What Carers say about their Experience of South Australian Mental Health Services 2021

Report on data from the Carer Experience Survey (CES)

Provided to the Office of the Chief Psychiatrist for
South Australia by Lived Experience Australia Ltd

Government
of South Australia

SA Health

ACKNOWLEDGEMENT

We gratefully acknowledge the support of the lived experience team within the South Australian Department of Health and Wellbeing Office of the Chief Psychiatrist (OCP) and the Carers Champions from each Local Health Network (LHN) who provided strategic guidance for the implementation of the CES project within the public mental health services in South Australia.

Many thanks to the SA Health staff and services for ensuring families and carers have opportunities to give feedback about the mental health services. Most importantly, thank you to the many carers who took the time and effort to give feedback about their experience.

Report produced by

Professor Sharon Lawn, Chair and Executive Director, Lived Experience Australia

Email: **slawn@livedexperienceaustralia.com.au**
Phone: 0459 098 772

Statistical support provided by Dr Jeremy Stevenson, Flinders University Published January 2022

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FOREWORD

South Australia's Mental Health Services aim to deliver mental health care of the highest quality that is effective and safe, uphold human rights, enhance wellbeing, and support people to fully participate and thrive in their chosen community, as described in the SA Mental Health Services Plan 2020-2025. Understanding the experience of consumers and carers provides a critical opportunity for safety and quality improvement at our services.

We recognise the significant role of carers in community mental health care and acknowledge the importance of identifying and engaging people who offer unpaid support to those impacted by mental health issues. Carers can provide valuable information to our mental health teams to support the recovery of the person they look after and improve service quality.

The first state-wide implementation of the Mental Health Carer Experience Survey (CES) is the result of the partnership between the OCP and the Local Health Networks, which led a project across 84 mental health services in South Australia.

I am pleased to present the first CES report elaborated by Professor Sharon Lawn, Chair of Lived Experience Australia. Sharon used her lived experience wisdom and academic expertise to understand the experience of carers who interact with our services. This baseline will allow us to advance in monitoring the improvement of the experience of carers who have contact with SA Health mental health services.

I want to extend my sincere thanks to the Carer Champions from each Local Health Network who supported the implementation of the project, as well as the local staff who assisted in promoting the survey and collecting the data in each service. This is an excellent example of the integration of lived experience, safety and quality, and data management perspectives to advance in delivering integrated mental health care.

Finally, I want to thank all the carers who completed the survey and helped us understand your experience interacting with SA Health mental health services. We are looking to continue working in partnership with you to improve the experience for you and the person you care for.

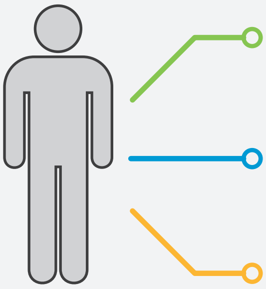
Dr John Brayley
Chief Psychiatrist

"Thank you to all the carers who completed the survey.

Your feedback is essential for providing personalised mental health care that responds to the needs of the community."

SUMMARY

This report uses the Mental Health Carer Experience of Service (CES) Survey to explore carer experiences of SA mental health services at State level and Local Health Network (LHN) level during 2021. Of note, the survey was completed at a time when SA experienced widespread restrictions and impacts of the COVID-19 pandemic.



781 consumers had an identified carer

There were **21,097** people active in the records of services that participated in the project during the collection period. Of these, had an identified carer **(3.7%)**

449 surveys analysed

476 surveys were completed and returned for analysis, inclusive of **27** invalid responses, leaving **449** surveys for analysis

57% carers in-scope

This equates to **57%** of carers who were in-scope, assuming one carer per consumer

What did carers say about their experience?

- Results are generally positive, with 79.2% of carers rating their overall experience of the service during the collection period as very good or excellent.
- Mental health carers reported more positive experiences of community services than hospital inpatient settings.
- In all service settings, carers scored questions relating to Showing Respect the highest and Providing Information and Support lowest.
- Women's & Children's Health Network (HN) received the highest question overall rating (94.0% for Showing Respect)
- Carer experience was varied across the different LHNs, but reasons for this are unclear.
- Carers of people who had more recently become clients of the mental health services reported better experiences that carers of people who had been clients of services for longer on overall experience and across all Domains. The longer the duration of being a client of services, the worse the carers' experience appeared to be.
- Few LHNs performed better than the State-wide average for the overall and carer experience Domain scores. Most variations were not significant.
- No LHN met the 80% threshold for the Providing Information and Support Domain.
- Few services met the 80% threshold for the Making a Difference Domain.
- One consistently low-rated individual CES question was Q2 – Explanation of Legal Issues, which was primarily relevant for people caring for people receiving involuntary treatment.
- Another consistently low-rated CES question was Q20 – Information on opportunities to participate in improving the service, across the LHNs.
- Several services also had low-ratings for Q5 – Able to Obtain Cultural and Language Support. This requires overall system action to support service action.
- Improvement is needed across all LHNs for the effect of the services on carers:
- Q23-Q26 - Support for Relationship with the Person, Hopefulness for Future, Overall Carer Wellbeing and Overall Experience of the Service.
- In almost all LHNs and subspecialities (Older Persons Services, Forensic and Veteran Services), 80% or more carers said their family member wanted them involved in the care.

INTRODUCTION

What is the CES Survey?

The CES surveys asks people who provide unpaid support (hereafter termed ‘carers’) to family members or friends with mental ill-health who use South Australia’s public mental health services about their experiences of care. This information is used by the services to identify what they are doing well and opportunities to improve service delivery.

The initiative is coordinated by the South Australian Office of the Chief Psychiatrist (OCP) with the support of Carers Champions of the LHNs and implemented by public hospital and community mental health services across South Australia. The CES Survey covers five broad Domains, with specific questions within each Domain, plus demographic questions about participants (see Appendices 1 and 2).

Why the CES is important

There are many reasons to ask families and carers about their experiences of care.

Routine collection of experience data assists SA’s public mental health services to:

- Identify what they are doing well, and where they can do better
- Make plans and take action on items identified by carers as not meeting expectations
- Provide a baseline from which to compare future CES surveys to determine if actions to improve services have had a measurable impact
- Compare how SA services are doing with other services providing similar types of mental health interventions, and to learn from each other where examples of outstanding service are identified
- Research demonstrates improved outcomes for consumers when they are active participants in their own health care, and when families and carers are actively involved and informed in a partnership as part of a Triangle of Care (consumer, carer, service) working together for the best consumer outcomes.

[1 2 3] Being actively involved means more than simply filling out a survey. It includes shared decision-making, care planning and information sharing between clinical staff, consumer and carers (whilst respecting the consumer’s right to confidentiality and privacy).

How the CES is collected

The SA Strategic Mental Health Quality Improvement Committee (SMHQIC) endorsed a toolkit and a protocol which included three main components: governance, communication, and survey business rules which provided a unified approach for the state-wide implementation of the CES.

The CES surveys was collected in South Australia over a five-month period from June to October 2021. Start and end dates varied across LHNs; Central Adelaide’s collection period was approximately 3.5 months. Methods of distribution of the CES to carers varied, with most being paper-based and carers approached ‘on the spot’ during their direct contact with the services.

Completing the CES is voluntary, and all responses are anonymous. No identifying information is requested or recorded, and reply-paid envelopes are provided with every survey to preserve confidentiality of responses. CES Surveys are offered to parents, families, carers or guardians during face-to-face interactions with mental health service staff during the collection period. Surveys may be offered by consumer and carer workers, peer support workers, administrative and clinical staff, depending on local processes.

METHODS

How we analysed the main research questions

We were primarily interested in the standardised (0-100/100) overall and domain scores of the CES, where higher scores indicate a better experience. The benchmark used was >80%, as displayed in the figures throughout this report. Further information about how to calculate the standardised scores can be found in the Carer Experience Survey guide.

We were also interested in reporting the individual CES survey question scores where carers reported 4 or 5 on the 5-point Likert-rated experience questions (e.g., very good/excellent; usually/always). This enables a more fine-grained understanding of which areas of service provision are working well in relation to the benchmark, and areas for improvement. In this report, the top five and bottom five scoring CES questions are highlighted for each LHN. Missing responses, 'Don't Know' and 'Not Needed' are treated as system missing and not included in the calculations.

The domains of the CES are:

Making a Difference Describes how the service contributed to outcomes for individuals. It includes social and emotional wellbeing and physical health.	**Q23, Q24, Q25, Q26**
Providing information and support Describes how the service works for the individual. It includes resources such as written information, a care plan, and access to peer support.	**Q1, Q2, Q3, Q15, Q17, Q18, Q19, Q20, Q21, Q22**
Valuing individuality Describes how the service meets individual's needs. It includes sensitivity to culture, gender and faith and the importance of personal values and beliefs.	**Q4, Q5, Q12, Q14**
Supporting active participation Describes how the service provides opportunities for engagement, choice and involvement in the process of service delivery.	**Q6, Q8, Q10, Q11, Q16**
Showing respect Describes how the service provides the individual with a welcoming environment where they are recognised, valued and treated with dignity.	**Q7, Q9, Q13**

We were also interested in the overall and domain scores for certain subgroups and whether these scores were different. The subgroups we were interested in comparing were: 1) LHNs, 2) community vs inpatient, and 3) demographics with sufficient cell/sample sizes.[4]

Carers' free-text comments were analysed thematically using Content Analysis and arranged according to each LHN, plus the Older Persons, Forensic and Veteran subspecialties, with connections to the CES Domains noted. Summary information about key qualitative results appear in each LHN-specific section, with more detailed results in Appendix 3.

Limitations and Cautions

Before exploring the findings, it is important to acknowledge their limitations. Several groups may be under-represented due to low response rates to the survey. Some services were not represented at all. For example, adult community mental health services across the Western region of Adelaide are not represented. Small sample sizes meant that responses for some services were combined (e.g., Regional LHNs) which may not have acknowledged potential service and regional differences. Overall, low sample sizes for Regional LHNs and Central Adelaide LHN mean the data may not have been representative of the true performance of these LHNs.

As noted in the Summary, the sample of carers in-scope for the CES Survey represented only 3.7% of consumers who accessed mental health services who had an identified carer noted in the service records system. It is likely that many more carers exist than those known to the system as 'identified carers'.

Therefore, this may have also biased the sample. This concern was alleviated somewhat, because the main method of recruitment was direct face-to-face approach using hardcopy surveys. Therefore, it is possible that many carers not listed as identified carers also participated.

Also, whilst reporting of data for Veteran and Forensic services is important because of the distinct nature of these services, low sample sizes means that results for these services should be considered with caution. For example, the response from veteran inpatient services was extremely low compared with veteran community services. We did not report separately on other distinct specialist groups such as the Huntington's Service or Neuro Behavioural Unit. Sample size for Older Persons Services was adequate.

We also note that the Women's and Children's HN includes several regional and rural services; these were reported in results for that Health Network rather than reported with results of the Regional LHNs.

A state-wide communication plan was implemented to encourage mental health teams to offer the survey, and for carers to provide their feedback. A good practice of the CES project was establishing a governance structure where each service nominated a staff member who was a local CES champion responsible for leading the survey at the local level. Nevertheless, recruiting carers to undertake the survey varied across services, responding to the local characteristics and dynamics that may have influenced the samples recruited.

Analysis of the free-text comments occurred manually and did not utilise qualitative analysis software. Free-text comments were coded by one individual. Independent coding by 2-3 individuals independently, followed by shared discussion would have improved overall rigor.

RECOMMENDATIONS

Recommendations are proposed across two levels: Outcomes (for LHNs in relation to the CES results) and Processes (related to the implementation of the CES). Within each level, gaps are identified and discussed.

