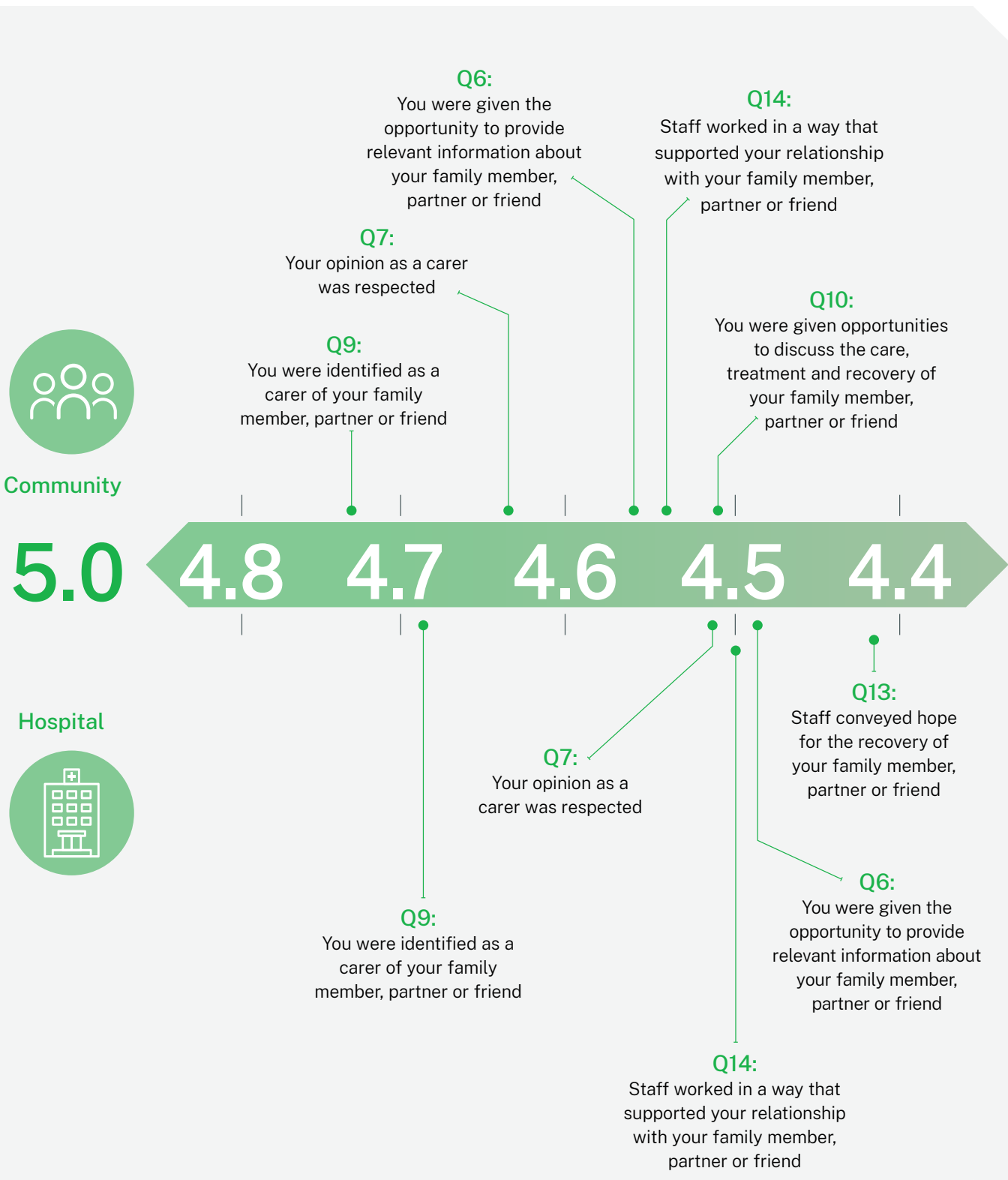
The overall experience of different groups of consumers



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.

Highest and lowest scoring questions





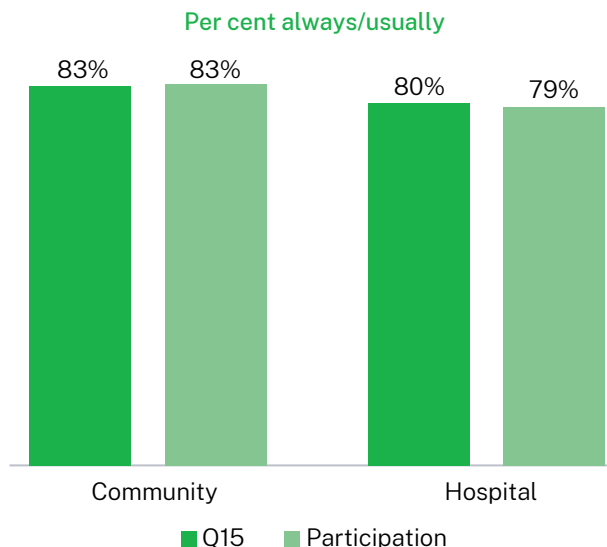
Additional NSW questions

During the implementation of the CES in NSW, two additional questions were added to the survey:

- 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

More than four in five carers said they were always given the information they needed to provide care (Q15)

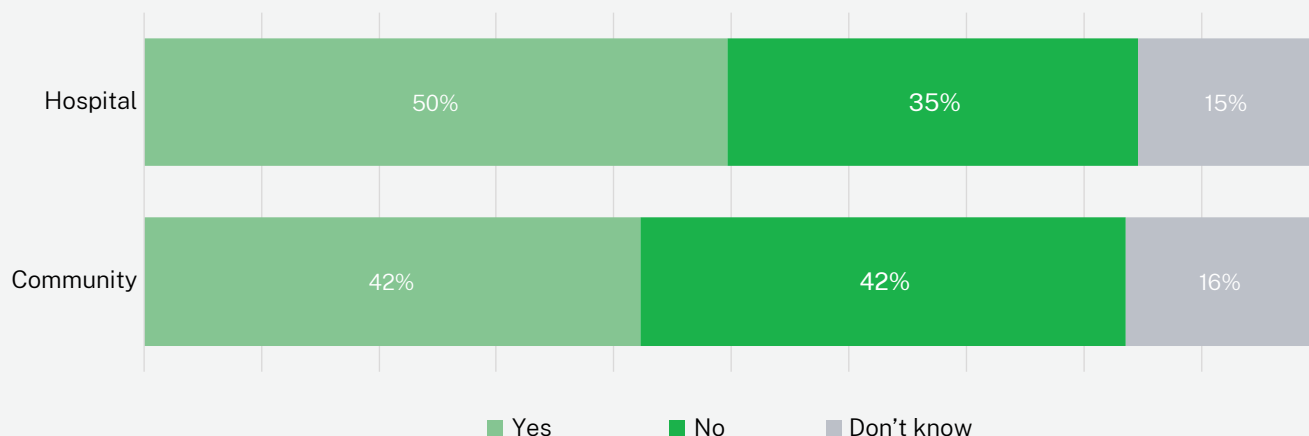
Over 80 per cent of carers rated Q15 as always or usually. Across both hospital and community settings, this question was rated similarly to the Participation domain questions, which ask if people had opportunities for engagement, choice and involvement in the care and support provided. In community settings, people caring for a parent rated Q15 more positively. In hospital settings, carers aged 18–24, those caring for a friend and those engaged with the service for more than five years rated Q15 less positively.



More than half did not recall being given information about the role and legal rights of designated carers and principal care providers in the last three months (Q19)

Around 50 per cent of carers in hospital settings and 42 per cent in the community recalled being given information about the role and legal rights of designated carers and principal care providers. In the community, people caring for a parent or spouse and those assisted by staff to complete the survey were more likely to respond positively to this question whereas those caring for a child were less likely to recall being given this information. In hospital settings, carers aged 55–64, those caring for a sibling and people who had been engaged with the service for more than five years were less likely to recall being given this information. Carers who were assisted by a peer worker to complete the survey were more likely to recall receiving this information. While this question includes a ‘Not needed’ response option, it is possible that some of the ‘No’ or ‘Don’t know’ responses were from people caring for voluntary consumers who were unsure if they should have been provided with this information.

Proportion of carers who recalled being given information about designated carers and principal care providers (Q19)



My experience would have been better if...

“We had more opportunities to discuss our daughters condition and strategies moving forward”

“There was assistance for new carers to teach them how to navigate the system”

“There was more frequent contact”

“More flexible time for the appointment including weekends”

“They kept me well informed at all times and invited me to all meetings about my sister”

The best things about this service were...

“Being able to ask anything about my husband’s mental health and being answered truthfully. He is getting wonderful help and there’s always help for me as well”

“They always listen to what we have to say”



How do LHDs and SHNs compare?

This section looks at the percentage of carers reporting an excellent or very good experience across Local Health Districts (LHDs) and Speciality Health Networks (SHNs) using the 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/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/SHN in both hospital and community settings.