Outcomes

1. Improvements are needed across all CES Domains, but particularly for Providing Information and Support and Making a Difference Domains which, for several LHNs and service types, did not achieve the 80% threshold of satisfaction.
2. For the Making a Difference Domain, carer experiences varied widely across LHNs; carer wellbeing was of particular concern. More supports for carers are indicated.
3. The outcomes of the survey should inform the development of action plans at service level to address the critical items and domains identified by the survey. Outcomes of the CES action plans need to be communicated to carers and to the South Australian mental health community each year to ensure accountability and encourage carers to respond to the survey in the future
4. The qualitative analysis included in this report provides critical inputs to develop strategies aimed at improving the carers' experience. Therefore, the results of this analysis should be considered when designing system and service action plans.
5. Participation in the CES was low for Culturally and Linguistically Diverse, Aboriginal and Torres Strait Islander, and young carers. Strategies need to be considered that maximise reach to these groups. Liaison with Aboriginal Health Services and CALD members on the OCP Lived Experience Group could be a starting point. Verifying the number of Aboriginal and Torres Strait Islander and CALD consumers currently listed within the system would also be helpful in determining whether this low participation reflects carer issues or a wider system issue with engaging carers from these groups. There may be other groups that are also marginalised (e.g., carers with lower literacy, carers located interstate, carers where family violence is present).
6. Overall, community services performed better than inpatient services. The reasons for this should be explored further and addressed. Whilst both met the threshold for Valuing Individuality, Supporting Active Participation, and Showing Respect, neither met the threshold for Providing Information and Support, in particular, or for Making a Difference where carer wellbeing and hopefulness for the future were particularly noted as concerns. Services across the spectrum need to do more to support carer wellbeing and provide them with more information and support generally.
7. Carers had a better experience of community mental health services, compared with their experience of inpatient settings. Community settings scored higher than inpatient settings on Valuing Individuality, Supporting Active Participation, and Showing Respect. It is recommended LHNs develop differentiated strategies to improve the experience of carers of people receiving mental health care in inpatient wards.
8. Responses to some CES questions were rated consistently low and below the 80% threshold, across virtually all LHNs and service types. One of these was carers being given an explanation of any legal issues that might affect the person they care for (Q2). One was how carers could make a compliment or complaint about the mental health service (Q18). Another was carers being given information on opportunities to participate in improving the mental health service (Q20). These gaps indicate that more is needed to inform and involve carers to enhance their knowledge and capacity for individual andsystems advocacy and should be addressed through action plans.
9. Carers across LHNs and service types consistently stressed that the person they cared for wanted them involved in their care and contact with services; however, this varied widely across LHNs and service types, and contrasted with their experiences of involvement. More staff education and training in how to include carers as part of the Triangle of Care (consumer, carer, service providers) is needed.

   Some LHNs clearly performed better than others. Despite nuanced differences between LHNs and services that may account for this due to the nature of the populations served, there is clear opportunity to learn from what is working well. Service leadership is likely an important contributor to carer experience because it is a major influence on service culture. Hence, more could be done to ensure service leaders 'walk the talk' of acknowledging the role of carers. This could include specific education and training, inclusive of service leaders.

10. The low percentage of consumers with a carer identified in the system indicates the need to improve carer engagement. It is recommended LHNs implement strategies like increasing the number of Carer Consultants at mental health services, reinforcing the procedures to identify carers in the data system, and educating the mental health workforce regarding the valuable role of carers in recovery-oriented practice. The practical guide for working with carers of people with a mental illness provides resources to include families and support people in mental health services.

Processes

1. The CES should be undertaken each year so that longitudinal comparison of progress and areas of ongoing concern are identified, and plans developed to address them as part of routine practice improvement and more focused reforms.
2. Local CES champions are needed to support survey distribution, though this needs to be more than one staff member to reduce staff burden, increase reach across shifts, and foster a team culture that supports CES collection. Champions could be any discipline or administration support staff, or both. Acknowledgement of their role, workload adjustments and associated time commitments, should be considered during the CES collection period. The governance structure needs to be maintained.
3. The CES should be distributed once per year and for a set collection period (e.g., three+ months, August-November) similar to a census, rather than as ongoing collection as part of routine service delivery. There are pros and cons of each approach, as outlined in the Carer Experience Survey guide, and services should develop protocols that consider their unique service and population needs. Benefits of a periodic approach are that it would ensure staff and services give specific focus to the activity, and to maximise the sample. This would also provide a clear process for: collection – analysis – reporting – action plans to address outcomes and implement improvements.
4. Paper-based surveys should continue offered as an alternative to collect data, complemented by a broad range of other modes to help maximise carer reach, access and participation in the CES. Not all carers physically attend services face-to-face or when designated staff are present to prompt them to complete the survey. Therefore, other modes are important to address the diversity of carers' needs and commitments. These include email, SMS, online portal, and mail-out to carers.
5. The establishment of a communication plan is a key element to increase the uptake of surveys. It requires diverse strategies and tactics to address mental health workforce and carers in the community. This communication plan could be reviewed in light of the results of this analysis.
6. South Australian mental health services have a significant opportunity for improvement in the identification of carers. There were 21,097 people active in CBIS and CCCME during the data collection stage, and only 721 (3.7%) had an identified carer. It is crucial to include procedures for staff to identify carers within the system and electronic records to ensure more carers are known by services and contactable for CES distribution.
7. The LHNs, with strategic assistance of the OCP, should provide dedicated resources to support the promotion of the CES periodic collection each year. This may involve delivery of training and support to local champions and teams to promote their engagement with carers and survey distribution, and also to ensure broad consistency in how the mental health services are undertaking the CES.
8. Specific experience of gender diverse carers could not be captured due to limitations in the CES question structure regarding gender identity. OCP should approach AMHCON with request to consider more inclusive language for the LGBTQI community for future CES surveys, given its AMHCON possess the licencing rights to the survey.

STATEWIDE SUMMARY

Who did the survey?

The total number of carer participants included in the survey was 476 but the number of participants who provided at least some usable data was 463 (some participants answered some demographic questions but did not answer any of the evaluative questions and so were excluded).

From the usable data, 74.4% of carers were female while 24.4% were male; 95.3% spoke mainly English at home; only 2.4% were of Aboriginal or Torres Strait Islander descent; and 95.5% did not receive any help in completing the survey. Carer age was relatively evenly distributed across the age groupings, with 74.9% being 45 years or older (Figure 1). Many carers (76.1%) have been carers of a family member, partner or friend with mental illness for two years or more, and almost half (44.9%) have been carers for over 10 years (Figure2). More than half of carers (55.3%) were caring for a son or daughter, with 24.4% caring for a spouse/partner (Figure 3). More than half (55.4%) of carer reported that the person they care for had been a client of the mental health services for less than one year

(Figure 4). Note, the length of carer role was often much longer than and length of time that the person was a client of the mental health service, and this difference was significant.

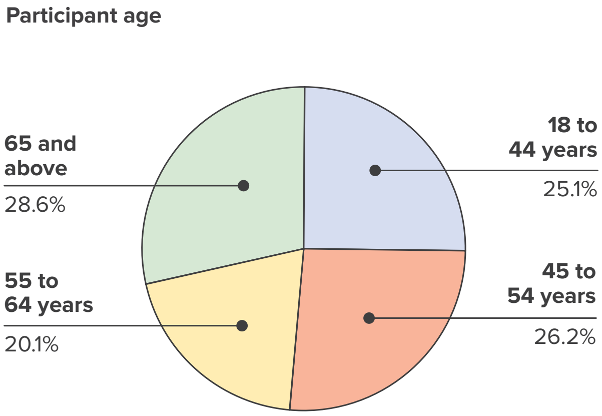


Figure 1: Carer Age

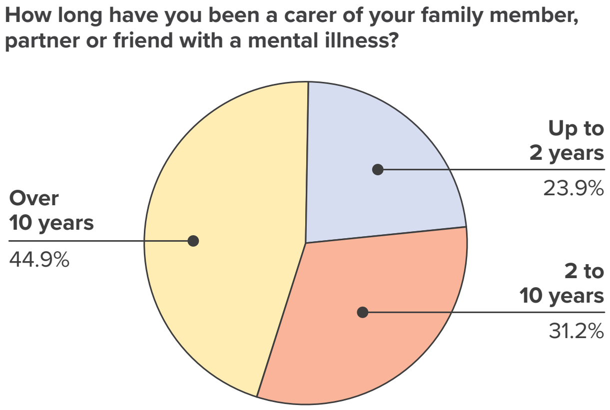


Figure 2: Length of Carer Role

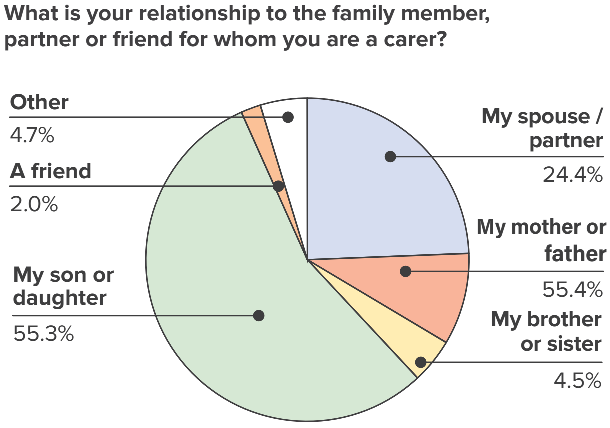


Figure 3: Carer Relationship Status

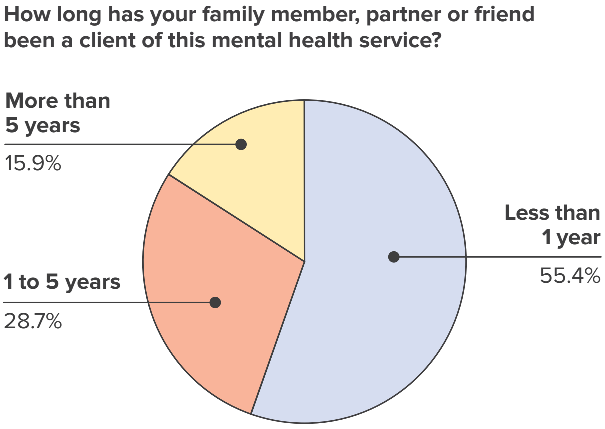


Figure 4: Length of Time the Person has been a Client of Mental Health Service

STATEWIDE SUMMARY

What were the services accessed by people whose carers completed the CES?

In total, there were nine Local Health Networks (LHNs) that were accessed by clients whose carers completed the CES survey; but, given the low number of participants who reported on Regional LHNs (n=30) (Barossa Hills Fleurieu; Eyre and Far North; Flinders and Upper North; Limestone Coast; Yorke and Northern; Riverland, Mallee and Coorong), we combined these into one for the analysis.

A disproportionately high number of carers (33.0%) were linked with Southern Adelaide LHN, and a disproportionately low number were linked with Central Adelaide LHN (7.6%) and Regional LHNs (6.7%) (Figure 5). Central Adelaide LHN was undertaking accreditation at the time of CES survey distribution which likely limited its capacity and focus on the CES.

Local Health Networks examined

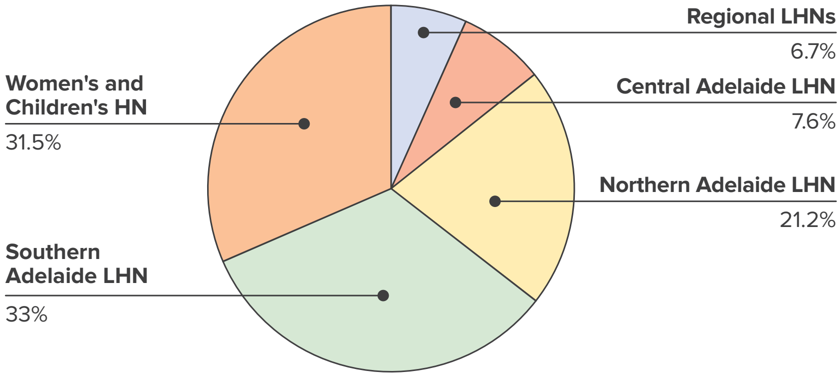


Figure 5: CES Participants by Local Health Network (LHN)

Inpatient and Community Spread of CES Survey Participants

There were ten inpatient wards examined based on age (e.g., youth, adult, older, veteran, forensic) and setting (community vs inpatient); but, given low numbers, we only reported on setting, which constituted 62.2% community and 37.8% inpatient.

Overall and domain scores for the entire sample (N = 449)

At a State-level, carers' overall experience was just under the 80% threshold, indicating that 79.2% of carers had a very good or excellent overall experience of service from the LHNs. Carers' experiences scored above the 80% threshold for three of the five domain scores; of note, Showing Respect was rated the highest (88.6%) and Providing Information and Support was rated the lowest (72.2%) (Figure 6).

Mean scores for overall sample (N = 449)

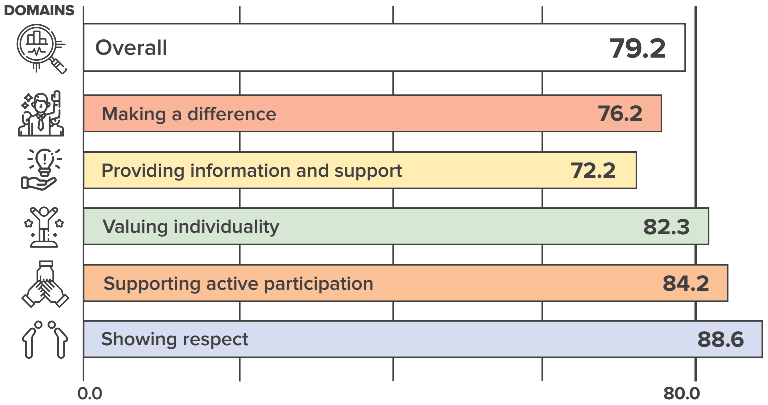


Figure 6: Overall and Domain Scores for the State of South Australia

CARER EXPERIENCE OF COMMUNITY MENTAL HEALTH CARE

At a State-level, carers' overall experience of community mental health services just met the 80% threshold, indicating that 80.5% of carers had a very good or excellent overall experience of these services from the LHNs. Overall, community mental health care was rated by carers as meeting the 80% threshold for three of the five domain scores (Figure 7).

Mean scores for community setting (N = 288)

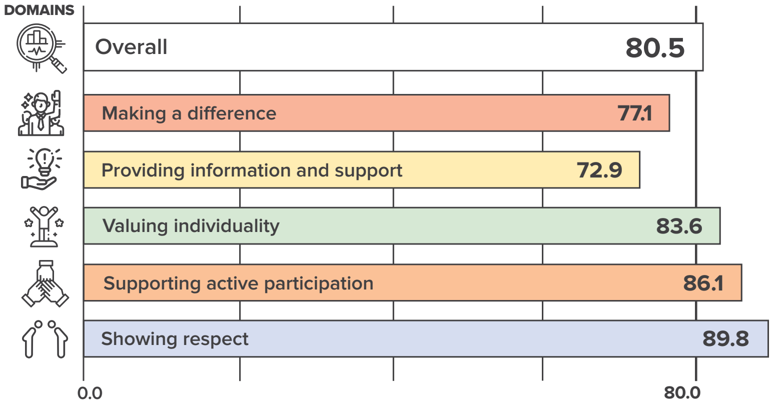


Figure 7: Carer Experience of Community Mental Health Care

CARER EXPERIENCE OF HOSPITAL MENTAL HEALTH CARE

At a State-level, carers' overall experience of hospital inpatient services did not quite meet the 80% threshold, indicating that 77.2% of carers had a very good or excellent overall experience of these services from the LHNs. Overall, hospital inpatient care rated by carers as meeting the 80% threshold for three of the five Domain scores, though only just for two of these three domains (Figure 8).

Mean scores for inpatient setting (N = 175)

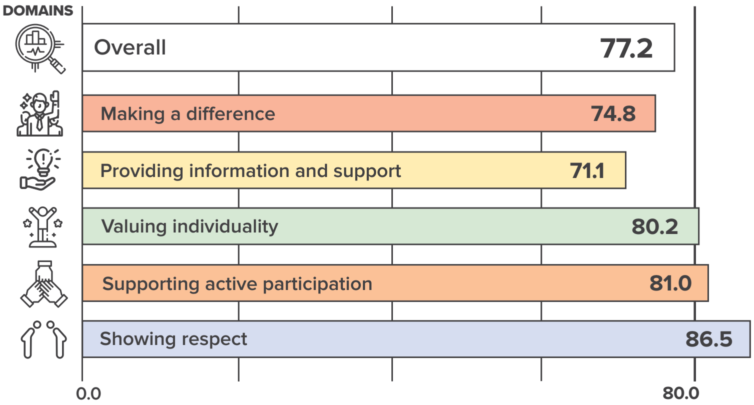


Figure 8: Carer Experience of Hospital Mental Health Care

Overall and Domain Scores for Community vs Inpatient Settings

Regarding comparisons, the following statistically significant differences were found:

- Carers had a better experience of community mental health services, compared with their experience of inpatient settings. Community settings scored higher than inpatient settings on Valuing Individuality, Supporting Active Participation, and Showing Respect.[15]

CARER EXPERIENCE BY GENDER, AGE AND CARER ROLE DURATION

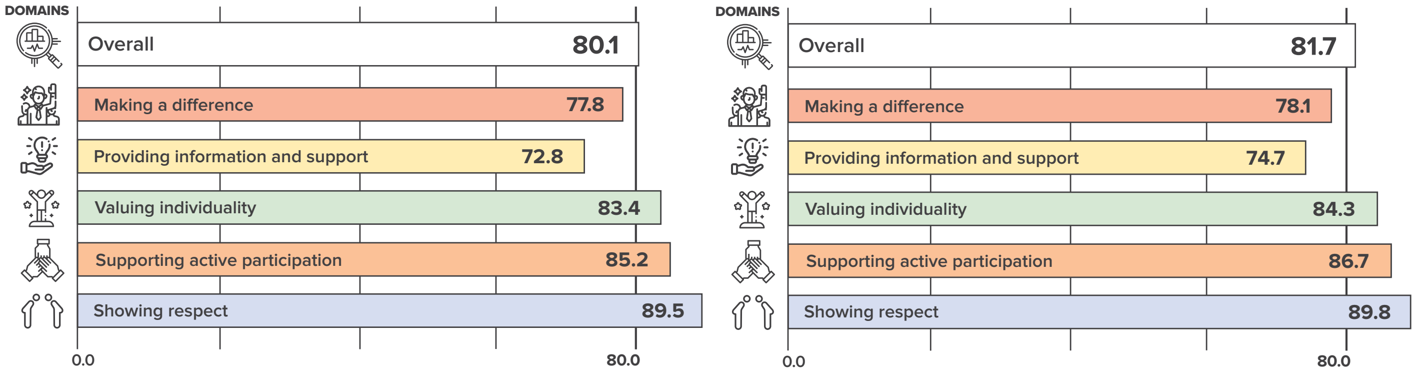
There were no statistically significant differences in overall carer experience or carer experience by Domain between female and male carers, carer age groups, or carer role duration groups (see Appendix 4). This was an unexpected finding, given pervasive stereotypes held about the caring role, the varying needs of younger and older carers, and the expectation that carers who were more experienced in their role through longer duration in the role would likely have a different experience to carers who were newer to the role.

CARER EXPERIENCE BY CLIENT SERVICE DURATION

Carers of people who had more recently become clients of the mental health services reported better experiences that carers of people who had been clients of services for longer on overall experience and across all Domains. The longer the duration of being a client of services, the worse the carers' experience appeared to be (Figure 9).

Regarding comparisons, the following statistically significant differences were found using a Bonferroni adjusted significance level of .016:

- Carers of clients with service duration less than one year scored higher than carers of clients with service duration of more than five years on Overall, and all domain scores: Making a Difference, Providing Information and Support, Valuing Individuality, Supporting Active Participation, and Showing Respect.[8]
- Carers of clients with service duration of one to five years scored higher than carers of clients with service duration of more than five years on Overall and all domain scores: Making a Difference, Providing Information and Support, Valuing Individuality, Supporting Active Participation, and Showing Respect.[9]



Mean scores for carers of clients with service duration less than one year (N = 243)

Mean scores for carers of clients with service duration of one to five years (N = 126)

Mean scores for carers of clients with service duration of more than five years (N = 70)

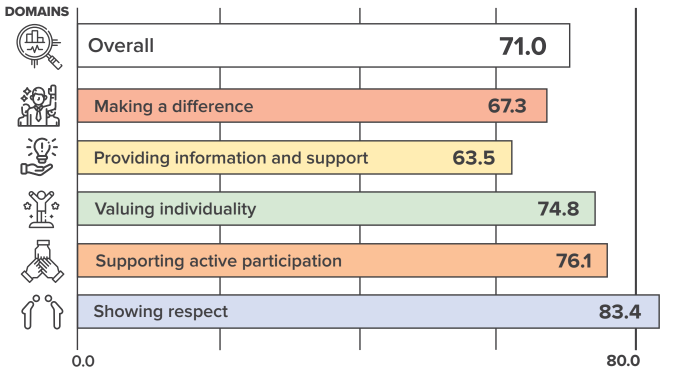


Figure 9: Overall and Domain Scores by Client Service Duration

CARER EXPERIENCE FROM EACH LOCAL HEALTH NETWORK

Central Adelaide Local Health Network

Overall Carer Experience from Central Adelaide LHN → Very Good or Excellent 78.9% in the last 3 months

Mean scores for Central Adelaide LHN (N = 35)

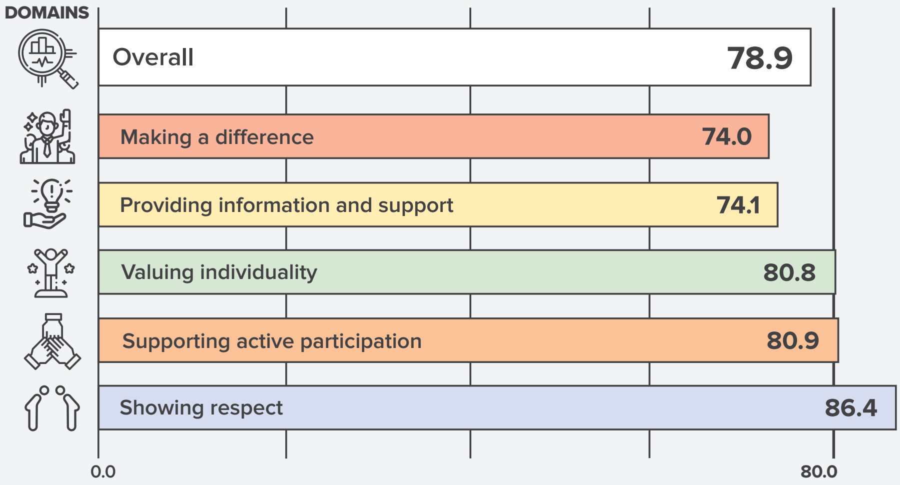


Figure 10 Overall and Domain Scores
Central Adelaide LHN (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q5	Able to Obtain Cultural & Language Support	**4.29**
Q7	Opinion as Carer Respected	**4.19**
Q9	Identified as Carer	**4.00**
Q14	Staff Supported Carer Relationship with the Person	**3.79**
Q6	Opportunity to Provide Information about the Person	**3.75**
Q23	Effect of Service on Carer Relationship with the Person	**2.95**
Q25	Effect on Overall Carer Wellbeing	**2.81**
Q26	Overall rating of Carer Experience with this Service	**2.79**
Q2	Given Explanation of Legal Issues	**2.60**
Q12	Given Opportunity to Enhance Abilities as a Carer	**2.59**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Central Adelaide Local Health Network

My experience would have been better if

*There was regular communication about progress, how I can help, discussion about medications and side effects.
The receptionist said I would not be able to speak to the doctor when I asked. I felt blocked in giving vital information. My family feels we need to 'pick up the pieces' when things go wrong, but we don't get clear information.*

My partner didn't have to repeat his story over and over to various clinicians. Not being heard about his medication making him unwell and the focus on his alcohol versus self-medicating his extreme trauma.

CALHN CARERS WANT MORE INVOLVEMENT AND COMMUNICATION WITH SERVICES

The best things about this service were

I have nothing but admiration for the health workers at the IRS.

Thank you.

The staff were fantastic supportive informative and compassionate and always approachable.

Caring committed staff. Openness and sharing practitioners. A sense of calm and positive atmosphere. Staff always willing to listen, reassure and follow-up. Sense that it's a community and we're on this journey together.

The interest and care offered by nursing staff. The ongoing support and communication with Social Worker(s). The interest and commitment by treating doctors to the needs of my family member.

CENTRAL ADELAIDE LHN CARERS VALUE COMMUNICATION AND STAFF COMMITMENT TO CARE

Northern Adelaide Local Health Network

Overall Carer Experience from Northern Adelaide LHN → Very Good or Excellent 78.2% in the last 3 months

Mean scores for Northern Adelaide LHN (N = 98)

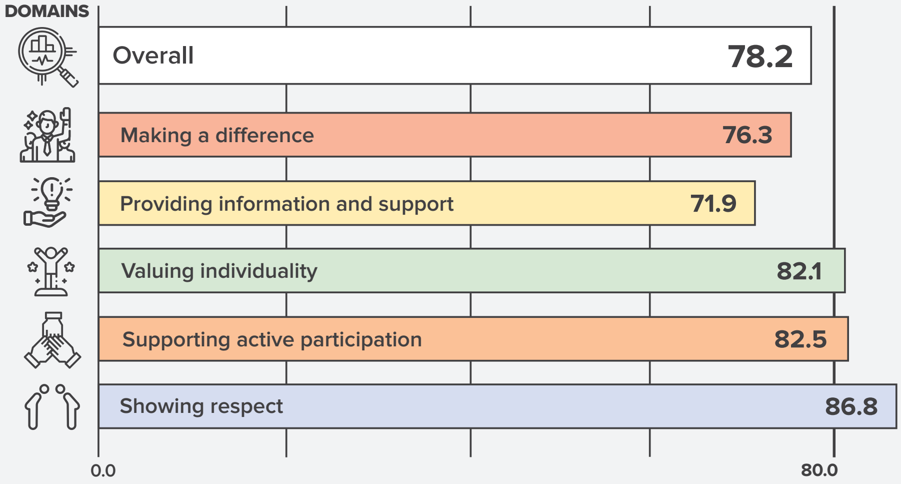


Figure 11 Overall and Domain Scores
Norhern Adelaide LHN (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q14	Staff Supported Carer Relationship with the Person	4.53
Q7	Opinion as Carer Respected	4.48
Q9	Identified as Carer	4.32
Q6	Opportunity to Provide Information about the Person	4.11
Q10	Given Opportunities to Discuss Care, Treatment & Recovery	4.11
Q24	Effect of Service on Hopefulness for Future	3.10
Q25	Effect of Service on Overall Carer Wellbeing	3.00
Q2	Given Explanation of Legal Issues	2.80
Q12	Opportunity to Enhance Ability as Carer	2.64
Q5	Cultural or Language Support	2.50

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Northern Adelaide Local Health Network

My experience would have been better if

Staff were more competent, professional and empathetic. Over 2 months my son was in an inpatient, we experienced conflicting medical advice, double dosing of my son's medication, double booking visits approx. 7 times and lost belongings. Most Team Leaders were rude, unhelpful and lacked integrity. Very poor.