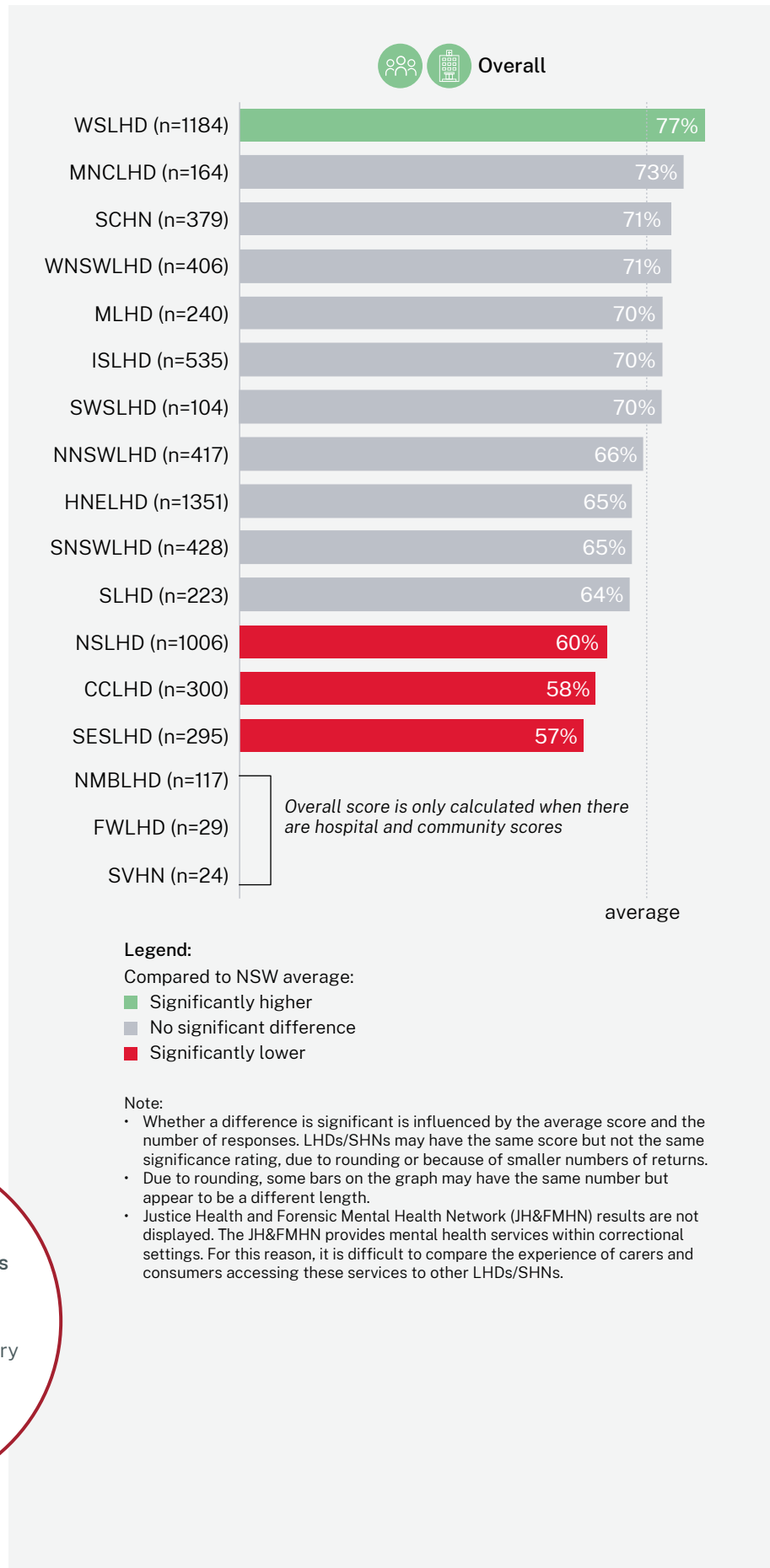
At this stage a target has not been developed for CES performance. The following graphs compare LHD/SHN scores to the NSW average. Significance testing was used to identify the districts that were rated significantly above or below the NSW average.

Using the CES data from August 2018 to June 2021, one district scored significantly above the NSW average (WSLHD) and two scored below (CCLHD and SESLHD).

The next section summarises more detailed results, showing individual hospitals and community service ‘catchments’. These catchments are groups of community teams that typically form part of one larger local service. Many large LHDs/SHNs organise their services into distinct geographical catchments in this way, and these local services often work in an integrated way with one or more individual hospitals.

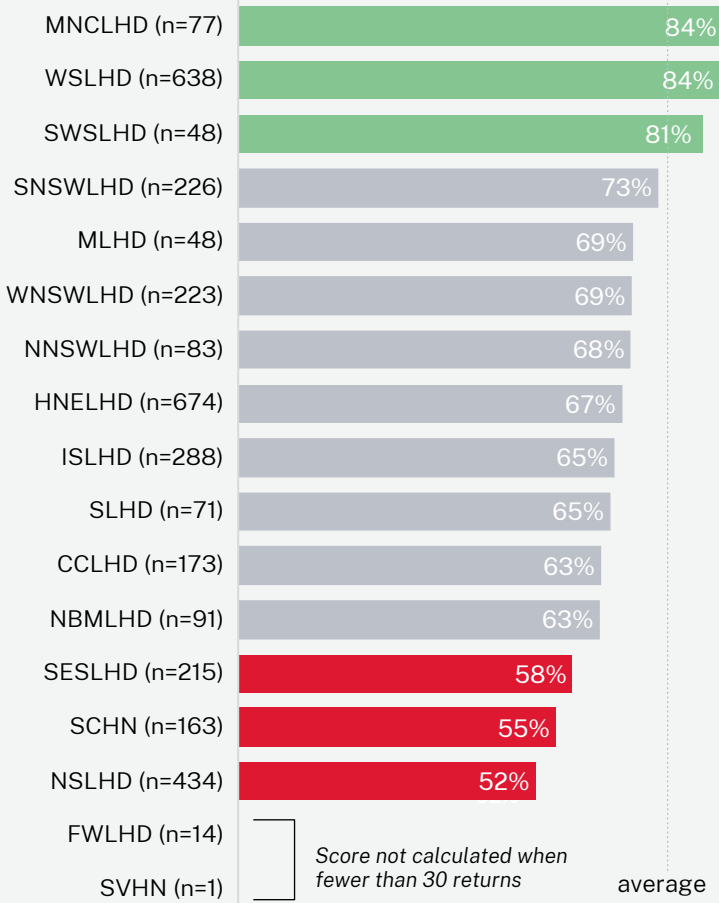
The best things about this service were...