I very rarely had a chance to talk (at Northgate) to other family members.

There was a follow-up outpatient facility and case manager to check on progress, treatment ongoing etc, including medication issues and counselling services - monitor and help prevent relapse.

NORTHERN ADELAIDE LHN CARERS WANT TO BE INCLUDED MORE IN CARE AND COMMUNICATION WITH SERVICES

Northern Adelaide Local Health Network

The best things about this service were

Caring staff, not treated as a number and pushed out quickly.

Staff kept me informed of any changes with my brother - multi-disciplinary meetings were excellent. Drs made regular contact with me regarding changes to medication.

Being so involved in my mother's care plan.

The contact between the focus nurse for my son and myself. She has been very good at keeping in touch to see how he is travelling and told me to contact her if there is a problem.

NORTHERN ADELAIDE LHN CARERS VALUE COMMUNICATION AND STAFF COMMITMENT TO CARE

My concerns always put into perspective, validated and strategies discussed. My opinions respected even if not agreed with. My daughter's mental health always the priority but I have always felt the concern and wellbeing of the whole family is being considered at all times.

NORTHERN ADELAIDE LHN CARERS VALUE SERVICES THAT CARE ABOUT THE WHOLE FAMILY

You didn't give up on her [mum]

The way they took time to understand my son and in turn to assist him in ways which would work for him.

NORTHERN ADELAIDE LHN SERVICES SHOWED RESPECT AND GAVE CARERS HOPE

Southern Adelaide Local Health Network

Overall Carer Experience from Southern Adelaide LHN → Very Good or Excellent 75.4% in the last 3 months

Mean scores for Southern Adelaide LHN (N = 153)

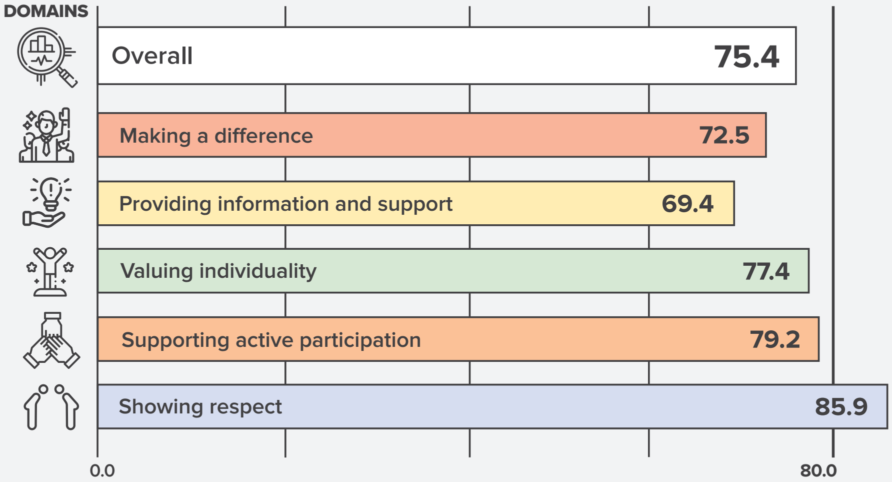


Figure 12 Overall and Domain Scores
Southern Adelaide LHN (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q9	Identified as Carer	**4.44**
Q7	Opinion as Carer Respected	**4.25**
Q14	Staff Supported Carer Relationship with the Person	**4.11**
Q6	Opportunity to Provide Information about the Person	**3.95**
Q4	Personal Values, Beliefs & Circumstances were Considered	**3.85**
Q23	Effect of Service on Carer Relationship with the Person	**2.75**
Q24	Effect of Service on Hopefulness for Future	**2.74**
Q5	Cultural or Language Support	**2.50**
Q2	Given Explanation of Legal Issues	**2.46**
Q12	Opportunity to Enhance Ability as Carer	**2.30**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Southern Adelaide Local Health Network

My experience would have been better if

I was recognised not only as a carer for over 40 years but also his guardian. Quite often I am seen and ignored or avoided until something goes wrong.

We were not referred to a new doctor/services/carers to whom we need to get to know again. We have been swapped between different services constantly which affects our trust and feel like it is all a waste of time. I start to disengage as I do not wish to raise my hopes waiting for it all to go wrong again.

I was repeatedly dismissed and ignored whilst provided information that could have prevented my partner from relapsing...[and] key points in time where I indicated to the mental health team that my partner is having early warning signs you need to act...completely dismissed. As a result, my partner has had a full-blown psychotic episode.... It failed at every point in time we needed them.

SOUTHERN ADELAIDE LHN CARERS WANT TO BE RECOGNISED, INCLUDED AND RESPECTED MORE BY SERVICES

Patients weren't left unattended for so long. I frequently had to ask for things for my daughter. Individual nurses were excellent but often you were ignored by nurses who kept chatting until you verbally interrupted....Overall, it was a poor experience. We also left with no management plan for the future. It's like being just cast adrift.

It did very little to help her resolve the underlying problems.

Doctors didn't change all the time.

SOUTHERN ADELAIDE LHN CARERS WANT BETTER CARE AND SUPPORT FOR THEIR FAMILY MEMBER

I had been given information about how this service was interacting with my family member - in particular what the plan was. I have never known who I should contact to find out this information or in fact whether I am permitted to.

SOUTHERN ADELAIDE LHN CARERS WANT MORE INFORMATION ABOUT SERVICES

Southern Adelaide Local Health Network

The best things about this service were

The genuine caring approach of staff.

My son was given the care and support when he needed it most - he was treated with respect... He was able to recover in a way which was beneficial to him and his family.

I felt a personal care approach. My feelings and ideas weren't dismissed. I felt a genuine concern for me and my family and that the person providing the support genuinely wanted us to be well.

STAFF COMPASSION HAS A BIG IMPACT ON THE SOUTHERN ADELAIDE LHN CARER EXPERIENCE

Regular communication and follow up....the ability to call or email if I had questions and they were always answered.

Meetings set up between Mental Health Service, Centacare representative, Housing...resulted in positive outcomes, and good follow up. We appreciated being involved...and the "strength- based" approach which focussed on what they COULD do, rather than deficiencies. The three of them worked as a TEAM.

The skills you gave my daughter to cope.

SOUTHERN ADELAIDE LHN CARERS VALUE EFFECTIVE CARE COORDINATION AND COMMUNICATION

Women's and Children's Health Network

Overall Carer Experience from Women's and Children's HN → Very Good or Excellent 84.1% in the last 3 months

Mean scores for Women's and Children's HN (N = 146)

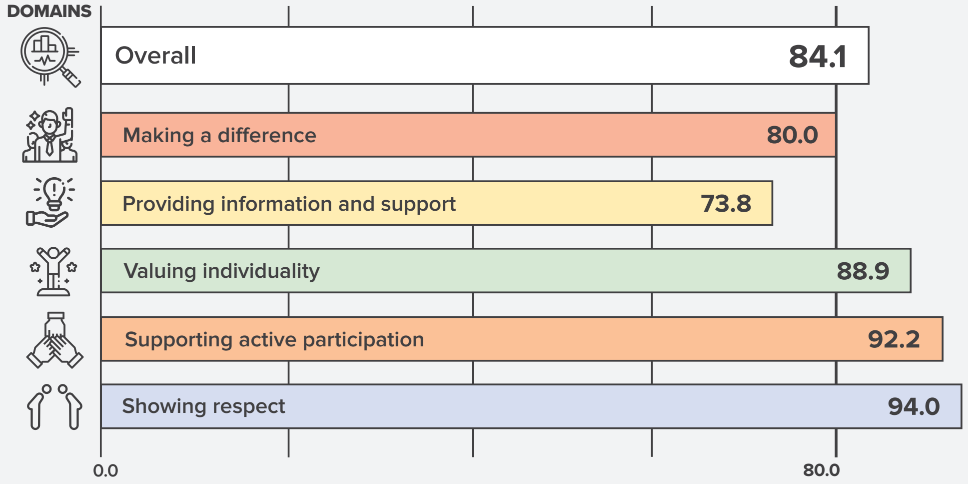


Figure 13 Overall and Domain Scores
Women's and Children's HN (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q9	Identified as Carer	**4.82**
Q7	Opinion as Carer Respected	**4.79**
Q10	Cultural or Language Support	**4.78**
Q5	Cultural or Language Support	**4.74**
Q6	Opportunity to Provide Information about the Person	**4.71**
Q23	Effect of Service on Carer Relationship with the Person	**3.92**
Q25	Effect of Service on Overall Carer Wellbeing	**3.78**
Q12	Opportunity to Enhance Ability as Carer	**3.72**
Q26	Overall rating of Carer Experience with this Service	**3.65**
Q2	Given Explanation of Legal Issues	**2.47**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Women's and Children's Health Network

My experience would have been better if

There were more resources allowing us an earlier appointment. Staff are clearly doing the best they can but they're over-stretched and wait times are far too long.

More psychiatrists were available to speed up referrals.

WOMEN'S AND CHILDREN'S HN CARERS WANT BETTER CONTINUITY OF CARE

There was more continuity of care instead of multiple mental health workers assigned.

Better communication with parent. Continuity in treating provider - always changing for various reasons, so feels like you're always starting again...communication between therapists needs to improve as very confusing to patient and parents.

Initial triage by CAMHS upon presentation of my child at hospital was inadequate and placed my child in danger of self-harm.

WOMEN'S AND CHILDREN'S HN CARERS WANT BETTER CONTINUITY OF CARE

Women’s and Children’s Health Network

The best things about this service were

Our daughter now has the knowledge and skills to be able to deal with her issues and we too are able to support her better knowing what we have learnt along the way. We can’t thank you enough for making all our lives a lot better. Thank you Thank you Thank you.

XXX took on my thoughts, views and concerns and she placed it all on the table to be addressed.

Getting advice and feedback.
Learning practical things to help.
Open lines of communication and contact.

WOMEN’S AND CHILDREN’S HN CARERS VALUE SERVICES THAT HELP THEM FIND ANSWERS AND UNDERSTAND MENTAL ILL-HEALTH

A family approach, being able to express difficulties in family dynamics in a safe environment.

They took the time to listen and try to understand to help the best way possible.

WOMEN’S AND CHILDREN’S HN CARERS VALUE STAFF COMPASSION AS THE FAMILY LEARNED TO COPE AND ADAPT

Regional Local Health Networks

Overall Carer Experience from Regional LHN Services → Very Good or Excellent 79.2% in the last 3 months

Mean scores for Regional LHNs* (N = 31)

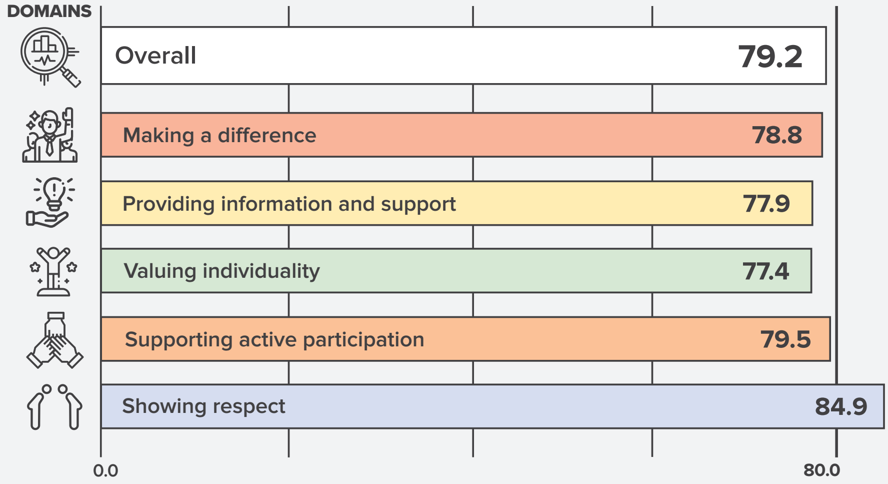


Figure 14 Overall and Domain Scores
Regional LHNs (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q9	Identified as Carer	**4.48**
Q8	Involved in Decisions Affecting the Person	**4.31**
Q6	Opportunity to Provide Information about the Person	**4.11**
Q7	Opinion as Carer Respected	**3.93**
Q14	Staff Supported Carer Relationship with the Person	**3.62**
Q11	Involved in Planning for Ongoing Care, Treatment & Recovery	**3.12**
Q10	Given Opportunities to Discuss Care, Treatment & Recovery	**3.03**
Q16	Opportunities to Communicate Confidentially with Doctor	**2.83**
Q2	Given Explanation of Legal Issues	**2.38**
Q12	Opportunity to Enhance Ability as Carer	**2.17**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Regional LHNs

My experience would have been better if

We have an amazing support team here, but it gets let down/lost at every hospital admission only to leave us and the community mental health team frustrated, confused and quite frankly annoyed. There is a need for more local Psychiatrists and Psychologists.

Things were better explained. Once in hospital (my son) I was forgotten. I had no idea of my rights as a mother and carer. Information was extremely difficult to get due to "privacy concerns".

If help was more available when required - after hours. A&E waiting times do not help. A little more information on help I can get to help my son.

RURAL CARERS WANTED MORE ACCESS, PRACTICAL INFORMATION AND SUPPORT

The best things about this service were

I really appreciated how quickly and efficiently XXX got things in order so that XXX's mental illness did not spiral out of control avoiding hospitalisation. Appointments and forms were completed within 2 weeks of contacting them, and we were informed of upcoming psychiatrists appt straight away, making me as a carer feel confident that professional help and diagnosis was all in place.

My knowledge that I can ring any time if I have concerns with my son's condition. I always get help and don't know where we would be without this service! I am forever grateful to XXX on KI for her amazing help. It is helpful that they communicate with the local Drs so that we are all on the same page.

That the doctors/nurses took into account what I wanted/needed for my wife's treatment. The staff were always respectful of my "insight" when treating my wife.

REGULAR COMMUNICATION, BEING INVOLVED, EFFECTIVE SERVICE COORDINATION, AND CARING STAFF HAD A BIG IMPACT ON THE RURAL CARER EXPERIENCE

CARER EXPERIENCE FROM SUBSPECIALTY SERVICES

Older Persons Services

Overall Carer Experience from Older Persons Services ⟶ Very Good or Excellent 82.4% in the last 3 months

Mean scores for carers of clients using older persons' services (N = 96)

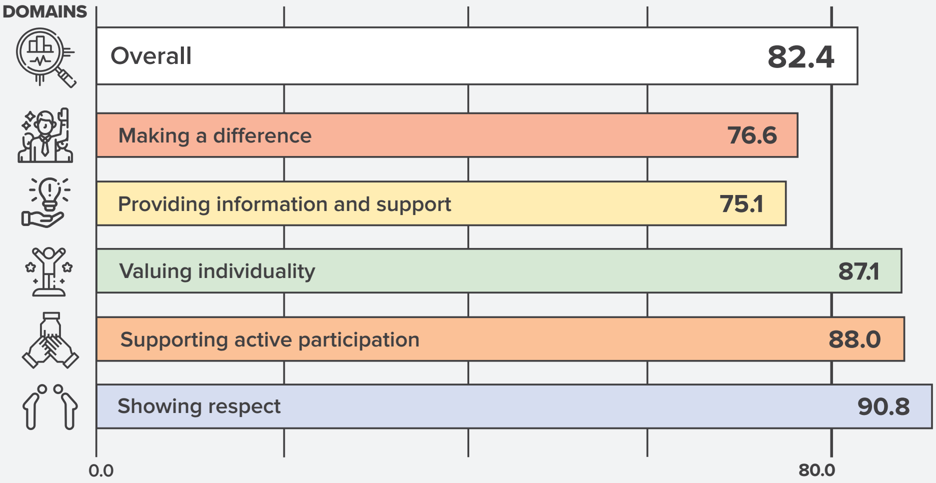


Figure 15 Overall and Domain Scores
Forensic Services (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q14	Staff Supported Carer Relationship with the Person	**4.84**
Q9	Identified as Carer	**4.63**
Q6	Opportunity to Provide Information about the Person	**4.52**
Q7	Opinion as Carer Respected	**4.52**
Q4	Personal Values, Beliefs & Circumstances were Considered	**4.39**
Q2	Given Explanation of Legal Issues	**3.18**
Q24	Effect of Service on Hopefulness for Future	**3.00**
Q25	Effect of Service on Overall Carer Wellbeing	**2.90**
Q23	Effect of Service on Carer Relationship with the Person	**2.78**
Q12	Opportunity to Enhance Ability as Carer	**2.65**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Older Persons Services

My experience would have been better if

I would like more accurate information of how my dad is going.

We have an amazing support team here, but it gets let down/lost at every hospital admission I had more support when my husband was acutely unwell. It was difficult to speak to his Psychiatrist and the Community Visitor was also hard to contact at times. I realise everyone is overstretched, but when you are alone caring for someone with psychiatric issues it can be very stressful.

My concern regarding my wife's health and ongoing care is when is it the right time to move on. With a high level of dementia and the ongoing deterioration of her mental and physical health, moving to a private care facility may not be the right move. Question!! Where do we go when the near future is death? When is palliative care right?

OLDER PERSONS SERVICES CARERS WANTED MORE COMMUNICATION AND SUPPORT

Mum wasn't allowed to lie on her bed to nap in the afternoon, something she always does. It was difficult to feel comfortable and happy in the visitors' room. A nice outdoor area with shade would make this nicer. Her personal items -knitting, photos etc went missing.

OLDER PERSONS SERVICES CARERS WERE CONCERNED ABOUT THE CARE ENVIRONMENT

Older Persons Services

The best things about this service were

Staff kept me informed of any changes with my brother - multi-disciplinary meetings were excellent. Drs made regular contact with me regarding changes to medication.

The team were always approachable from psychiatrist to the RN case worker and Dr at Southern Mental Health Services for Older People. Great support for me as a carer as well as the patient.

Caring staff, not treated as a number and pushed out quickly.

My mind was at ease knowing the staff were giving my mum the best holistic care.

FRIENDLY AND ENGAGED STAFF WERE VALUED BY OLDER PERSONS SERVICES CARERS

… the empathetic staff who expressed insight and demonstrated experience in dealing with the specific issues my family member faced.

I think one of the most critical treatments when someone is dying, is treating the person with respect and dignity. I thank the facility, the manager, doctor and all involved as they definitely ticked both boxes!

All staff on the ward genuinely care about the patient and their recovery. They display empathy!

EMOTIONAL SUPPORT, COMPASSIONATE AND EMPATHY WERE VALUED BY OLDER PERSONS SERVICES CARERS

My husband was looked after exceptionally well. Staff were very friendly, helpful and caring to both of us. It is the best facility my husband could have been in. I am very grateful for the way the staff looked after both of us.

I felt like I too was being carried and cared for by this service.

SUPPORTING THE FAMILY/COUPLE, NOT JUST THE INDIVIDUAL, WAS VALUED BY OLDER PERSONS SERVICES CARERS

Forensic Services

Overall Carer Experience from Forensic Services → Very Good or Excellent 76.8% in the last 3 months

Mean scores for carers of forensic clients (N = 18)

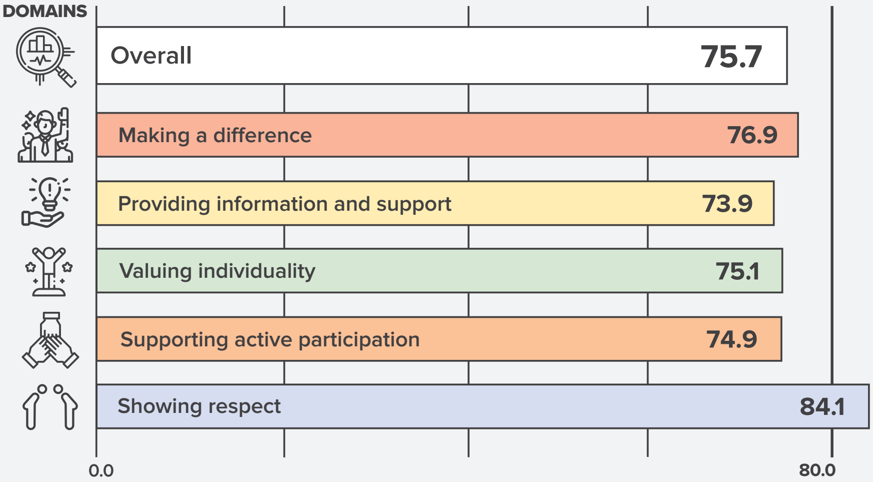


Figure 16 Overall and Domain Scores
Forensic Services (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q7	Opinion as Carer Respected	**4.41**
Q9	Identified as Carer	**4.41**
Q14	Staff Supported Carer Relationship with the Person	**4.37**
Q10	Given Opportunities to Discuss Care, Treatment & Recovery	**4.12**
Q3	Understanding Rights & Responsibilities	**4.12**
Q2	Given Explanation of Legal Issues	**3.23**
Q13	Staff Conveyed Hope for Recovery	**3.23**
Q12	Opportunity to Enhance Ability as Carer	**2.92**
Q15	Given Information & Strategies if Person Became Unwell Again	**2.86**
Q5	Cultural or Language Support	**1.43**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Forensic Services

My experience would have been better if

The doctors had more time to speak to the family; explain what my son suffers; how long he will stay here in JNH for; the medication he is on.

I wonder if having therapy animals might be of benefit to patients.

Lots of confusion in the very beginning, so more information on things "allowed" would have saved some frustrations and emotions.

FORENSIC CARERS WANTED MORE INFORMATION AND INVOLVEMENT TO UNDERSTAND THIS SPECIALISED SYSTEM

The best things about this service were

My knowledge that I can ring any time if I have concerns with my son's condition. I always get All staff are very caring and very respectful of my family member. I feel he is very well looked after, not just as a patient but as a human being.

Amazing staff! They work with the patients and family and have a patient centred approach. They have been incredibly kind and supportive.

Friendly staff, always happy to chat and inform about the patient. Willingness to engage with me about progress and treatment, and my deep knowledge of the patient. KNOWING HE IS IN A SAFE PLACE!

SAFE AND EFFECTIVE SUPPORT BY CARING STAFF HAD A BIG IMPACT ON THE FORENSIC CARER EXPERIENCE

Veteran Services

Overall Carer Experience from Veteran Services → Very Good or Excellent 75.7% in the last 3 months

Mean scores for carers of veterans (N = 18)

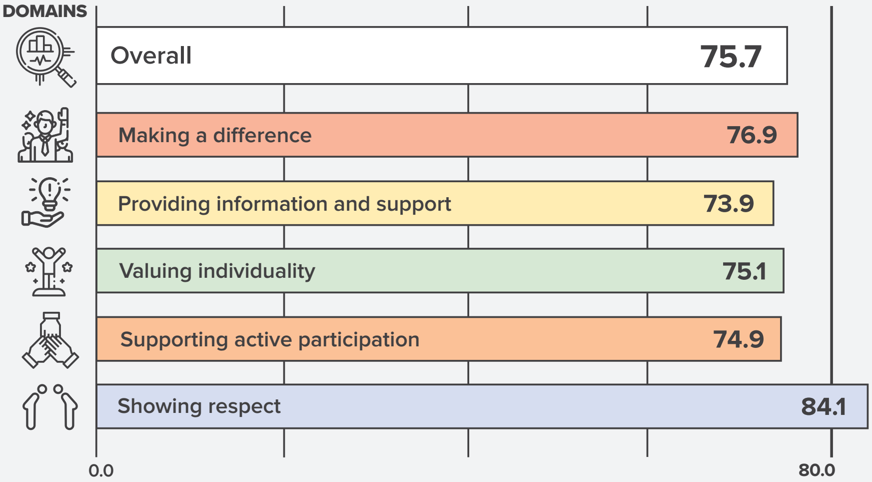


Figure 17 Overall and Domain Scores
Veteran Services (including CES 80% benchmark)

CARER EXPERIENCES

Question	Topic	Score
Q9	Identified as Carer	**4.33**
Q14	Staff Supported Carer Relationship with the Person	**4.06**
Q13	Staff Conveyed Hope for Recovery	**3.53**
Q15	Given Information & Strategies if Person Became Unwell Again	**3.53**
Q16	Opportunities to Communicate Confidentially with Doctor	**3.53**
Q12	Q12 Opportunity to Enhance Ability as Carer	**2.67**
Q26	Overall rating of Carer Experience with this Service	**2.67**
Q25	Effect of Service on Overall Carer Wellbeing	**2.65**
Q5	Cultural or Language Support	**2.50**
Q2	Given Explanation of Legal Issues	**2.31**

5
Highest Possible Score

Survey questions with highest score

Survey questions with lowest score

1
Lowest Possible Score

Veteran Services

My experience would have been better if

There is communication with me as the carer with all Drs involved in treatment and aftercare. Of three visits over 12 months, I was only invited on one occasion to speak with a part-time junior training Dr.