The knowledge, care and support of the staff was very reassuring

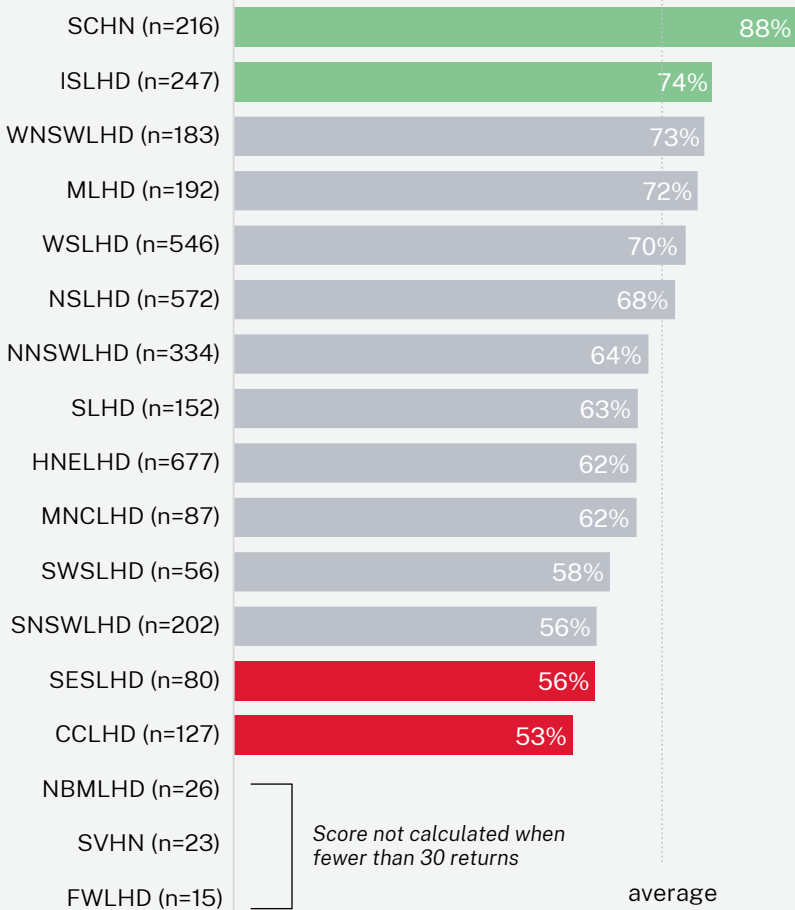




Community



Hospital



My experience would have been better if...
The role of the carer while on the ward was made clearer from the beginning



The best things about this service were...
They were always available if we needed to talk about my grandson if he was having a bad day



Legend:
Compared to NSW average:
■ Significantly higher
■ No significant difference
■ Significantly lower

CES domain results: community

Hospital	Valid returns	Overall experience	Respect	Individuality	Participation	Info & support	Making a difference
Hastings Macleay Amb	62	90%	●	●	●	●	●
Parramatta Amb	476	86%	●	●	●	●	●
Goulburn Amb	57	82%	●	●	●	●	●
Clarence Amb	64	78%	●	●	●	●	●
Maitland Amb	116	77%	●	●	●	●	●
Blacktown Amb	85	75%	●	●	●	●	●
Hornsby C&Y Amb	35	74%	●	●	●	●	●
Queanbeyan Amb	38	71%	●	●	●	●	●
Murrumbidgee Amb	186	69%	●	●	●	●	●
Orange Amb	48	69%	●	●	●	●	●
Newcastle/Lake Macquarie Amb	413	68%	●	●	●	●	●
Gosford Amb	90	67%	●	●	●	●	●
Blue Mountains & Lithgow Amb	33	67%	●	●	●	●	●
Wollongong/Shellharbour Amb	209	66%	●	●	●	●	●
Shoalhaven Amb	60	63%	●	●	●	●	●
Rivendell Amb	32	63%	●	●	●	●	●
Hornsby Adult Amb	47	60%	●	●	●	●	●
St George Amb	67	58%	●	●	●	●	●
Wyong Amb	39	59%	●	●	●	●	●
Eastern Suburbs Amb	153	58%	●	●	●	●	●
CHW Amb	153	55%	●	●	●	●	●
New England Amb	97	53%	●	●	●	●	●
RNS Adult Amb	78	45%	●	●	●	●	●
Ryde Adult Amb	51	43%	●	●	●	●	●
Northern Beaches Adult Amb	145	43%	●	●	●	●	●
Penrith Amb	30	40%	●	●	●	●	●
Eurobodalla Amb	29						
Cooma Amb	27						
NSLHD C&Y Amb	24						
WSLHD C&Y Amb	24						
Dubbo Amb	29						
Justice Health Amb	19						
NBMLHD Amb	22						
Liverpool Amb	16						
Tweed/Byron Amb	16						
Braeside Amb	14						
Camperdown/Redfern Amb	14						
Broken Hill Amb	13						
Central Coast Amb	14						
Bega Amb	11						
Sutherland Amb	11						
Yass Amb	11						
Bankstown Amb	10						
Croydon Amb	11						
North Shore/Ryde C&Y Amb	11						
Northern Beaches C&Y Amb	10						
SNSWLHD Amb	10						
Taree Manning Amb	9						
Coffs Harbour Amb	8						
Macarthur Amb	7						
NSLHD Adult Amb	6						
Canterbury Amb	4						
Hawkesbury Amb	4						
HNELHD Amb	3						
SLHD Amb	3						
Richmond Amb	2						
Community Mental Health SSW eastern zone	1						
WSLHD Adult Amb	1						