If I could have had more chances to discuss treatment for my partner at home…how I am feeling and what I can do better to help not only my partner, but also myself.

More time for partners to chat in separate sessions with treating doctor.

On discharge/coming out of JLC would have been nice to know "the plan". I knew there were appointments, but I felt very uncertain about what would happen next.

VETERAN CARERS WANTED MORE KNOWLEDGE, PARTNERSHIP AND CONTINUITY OF CARE

The best things about this service were

Getting to find out more about PTSD and ways to support my partner and myself. Involving partners with Trauma Recovery Programme. I have learnt extremely useful tools.

My husband and I were treated with respect and our opinions noted.

The staff. Exceptional people who made us both feel valued and important and that their contribution would involve greater hope and beneficial outcomes…The other thing is honesty. Totally trust all at the JLC. Lastly, Dr XXX is so good at explaining things and knows both of us so well…JLC is our safe place and that's because we/I trust them to find the best way forward for my partner and, in consequence, me.

TRUST AND BEING LISTENED TO, RESPECTED AND INCLUDED WAS VALUED BY VETERAN CARERS

DOMAINS WHERE IMPROVEMENT IN SERVICE IS INDICATED

Making a Difference Domain

The Making a Difference Domain is one of two Domains for which the overall state-wide score and the score for two LHNs (Central Adelaide and Southern Adelaide, including Veteran Services) indicated that improvements are needed, to address adverse impacts of services on carers.

The data suggest that these services, in particular, need to be pay greater attention to how their services effect: carers' relationship with the person for whom they care; carers' overall wellbeing; and carers' overall rating of experiences as a carer with these services (see Appendix 5).

Providing Information and Support Domain

The Providing Information and Support Domain is the second of two Domains for which the overall state-wide score indicated that improvements are needed. This was also the case for the individual Domain score for each and all LHNs.

Of note, scores for the following questions within this Domain were particularly low across the LHNs: explanation of legal issues (Q2); information about how to make a compliment or complaint about the service (Q18); information on opportunities to participate in improving the services (Q20); and information about taking a support person to meetings or hearings if the carer wished (Q22) (see Appendix 6).

Also, of note, across all data for Q17-Q22, only one LHN (Regional) reached the 80% threshold and only in response to one question (Q21 – A number you could call after hours for the service);

all other scores across LHNs for these questions fell below the 80% threshold. A small number of questions reached the 80% threshold for other questions in this Domain (e.g., three LHNs reached the threshold for Q3- You understand your rights and responsibilities) (see Appendix 5).

COMPARING LHN DOMAIN SCORES WITH STATE-WIDE DOMAIN SCORES

LHN mental health service Domain scores were compared with Overall (State-wide) Domain scores to determine whether there were any significant differences. Table 1 provides an overall comparison of Domain scores for the LHNs with State-wide Domain scores. Table 2 provides a comparison of State-wide and LHN Domain Scores with the CES 80% Threshold. Table 3 provides a comparison of Subspecialty Services Domain Scores with State-wide Domain Scores and the CES 80% Threshold.

🟩	Scores exceeding State-wide
🟨	Scores on par with State-wide
🟥	Scores below State-wide

Table 1: Comparing LHN Domain Scores with State-wide Domain Scores

LHN/MENTAL HEALTH SERVICE TYPE#	OVERALL	MAKING A DIFFERENCE	PROVIDING INFORMATION & SUPPORT	VALUING INDIVIDUALITY	SUPPORTING ACTIVE PARTICIPATION	SHOWING RESPECT
State-wide	**79.2**	**76.2**	**72.2**	**82.3**	**84.2**	**88.6**
Community Mental Health Services	80.5	77.1	72.9	83.6	86.1	89.8
Hospital Mental Health Services	77.2	74.8	71.1	80.2	81.0	86.5
Central Adelaide LHN	78.9	74.0	74.1	80.8	80.9	86.4
• Community	83.2	82.3	83.0	88.8	88.9	91.3
• Inpatient	72.1	67.5	65.5	74.0	74.1	82.3
Northern Adelaide LHN	78.2	76.3	71.9	82.1	82.5	86.8
• Community	75.9	77.6	69.0	78.8	80.3	85.8
• Inpatient	79.0	75.8	72.8	83.1	83.2	87.1
Southern Adelaide LHN	75.4	72.5	69.4	77.4	79.2	85.9
• Community	75.0	71.7	69.4	76.7	78.6	85.7
• Inpatient	76.0	73.6	69.4	78.4	80.0	86.1
Women's & Children's HN	84.1	80.0	73.8	88.9	92.2	94.0
• Community	84.4	80.0	73.9	89.4	92.8	94.1
• Inpatient	78.1	81.3	72.3	80.4	81.5	91.7
Combined Regional LHNs	79.2	78.8	77.9	77.4	79.5	84.9
• Community	78.4	76.5	78.1	76.0	77.6	83.2
• Inpatient	80.7	83.9	77.4	80.7	83.8	88.9
Older Persons Services	82.4	76.6	75.1	87.1	88.0	90.8
Forensic Services	76.8	83.1	71.3	78.0	80.6	86.3
Veteran Services	75.5	76.9	73.9	75.1	74.9	84.1

- Scores represent % of carers ratings standardised (0-100/100) overall and domain scores of the CES, where higher scores indicate a better experience.

Table 2: Comparing State-wide and LHN Domain Scores with the CES 80% Threshold

LHN/MENTAL HEALTH SERVICE TYPE#	OVERALL	MAKING A DIFFERENCE	PROVIDING INFORMATION & SUPPORT	VALUING INDIVIDUALITY	SUPPORTING ACTIVE PARTICIPATION	SHOWING RESPECT
CES Threshold	80%	80%	80%	80%	80%	80%
Community Mental Health Services	80.5	77.1	72.9	83.6	86.1	89.8
Hospital Mental Health Services	77.2	74.8	71.1	80.2	81.0	86.5
Central Adelaide LHN	78.9	74.0	74.1	80.8	80.9	86.4
• Community	83.2	82.3	83.0	88.8	88.9	91.3
• Inpatient	72.1	67.5	66.5	74.0	74.1	82.3
Northern Adelaide LHN	78.2	76.3	71.9	82.1	82.5	86.8
• Community	75.9	77.6	69.0	78.8	80.3	85.8
• Inpatient	79.0	75.8	72.8	83.1	83.2	87.1
Southern Adelaide LHN	75.4	72.5	69.4	77.4	79.2	85.9
• Community	75.0	71.7	69.4	76.7	78.6	85.7
• Inpatient	76.0	73.6	69.4	78.4	80.0	86.1
Women's & Children's HN	84.1	80.0	73.8	88.9	92.2	94.0
• Community	84.4	80.0	73.9	89.4	92.8	94.1
• Inpatient	78.1	81.3	72.3	80.4	81.5	91.7
Combined Regional LHNs	79.2	78.8	77.9	77.4	79.5	84.9
• Community	78.4	76.5	78.1	76.0	77.6	83.2
• Inpatient	80.7	83.9	77.4	80.7	83.8	88.9
Older Persons Services	82.4	76.6	75.1	87.1	88.0	90.8
Forensic Services	76.8	83.1	71.3	78.0	80.6	86.3
Veteran Services	75.5	76.9	73.9	75.1	74.9	84.1

- Scores represent % of carers ratings standardised (0-100/100) overall and domain scores of the CES, where higher scores indicate a better experience.

Table 3: Comparing Sub-Specialty Services Domain Scores with State-wide Domain Scores and the CES 80% Threshold

LHN/MENTAL HEALTH SERVICE TYPE#	OVERALL	MAKING A DIFFERENCE	PROVIDING INFORMATION & SUPPORT	VALUING INDIVIDUALITY	SUPPORTING ACTIVE PARTICIPATION	SHOWING RESPECT
State-wide	79.2	76.2	72.2	82.3	84.2	88.6
Older Persons Services	82.4	76.6	75.1	87.1	88.0	90.8
Forensic Services	76.8	83.1	71.3	78.0	80.6	86.3
Veteran Services	75.5	76.9	73.9	75.1	74.9	84.1
CES Threshold	80%	80%	80%	80%	80%	80%
Older Persons Services	82.4	76.6	75.1	87.1	88.0	90.8
Forensic Services	76.8	83.1	71.3	78.0	80.6	86.3
Veteran Services	75.5	76.9	73.9	75.1	74.9	84.1

- Scores represent % of carers ratings standardised (0-100/100) overall and domain scores of the CES, where higher scores indicate a better experience.

The following significant differences were found:

Central LHN:

- Central LHN did not significantly differ from the overall sample on any scores.
- Community Central LHN (n=16) scored significantly higher than the overall sample on Overall and Providing Information and Support.[10]

Northern LHN:

- Northern LHN did not significantly differ from the overall sample on any scores.
- Community Northern LHN (n = 24) did not significantly differ from the Overall sample on any scores.
- Inpatient Northern LHN (n = 74) did not significantly differ from the overall sample on any scores.

Southern LHN:

- Southern LHN scored significantly lower than the overall sample on Valuing Individuality and Supporting Active Participation.[11]
- Community Southern LHN (n = 89) scored significantly lower than the overall sample on Overall, Valuing Individuality, and Supporting Active Participation.[12]
- Inpatient Southern LHN (n = 64) did not significantly differ from the overall sample on any scores.

Women's & Children's HN:

- Women's and Children's HN scored significantly higher than the overall sample on Overall, Making a Difference, Valuing Individuality, Supporting Active Participation, and Showing Respect.13
- Community Women's and Children's HN (n = 138) scored significantly higher than the overall sample on Overall, Making a Different, Valuing Individuality, Supporting Active Participation, and Showing Respect.14
- Inpatient Women's and Children's HN (n = 8) did not significantly differ from the overall sample on any scores.

Regional LHNs:

- Regional LHNs did not significantly differ from the overall sample on any scores
- Community Regional LHNs (n = 21) scored significantly lower than the overall sample on Supporting Active Participation.[15]
- Inpatient Regional LHNs (n = 10) did not differ significantly from the Overall sample on any scores.

Sub-Specialty Services:

- Older Persons Services (n = 96) scored significantly higher than the overall sample on Supporting Active Participation.[16]
- Forensic group did not significantly differ from the Overall sample on any scores
- Veteran group did not significantly differ from the Overall sample on any scores

Comparisons between LHNs

Regarding comparisons between the different LHNs, the following statistically significant differences were found using a Bonferroni adjusted significance level of .005:

- Women’s and Children’s HN scored higher than Regional LHNs on Supporting Active Participation and Showing Respect.[17]
- Women’s and Children’s HN scored higher than Northern LHN on Supporting Active Participation and Showing Respect.[18]
- Women’s and Children’s HN scored higher than Southern LHN on Overall, Making A Difference, Valuing Individuality, Supporting Active Participation and Showing Respect.[19]

DID THE PERSON WANT THEIR CARER INVOLVED IN THEIR CARE?

Across almost all LHNs (except Central Adelaide LHN) and service subspecialities, CES participants overwhelmingly rated that the person they cared for did want them involved in their care. This is in clear contrast to many ratings in other areas of the CES survey where improvements in how services involved carers was indicated as needed (see Appendix 7).

APPENDIX

Appendix 1: CES 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.

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?

Please tick one box for each statement	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	☐	☐	☐	☐	☐	☐
2. You were given an explanation of any legal issues that might affect your family member, partner or friend	☐	☐	☐	☐	☐	☐
3. You understood your rights and responsibilities	☐	☐	☐	☐	☐	☐
4. Your personal values, beliefs and circumstances were taken into consideration	☐	☐	☐	☐	☐	☐
5. You were able to obtain cultural or language support (such as an interpreter) when you needed	☐	☐	☐	☐	☐	☐

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?

Please tick one box for each statement	Never	Rarely	Sometimes	Usually	Always	Not Needed
6. You were given the opportunity to provide relevant information about your family member, partner or friend	☐	☐	☐	☐	☐	☐
7. Your opinion as a carer was respected	☐	☐	☐	☐	☐	☐

Mental Health Carer Experience Survey

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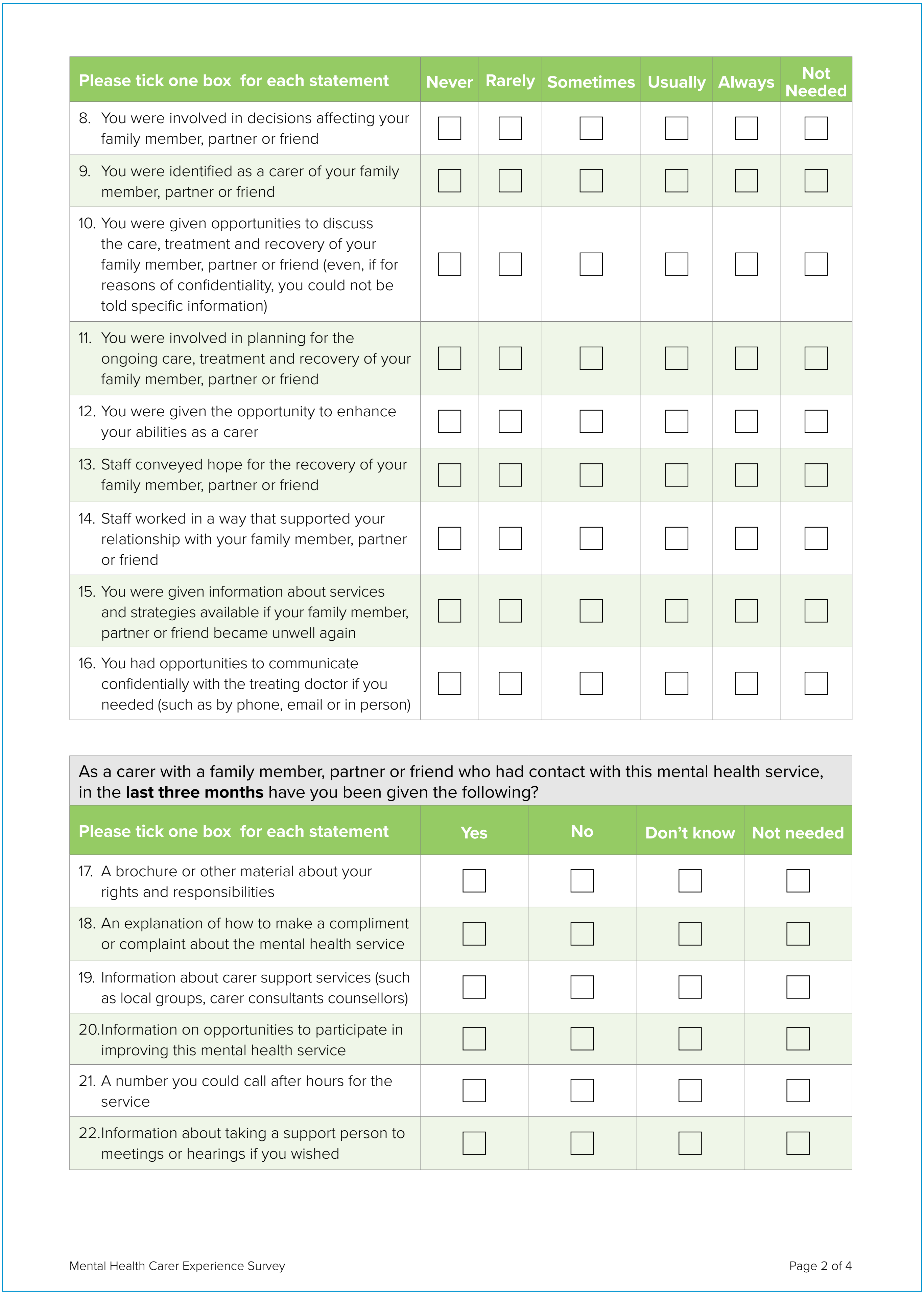

Please tick one box for each statement	Never	Rarely	Sometimes	Usually	Always	Not Needed
8. You were involved in decisions affecting your family member, partner or friend	☐	☐	☐	☐	☐	☐
9. You were identified as a carer of your family member, partner or friend	☐	☐	☐	☐	☐	☐
10. You were given opportunities 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)	☐	☐	☐	☐	☐	☐
11. You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend	☐	☐	☐	☐	☐	☐
12. You were given the opportunity to enhance your abilities as a carer	☐	☐	☐	☐	☐	☐
13. Staff conveyed hope for the recovery of your family member, partner or friend	☐	☐	☐	☐	☐	☐
14. Staff worked in a way that supported your relationship with your family member, partner or friend	☐	☐	☐	☐	☐	☐
15. You were given information about services and strategies available if your family member, partner or friend became unwell again	☐	☐	☐	☐	☐	☐
16. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)	☐	☐	☐	☐	☐	☐

As a carer with a family member, partner or friend who had contact with this mental health service, in the **last three months** have you been given the following?

Please tick one box for each statement	Yes	No	Don’t know	Not needed
17. A brochure or other material about your rights and responsibilities	☐	☐	☐	☐
18. An explanation of how to make a compliment or complaint about the mental health service	☐	☐	☐	☐
19. Information about carer support services (such as local groups, carer consultants counsellors)	☐	☐	☐	☐
20.Information on opportunities to participate in improving this mental health service	☐	☐	☐	☐
21. A number you could call after hours for the service	☐	☐	☐	☐
22.Information about taking a support person to meetings or hearings if you wished	☐	☐	☐	☐

Mental Health Carer Experience Survey

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

Please tick one box for each statement	A lot worse	A little worse	No change	A little better	A lot better	Not needed
23. Your relationship with the person for whom you care	☐	☐	☐	☐	☐	☐
24. Your hopefulness for your future	☐	☐	☐	☐	☐	☐
25. Your overall wellbeing	☐	☐	☐	☐	☐	☐

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

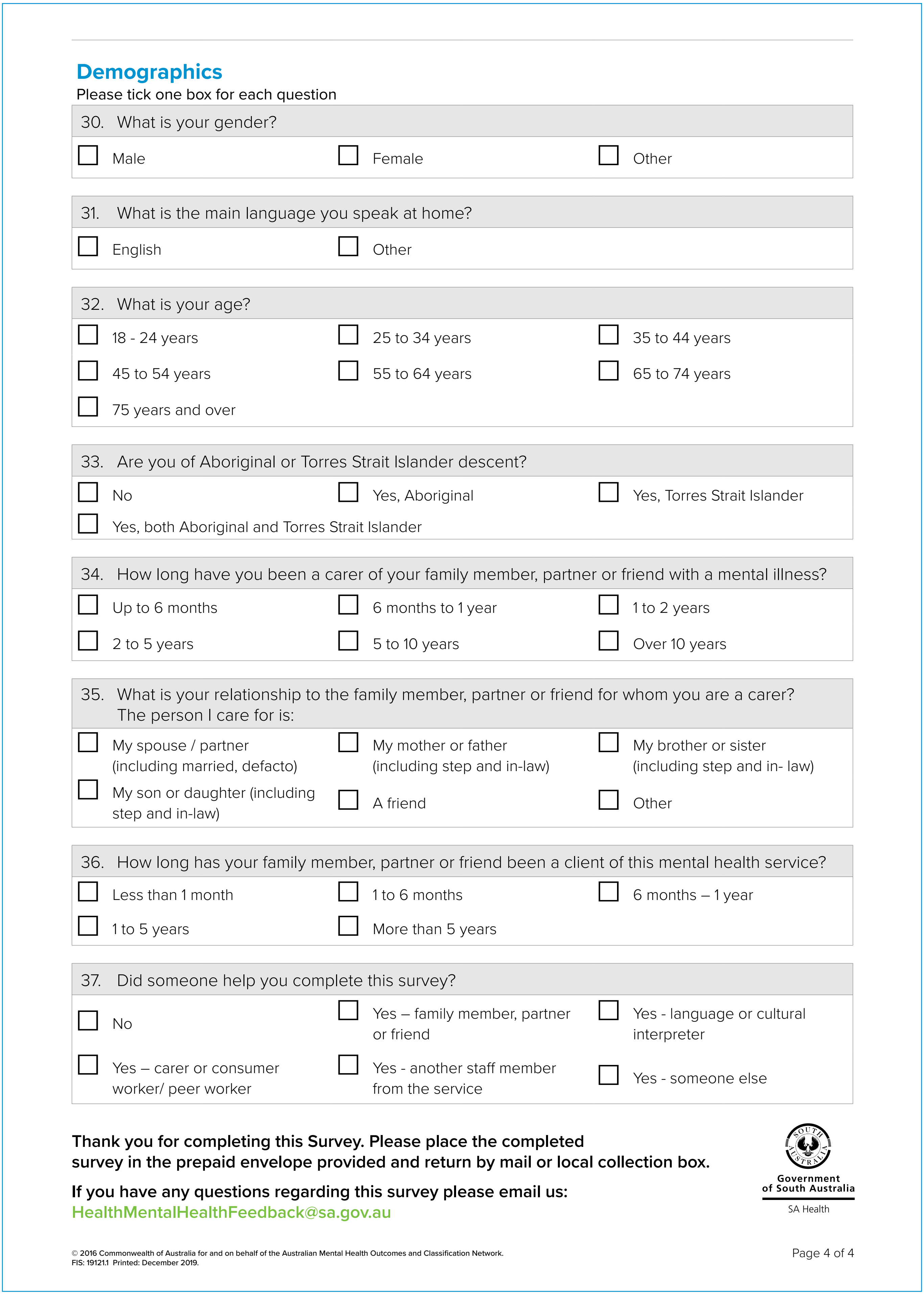
Poor	Fair	Good	Very Good	Excellent	Don't know
☐	☐	☐	☐	☐	☐

27. 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
☐	☐	☐	☐	☐	☐

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

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



Demographics

Please tick one box for each question

30. What is your gender?

☐ Male ☐ Female ☐ Other

31. What is the main language you speak at home?

☐ English ☐ Other

32. What is your age?

☐ 18 - 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

33. Are you of Aboriginal or Torres Strait Islander descent?

☐ No ☐ Yes, Aboriginal ☐ Yes, Torres Strait Islander
☐ Yes, both Aboriginal and Torres Strait Islander

34. 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

35. 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 mother or father (including step and in-law) ☐ My brother or sister (including step and in- law)
☐ My son or daughter (including step and in-law) ☐ A friend ☐ Other

36. 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

37. Did someone help you complete this survey?

☐ No ☐ Yes – family member, partner or friend ☐ Yes - language or cultural interpreter
☐ Yes – carer or consumer worker/ peer worker ☐ Yes - another staff member from the service ☐ 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.

If you have any questions regarding this survey please email us:
HealthMentalHealthFeedback@sa.gov.au

Government of South Australia
SA Health

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Appendix 2: The CES Domains

Making a difference

This domain describes how the service contributed to outcomes for individuals. It includes social and emotional wellbeing and physical health.

Q23	Your relationship with the person for whom you care
Q24	Your hopefulness for your future
Q25	Your overall wellbeing
Q26	Overall, how would you rate your experience as a carer with this mental health service over the last three months?

Providing information and support

This domain describes how the service works for the individual. It includes resources such as written information, a care plan, and access to peer 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
Q15	You were given information about services and strategies available if your family member, partner or friend became unwell again
Q17	A brochure or other material about your rights and responsibilities
Q18	An explanation of how to make a compliment or complaint about the mental health service
Q19	Information about carer support services (such as local groups, carer consultants, counsellors)
Q20	Information on opportunities to participate in improving this mental health service
Q21	A number you could call after hours for the service
Q22	Information about taking a support person to meetings or hearings if you wished

Valuing individuality

This domain describes how the service meets individual’s needs. It includes sensitivity to culture, gender and faith and the importance of personal values and beliefs.

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

This domain describes how the service provides opportunities for engagement, choice and involvement in the process of service delivery.

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
Q16	You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person

Showing respect

The domain describes how the service provides the individual with a welcoming environment where they are recognised, valued and treated with dignity.

Q 7.	Your opinion as a carer was respected
Q 9.	You were identified as a carer of your family member, partner or friend
Q 13.	Staff conveyed hope for the recovery of your family member, partner or friend

Appendix 3: Qualitative Analysis

The CES offers carers the opportunity to provide additional information about their experience by asking:

- Q28 My experience with this service would have been better if…
- Q29 The best things about this service were…

Carers' free-text comments were analysed thematically using Content Analysis and arranged according to each LHN, plus the Older Persons, Forensic and Veteran subspecialties, with connections to the CES Domains noted.

Central Adelaide LHN

Central Adelaide LHN covers the Adelaide central business district, inner metropolitan and western suburbs of Adelaide. Sixteen Central Adelaide LHN carers shared what could have been better (five reported no concerns) and 22 shared what was best about the service. The following themes were apparent from the free-text comments from Central Adelaide LHN carers.

CALHN Carers want more involvement and communication with services

A commonly expressed experience was carers' desire for more involvement and communication with service providers about their family member's care, which aligned with the Supporting Active Participation Domain. They said their experience would have been better if:

> *There was more interaction between me and nursing staff. More effective and consistent rules in place for XXX's recovery are required for nursing staff only.*
>
> *I was notified of my mum's progress whether it be improving or on the decline, and what is the next process.*
>
> *There was regular communication about progress, how I can help, discussion about medications and side effects. The receptionist said I would not be able to speak to the doctor when I asked. I felt blocked in giving vital information. My family feels we need to 'pick up the pieces' when things go wrong, but we don't get clear information.*

Two carer comments indicate problems with system fragmentation of the care experience and problems with service boundaries, one with dire consequences for the person and their family carer. Whilst not specific, these experiences reflect adversely on all five CES Domains.