Score not calculated when fewer than 30 returns



CES domain results: hospital

Hospital	Valid returns	Overall experience	Respect	Individuality	Participation	Info & support	Making a difference
Children's Hosp Westmead	208	88%	●	●	●	●	●
Orange Hosp	149	79%	●	●	●	●	●
Hornsby Hosp	343	77%	●	●	●	●	●
Shellharbour Hosp	201	77%	●	●	●	●	●
Westmead Hosp	314	74%	●	●	●	●	●
Wagga Wagga Hosp	184	72%	●	●	●	●	●
John Hunter Hosp	271	71%	●	●	●	●	●
Armidale Hosp	65	69%	●	●	●	●	●
South East Regional Hosp	44	68%	●	●	●	●	●
Cumberland Hosp	57	68%	●	●	●	●	●
Greenwich Hosp	51	67%	●	●	●	●	●
Port Macquarie Hosp	63	65%	●	●	●	●	●
Lismore Hosp	245	65%	●	●	●	●	●
Morisset Hosp	63	63%	●	●	●	●	●
Concord Hosp	82	62%	●	●	●	●	●
Blacktown Hosp	150	62%	●	●	●	●	●
Maitland Hosp	44	59%	●	●	●	●	●
St George Hosp	38	55%	●	●	●	●	●
Wyong Hosp	109	55%	●	●	●	●	●
HNE Mater Hosp	153	52%	●	●	●	●	●
Goulburn Hosp	127	50%	●	●	●	●	●
RNS Hosp	47	38%	●	●	●	●	●
Macquarie Hosp	50	38%	●	●	●	●	●
Tamworth Hosp	36	33%	●	●	●	●	●
Forensic Hosp	82	30%	●	●	●	●	●
RPA Hosp	25						
Nepean Hosp	22						
Sutherland Hosp	22						
Braeside Hosp	21						
Rivendell Hosp	21						
Liverpool Hosp	20						
Dubbo Hosp	18						
St Vincents Hosp	18						
POW Hosp	15						
Kenmore Hosp	14						
Tweed Hosp	14						
Campbelltown Hosp	13						
Wollongong Hosp	11						
Broken Hill Hosp	11						
Gosford Hosp	11						
Coffs Harbour Hosp	9						
Manning Base Hosp	8						
Bathurst Hosp	6						
Byron Central Hosp	6						
Kempsey Hosp	5						
Long Bay Hosp	5						
Coral Tree Hosp	3						
Blue Mountains Hosp	2						
St Josephs Hosp	2						
Bankstown Hosp	1						

Score not calculated when fewer than 30 returns

My experience would have been better if...
 Even though we are experienced in the system it would be good to get updated information such as rights and responsibilities

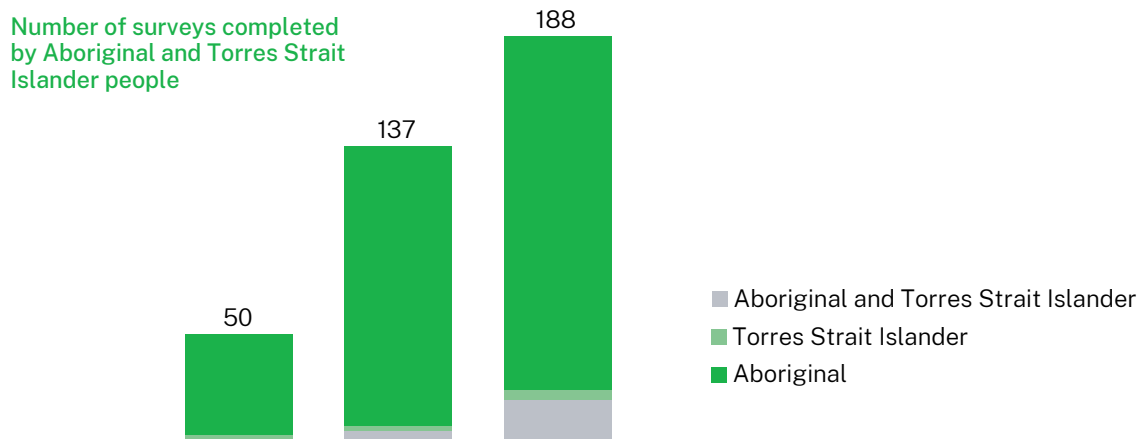


Aboriginal and/or Torres Strait Islander carers



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.

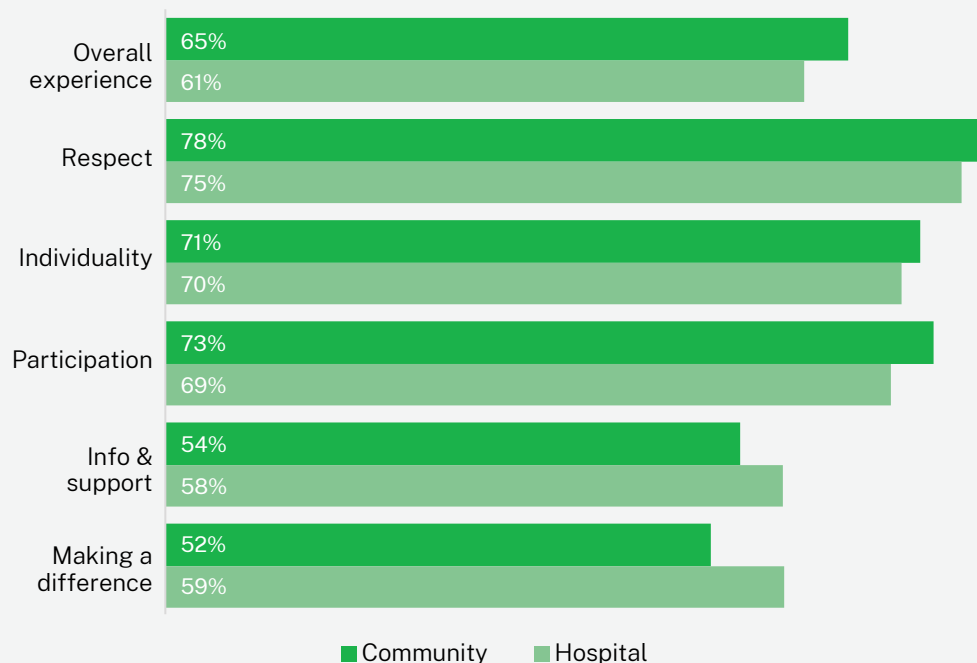
In 2020–21, 10 per cent of all people accessing hospital and community mental health services in NSW identified as Aboriginal. Since the implementation of the CES in 2018, 375 surveys have been completed by Aboriginal carers (4% of community returns and 6% of hospital returns). The number of surveys completed by Aboriginal people has continued to increase each year and the proportion of all responses completed by Aboriginal people has remained consistent.



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

Around 65 per cent of Aboriginal carers in the community and 61 per cent in hospitals reported an excellent or very good overall experience. Aboriginal carers in the community reported a more positive experience across the domains of Respect, Individuality and Participation. Information & support and Making a difference were rated more positively in hospital settings compared to community settings.

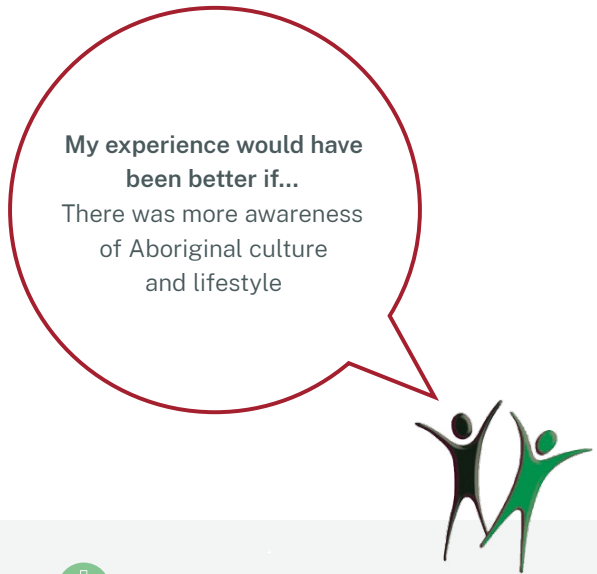
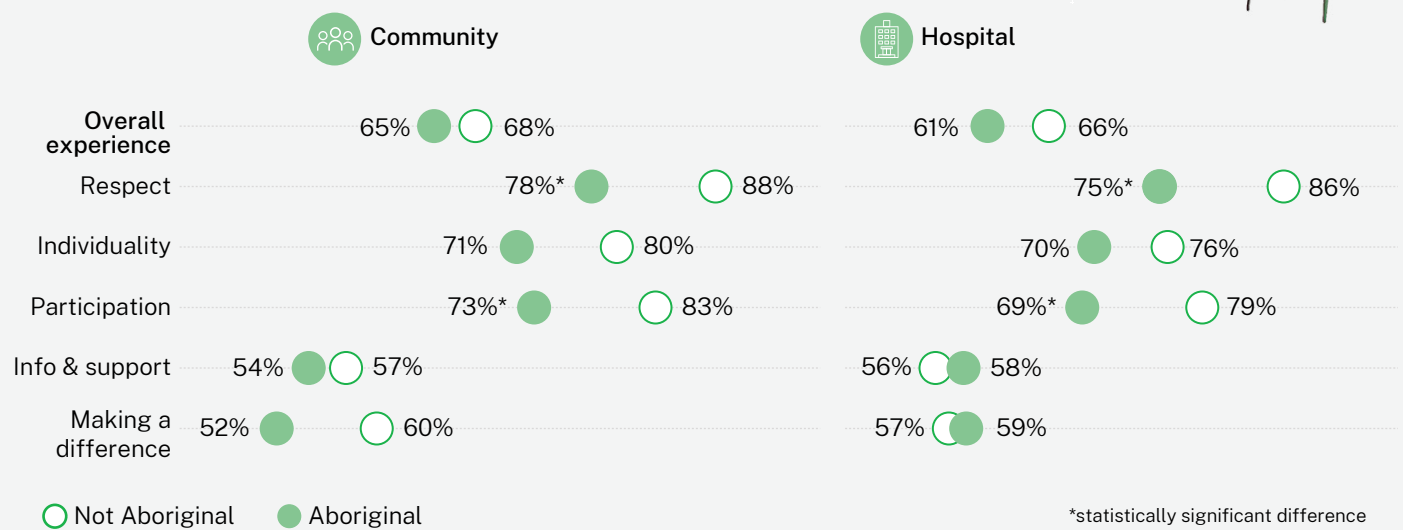
Percentage of Aboriginal carers reporting an excellent or very good experience across CES domains



Respect and Participation were rated significantly lower by Aboriginal carers

When comparing the experience of Aboriginal and non-Aboriginal carers, the largest gaps were in the domains of Respect and Participation. In hospital settings, Information & support and Making a difference were rated similarly by Aboriginal and non-Aboriginal carers. Across the other domains, Aboriginal carers reported a less positive experience. In community settings, Aboriginal consumers reported a less positive experience across all domains.

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



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

Although, overall experience in hospital services was reported as less positive by Aboriginal carers, three questions were rated higher when compared to non-Aboriginal carers:

Q20. *An explanation of how to make a compliment or complaint about the mental health service*

Q22. *Information on opportunities to participate in improving this mental health service*

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

These questions asked about specific information that was provided. The questions that were rated significantly less positive by Aboriginal carers asked broader questions about expectations, opportunities for involvement and feeling respected.





*statistically significant difference

○ Not Aboriginal ● Aboriginal

Themes from the free-text responses

When completing the CES, carers are asked to provide more 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 more likely to comment on the best things about the service (4062 surveys) compared to the things that could be improved (2940 surveys). Responses to these comments were examined to identify key themes.

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

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.

My experience with this service would have been better if...
'There was more communication on admission, especially over the weekend'

'There was consistency and better communication.'

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

The best things about this service were...
'The staff communication. I felt supported and at ease knowing that my child was safe and cared for.'

'The ongoing support and excellent communication. There was consistent contact and follow up.'

Many carers needed more information

As with the theme of communication, information was also often mentioned as something that impacted experience, both positively and negatively. In the 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. Many carers mentioned that more detailed information at the beginning would have helped with expectations and making carers feel more supported.

My experience with this service would have been better if...
'There was more information on what the service provides and what to expect e.g. information about the tribunal and carer support services'

'The admission process lacked a cohesive service that enabled me to understand as a carer what was going on'

The best things about this service were...
'Follow-up emails and phone calls to enquire about our well-being and provide current information about services and educational workshops'

'Parent/carers information sessions'

'Care plans included my input as a carer.'

Positive interactions with staff are often the best things about a service, but access to 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.

My experience with this service would have been better if...
'It was easier to access staff, if I could make an appointment to speak with them'

'We had more access to other professions within the service such as an OT and Psychiatrist'

The best things about this service were...
'The staff were friendly and made us feel that we could contact them with any problems'

'The time afforded to me as a carer to talk about my worries and concerns. The frequency of visits, having the access by phone, email or text for updates & even appointment times.'

What's next in measuring carer experience?

Hearing from more carers

Implementing the CES tool 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 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 peer workers understand the CES results for their services. Developing their ability to interpret results will help peer workers to identify areas for improvement and to assist services in making evidence-based decisions on service reforms to enhance carers' experiences with public mental health services. These resources and supports will be promoted by MHCN through its new 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.

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



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"/>
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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
25. Your relationship with the person for whom you care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Your hopefulness for your future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Your overall wellbeing	<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 – 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 (i) it can be more accurately scanned than a handwritten service name, and (ii) 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 7491 surveys completed, 7321 (98%) had a valid four-digit service code.

Analysis

Initial data manipulation for this report was conducted using SAS and statistical analyses were conducted using Stata SE v15. Missing, invalid or duplicate answers were recoded as null. CES returns with less than 12 of the first 24 questions completed were excluded from analysis. Overall scores and domain scores were constructed following the methods prepared during the national CES development and align with the methods used in the Your Experience of Service (YES) reporting. Testing of significant differences between groups or across LHDs/SHNs was conducted using 95 per cent confidence intervals. These were calculated using Wald's formula for proportions. LHD/SHN totals were calculated for all settings (hospital and community). 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 (CIs) for an LHD/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.

No standardisation or weighting of items was undertaken 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	2373	68.3%	66.4–70.1	2262	65%	63.4–67.3
Male	798	66.9%	63.6–70.2	1039	66%	63.5–69.3
Other	8	25.0%	-5.0–55.0	9	22%	-4.9–49.4
Aboriginal status						
Aboriginal	147	64.6%	56.9–72.4	195	61%	53.7–67.4
Not Aboriginal	3028	68.0%	66.3–69.7	3099	66%	64.2–67.5
Age group (years)						
Under 18	5	100.0%	100.0–100.0	11	82%	59.0–104.6
18–24	29	65.5%	48.2–82.8	86	60%	50.1–70.8
25–34	166	72.3%	65.5–79.1	206	63%	56.5–69.7
35–44	585	67.4%	63.5–71.2	691	66%	62.0–69.1
45–54	1001	72.2%	69.5–75.0	1216	73%	70.6–75.6
55–64	631	64.0%	60.3–67.8	560	56%	52.1–60.4
65–74	503	63.8%	59.6–68.0	362	59%	54.3–64.5
75 and over	252	64.7%	58.8–70.6	150	59%	50.8–66.5
Duration as a carer						
Up to 6 months	231	71.4%	65.6–77.3	441	62%	57.1–66.2
6 months – 1 year	234	68.8%	62.9–74.7	212	71%	64.6–76.9
1–2 years	287	71.1%	65.8–76.3	224	69%	62.7–74.8
2–5 years	518	70.7%	66.7–74.6	443	63%	58.5–67.5
5–10 years	465	71.0%	66.8–75.1	275	64%	58.3–69.7
Over 10 years	1402	64.1%	61.6–66.6	1595	67%	64.7–69.3
Relationship						
Spouse	467	74.3%	70.3–78.3	468	60%	55.6–64.5
Child	1929	66.4%	64.3–68.5	2016	69%	66.7–70.8
Parent	363	76.9%	72.5–81.2	280	69%	63.5–74.3
Friend	53	60.4%	47.2–73.6	80	46%	35.3–57.2
Sibling	150	58.7%	50.8–66.6	197	50%	43.3–57.2
Other	195	57.4%	50.5–64.4	217	66%	60.1–72.6
Duration with service						
Less than 1 month	265	64.2%	58.4–69.9	1362	67%	64.3–69.3
1–6 months	827	72.4%	69.4–75.5	796	71%	68.0–74.3
6 months – 1 year	536	72.6%	68.8–76.4	236	65%	58.7–70.9
1–5 years	834	65.5%	62.2–68.7	478	65%	60.8–69.3
More than 5 years	685	61.9%	58.3–65.5	387	52%	46.7–56.7
Assistance completing						
No	2980	66.8%	65.1–68.5	3107	66%	63.9–67.3
Staff	58	91.4%	84.2–98.6	32	78%	63.8–92.4
Peer worker	61	82.0%	72.3–91.6	44	64%	49.4–77.9
Family or friend	61	67.2%	55.4–78.9	86	65%	55.0–75.2
Interpreter	1	100.0%	100.0–100.0	5	100%	100.0–100.0
Other assistance	13	76.9%	54.0–99.8	23	43%	23.2–63.7

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	73.47%	66.3–80.6	83.81%	82.5–85.1	65.46%	58.8–72.2	75.39%	73.9–76.9
Q2	57.26%	48.3–66.2	63.42%	61.4–65.4	49.12%	41.6–56.6	60.58%	58.7–62.5
Q3	76.55%	69.7–83.4	83.77%	82.4–85.1	70.83%	64.4–77.3	78.35%	76.9–79.8
Q4	76.22%	69.2–83.2	87.35%	86.1–88.6	73.80%	67.5–80.1	83.77%	82.4–85.1
Q5	74.32%	64.4–84.3	84.98%	82.5–87.5	69.44%	60.8–78.1	77.55%	74.5–80.6
Q6	80.14%	73.7–86.6	89.96%	88.9–91.0	76.44%	70.4–82.5	87.69%	86.5–88.9
Q7	82.99%	76.9–89.1	91.71%	90.7–92.7	79.69%	74.0–85.4	87.93%	86.8–89.1
Q8	73.97%	66.9–81.1	85.39%	84.1–86.7	71.28%	64.9–77.6	80.76%	79.4–82.2
Q9	80.82%	74.4–87.2	94.25%	93.4–95.1	84.97%	79.9–90.0	93.08%	92.2–94.0
Q10	76.55%	69.7–83.4	88.05%	86.9–89.2	75.52%	69.4–81.6	85.49%	84.3–86.7
Q11	76.71%	69.9–83.6	85.70%	84.4–87.0	76.02%	70.0–82.0	82.67%	81.3–84.0
Q12	69.85%	62.1–77.6	74.93%	73.3–76.6	67.23%	60.3–74.1	70.92%	69.2–72.6
Q13	76.76%	69.8–83.7	83.32%	82.0–84.7	77.60%	71.7–83.5	85.36%	84.1–86.6
Q14	78.62%	71.9–85.3	88.84%	87.7–90.0	77.95%	72.1–83.8	88.12%	87.0–89.3
Q15	78.87%	72.2–85.6	82.50%	81.1–83.9	75.00%	68.8–81.2	80.44%	79.0–81.9
Q16	74.48%	67.4–81.6	81.89%	80.5–83.3	77.13%	71.1–83.1	80.75%	79.3–82.2
Q17	74.64%	67.4–81.9	78.90%	77.4–80.4	73.98%	67.8–80.1	79.95%	78.5–81.4
Q18	52.17%	43.0–61.3	58.59%	56.5–60.7	72.12%	65.3–79.0	64.45%	62.6–66.3
Q19	43.64%	34.4–52.9	50.77%	48.6–53.0	65.81%	58.3–73.3	57.84%	55.8–59.9
Q20	46.43%	37.2–55.7	52.12%	50.0–54.2	63.58%	56.2–71.0	52.04%	50.0–54.1
Q21	59.17%	50.4–68.0	68.53%	66.7–70.4	72.19%	65.4–78.9	71.39%	69.7–73.1
Q22	57.63%	48.7–66.5	56.27%	54.3–58.3	66.67%	59.2–74.1	57.38%	55.4–59.3
Q23	62.90%	54.4–71.4	76.78%	75.2–78.4	82.94%	77.3–88.6	77.34%	75.8–78.9
Q24	63.33%	54.7–72.0	61.13%	59.0–63.3	70.78%	63.6–78.0	60.09%	58.1–62.1
Q25	62.50%	54.4–70.6	66.79%	65.1–68.5	68.00%	61.1–74.9	64.59%	62.8–66.3
Q26	73.53%	66.1–80.9	73.33%	71.7–74.9	75.98%	69.7–82.2	76.62%	75.1–78.2
Q27	57.46%	49.1–65.8	66.11%	64.4–67.8	66.47%	59.4–73.6	64.35%	62.6–66.1
Q28	60.00%	52.0–68.0	69.47%	67.8–71.1	52.85%	45.8–59.9	63.40%	61.7–65.1
Q29	78.47%	71.8–85.2	83.52%	82.2–84.8	78.31%	72.4–84.2	81.99%	80.6–83.4

Appendix 3 – 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

The additional NSW questions and Q29 do not contribute to the overall score.

Appendix 4 – Glossary and acronyms

Glossary

Adult and general services	Services that provide mental health support to people aged 18 to 65 years.
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.
CES returns	The number of carer surveys completed in a period.
Child and adolescent services (CAMHS)	Services that provide specialist mental health support to people aged less than 18 years.
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'.
Forensic services	Services that provide specialist mental health support for persons the Court has: <ul style="list-style-type: none"> • found unfit to be tried for an offence and ordered to be detained in a correctional centre, mental health facility or other place; • found not guilty by reason of mental illness or nominated a limiting term and ordered to be detained in a prison, hospital or other place; or • found not guilty by reason of mental illness and released into the community subject to conditions.
Older people's services (OPMHS)	Services that provide specialist mental health support to people aged 65 years and over.
Voluntary care	A person with voluntary status received treatment and this was not under compulsory treatment provisions.

Acronyms

Community services and hospitals	
Amb	Ambulance service
C&Y	Child & Youth
Children's Hosp Westmead	Children's Hospital at Westmead
Hosp	Hospital
POW	Prince of Wales
RNS	Royal North Shore
RPA	Royal Prince Alfred
SSW	South South West
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