> *My son spent 3 nights in RAH in desperate need of a bed but no beds in RAH mental ward. On XXX he was sent to Glenside Hospital hoping for a bed there. He was discharged from there on the same day. As his mother and carer NO WHERE was I consulted in this process. He was found dead in his unit 13 weeks later. I am grief stricken than my beautiful son died. PLEASE HEAR ME "This system let him down miserably."*
>
> *My partner didn't have to repeat his story over and over to various clinicians. Not being heard about his medication making him unwell and the focus on his alcohol versus self-medicating his extreme trauma.*

Central Adelaide LHN Carers value communication and staff commitment to care

Several Central Adelaide LHN carers emphasised their positive experiences of services, including the helpfulness, professionalism and compassion shown by many staff. Carers expressed feeling included and listened to; they appreciated staff being proactive in contacting the carer. These qualities aligned with the Supporting Active Participation, Showing Respect and the Making a Difference Domains, in particular, as part of the overall positive experiences expressed by carers. Examples of the best things about the services were:

> *I have nothing but admiration for the health workers at the IRS. Thank you.*
>
> *The staff were fantastic supportive informative and compassionate and always approachable. (Carer consultant)'s compassion towards her job!*
>
> *The interest and care offered by nursing staff. The ongoing support and communication with Social Worker(s). The interest and commitment by treating doctors to the needs of my family member.*
>
> *Caring committed staff. Openness and sharing practitioners. A sense of calm and positive atmosphere. Staff always willing to listen, reassure and follow-up. Sense that it's a community and we're on this journey together.*
>
> *They kept me in the loop.*
>
> *The drug and alcohol worker willing to speak to me about strategies to support family members. Very helpful. Once, but not in the past 3 months, the new doctor phoned me and asked how I felt my family member was going - this was fantastic. It would be good if the new doctors rotating would contact me to have a background check on how we see things progressing. This call (from Dr) has happened only twice in several years!*

Northern Adelaide LHN

Northern Adelaide LHN covers the northern metropolitan suburbs of Adelaide. Forty-one NALHN carers shared what could have been better (8 reported no concerns) and 60 shared what was best about the service. The following themes were apparent from the free-text comments from NALHN carers.

Northern Adelaide LHN Carers want to be included more in care and communication with services

A commonly expressed experience was carers' desire for more inclusion in care and communication with service providers, which aligned with the Supporting Active Participation Domain. They said their experience would have been better if:

> *More communication with doctors because nurses couldn't supply proper information.*
>
> *They could only listen to me that my son is not well. When they go around to see my son (at my request) they will say he was racing his words but otherwise he is OK. Then he will stop taking his meds, go into hospital and have to start slowly back on his meds and takes longer to get well again.*
>
> *Staff were more competent, professional and empathetic. Over 2 months my son was in 1G, we experienced conflicting medical advice, double dosing of my son's medication, double booking visits approx. 7 times and lost belongings. Most Team Leaders were rude, unhelpful and lacked integrity. Very poor.*

Many carers' comments related to their concerns for the person they cared for rather than their own carer experiences with services, suggesting that these carers were already involved in more diligent ways with services. They said their experience would have been better if:

> *There was a follow-up outpatient facility and case manager to check on progress, treatment ongoing etc, including medication issues and counselling services - monitor and help prevent relapse.*
>
> *If my child had opportunities in the care of the hospital to do during the day and therefore wasn't bored. There isn't much for them to do in there all day - so no motivation to get up and engage in life. Needs exercise program too as she's gained a lot of weight.*
>
> *My son had wanted the family to be more involved.*

A few carers expressed the need for more support to cope with their carer role, or for more consideration of the personal circumstances of the person they cared for. These concerns aligned with the Valuing individuality Domain, and particularly services for older people.

> *When my husband was in Northgate for 6 months, I met XXX in MHU. I related to her - but there was no counselling for me in Northgate House. I made friends at Dementia Cafe. My husband and I were married for over 50 years. The last 12 months of his life he had mental health issues (in care). I found the trauma too much, after caring for him for 9 years. I very rarely had a chance to talk (at Northgate) to other family members.*
>
> *Mum wasn't allowed to lie on her bed to nap in the afternoon, something she always does. It was difficult to feel comfortable and happy in the visitors' room. A nice outdoor area with shade would make this nicer. Her personal items -knitting, photos etc went missing.*

Three carers also noted concerns about restrictions on visiting their family member due to COVID-19 but accepted why these restrictions were needed.

Northern Adelaide LHN Carers value communication and staff commitment to care

Many NALHN carers emphasised their positive experiences of services, as evidenced by the much higher number of carers who responded to this question, compared with the question seeking their views on what needed to improve. Respect, care, friendliness and compassion of staff were noted in many of carers' comments. Carers expressed feeling proactively included and listened to. These qualities aligned with the Supporting Active Participation, Showing Respect and the Making a Difference Domains. Many of the comments reflected high levels of interpersonal involvement and collaboration with service staff and the person receiving care. Examples of the best things about the services were:

> *Being so involved in my mother's care plan.*
>
> *The contact between the focus nurse for my son and myself. She has been very good at keeping in touch to see how he is travelling and told me to contact her if there is a problem.*
>
> *The assistance, compassion and undertaking of the complete staff in 1H. To witness the transformation over 6-8 weeks quite remarkable which provides a better future. Continuing the process as an outpatient which is also a benefit. Hopefully do not experience a relapse but if do, do not have any concern for ongoing treatment.*
>
> *Caring staff, not treated as a number and pushed out quickly.*
>
> *Thorough, calm and professional care to high standard. Reassuring to have access to care that is extremely difficult to access as an outpatient. Good outcome for the patient.*
>
> *The flexibility for everything (phone calls), appointments, the way that they are responding if we need something. Always kind.*
>
> *Staff kept me informed of any changes with my brother - multi-disciplinary meetings were excellent. Drs made regular contact with me regarding changes to medication.*
>
> *Amazing staff! They work with the patients and family and have a patient centred approach. They have been incredibly kind and supportive.*
>
> *The staff were wonderful, very friendly and were always checking on my family member. Nurses and doctors were always welcoming and willing to chat. We felt included in the care and felt comfortable that my family were getting the care they needed.*

Northern Adelaide LHN carers value services that care about the whole family

Further examples of carers' experiences suggested that mental health staff are demonstrating family- centred service, not merely service to patients as individuals in isolation from their families.

> *The kind staff that supported my mental health and encouraged me to physically stay away until mum was settled. I appreciated and need this push. I felt like I too was being carried and cared for by this service.*
>
> *My concerns always put into perspective, validated and strategies discussed. My opinions respected even if not agreed with. My daughter's mental health always the priority but I have always felt the concern and wellbeing of the whole family is being considered at all times.*
>
> *The particular doctor (Dr XXX) particularly was a great engaging doctor. My mind was at ease knowing the staff were giving my mum the best holistic care. XXX at Northgate was in my world the most engaged but all staff were good. The main admin lady at Northgate was also beautiful, great with communication and update. Thank you.*

Northern Adelaide LHN services showed respect and gave carers hope

Northern Adelaide LHN Carers likewise, made strong comments that aligned with the Showing Respect Domain, in particular. Positive attitudes and values, as part of compassionate care, coupled with more holistic ways of working that included family carers, aligned clearly with the Making a Difference Domain.

> *You didn't give up on her [mum]*
>
> *The way they took time to understand my son and in turn to assist him in ways which would work for him.*
>
> *All staff on the ward genuinely care about the patient and their recovery. They display empathy!*
>
> *The staff and doctors have gone above and beyond to help my child and me during this time, which I have really appreciated.*

Southern Adelaide LHN

A commonly expressed experience was of feeling excluded by services, aligning with the Showing Respect Domain. They said their experience would have been better if:

> *I was recognised not only as a carer for over 40 years but also his guardian. Quite often I am seen and ignored or avoided until something goes wrong. His needs for care are not met at the moment on a lot of levels. His condition is not respected in a way that is at all individual. Carers need to be respected and valued. Right now, I do not feel that way.*
>
> *We were not referred to a new doctor/services/carers to whom we need to get to know again. We have been swapped between different services constantly which affects our trust and feel like it is all a waste of time. I start to disengage as I do not wish to raise my hopes waiting for it all to go wrong again.*
>
> *I was repeatedly dismissed and ignored whilst provided information that could have prevented my partner from relapsing…There were key points in time where I indicated to the mental health team that my partner is having early warning signs you need to act, and I was completely dismissed. As a result, my partner has had a full-blown psychotic episode. We were given incorrect information that delayed her re-admission to the emergency department for treatment and were abandoned when asking the team for help when the situation reached crisis point. This has had a significant and ongoing effect on myself my family and my partner and will continue to have…This service was completely useless. It failed at every point in time we needed them.*
>
> *My daughter is only 16 years old, and I felt totally excluded as a parent and carer by the medical team. I had to push to get some meetings with the doctors and even felt very unwelcome. Only one nurse was very nice and supportive. For me it was a terrible experience.*
>
> *Staff had conveyed hope for the recovery of my family member and an appropriate mental health care plan had been in place as requested by myself on several occasions. Issues relevant to my son's cultural identify as an indigenous person had been considered by relevant treating staff.*

Southern Adelaide LHN carers want better care and support for their family member

Comments from several carers suggest that they experienced a lack of individualised and consistent care and support for their family member. Instead, they experienced the impacts of fragmented, access problems, and busy systems in which their needs and those of their family members fell through the gaps. This situation impacted their experiences directly and indirectly across all 5 Domains, but particularly the Supporting Active Participation Domain. They said their experience would have been better if:

> *Patients weren't left unattended for so long. I frequently had to ask for things for my daughter. Individual nurses were excellent but often you were ignored by nurses who kept chatting until you verbally interrupted. It was a very noisy environment including at night where TVs were left on long after the time the patient had fallen asleep. Overall, it was a poor experience. We also left with no management plan for the future. It's like being just cast adrift. On a previous visit we left after 4 hours in ED. Didn't see anyone from mental health.*
>
> *Doctors didn't change all the time.*
>
> *Consistency of the medical doctor treating the case - regular change of doctors does not provide rapport or consistency, or a feeling of security and safety. Lack of information from treating doctor.*
>
> *More involved in discharge planning.*
>
> *The demand for the service was not so great. The system is under-resourced and is unable to provide a service that is not rushed and very difficult to navigate. No one is able to address any issue that is outside of their "core business" due to budget constraints. My daughter's...2 weeks in the system kept her safe (and I am grateful for that) but it did very little to help her resolve the underlying problems.*

Southern Adelaide LHN carers want more information about services

Some carers expressed feeling ill-equipped to understand the service system, and how to get the help they needed for their family member and themselves, aligning with the Providing Information and Support Domain. They said their experience would have been better if:

> *I had been given information about how this service was interacting with my family member - in particular what the plan was. I have never known who I should contact to find out this information or in fact whether I am permitted to.*
>
> *We received information about the service, what treatment would look like, what to expect in terms of our daughter's journey through treatment, rules/expectations of/for carers when visiting, a discharge plan, information about where to seek help if required post discharge, opportunities to communicate with the treating doctor, information about carer support... when contacting SEDS re carer training by phone I had been treated respectfully and kindly on the first contact.*

Staff compassion has a big impact on the Southern Adelaide LHN carer experience

Several Southern Adelaide LHN carers noted their appreciation for the care and compassion shown by staff towards the person they care for and for themselves as carers. This included kindness and

friendliness displayed by staff towards carers. Whilst not directly aligned with a particular CES Domain, staff compassion had an overall influence on how carers perceived the service, particularly for the Making a Difference Domain. Carers also felt listened to and therefore included as a consequences of positive staff behaviours towards them, aligning with the Supporting Active Participation Domain.

> *All the staff really do care about my brother. They try their best always.*
>
> *The nurses. They are very kind, thoughtful, engaging, friendly. Always willing to talk about related matters and do their jobs to the best of their abilities and go beyond the basic needs. They show a genuine interest in the patients and always listen.*
>
> *The helpful and friendly staff.*
>
> *I felt a personal care approach. My feelings and ideas weren't dismissed. I felt a genuine concern for me and my family and that the person providing the support genuinely wanted us to be well.*
>
> *The genuine caring approach of staff.*
>
> *The staff were very attentive and kind. I was included in all conversations (where appropriate) and was kept up to date with progress.*
>
> *My son was given the care and support when he needed it most - he was treated with respect from his OT and all the staff at Morier. He was able to recover in a way which was beneficial to him and his family.*
>
> *The doctors, nurses and medical professionals were so supportive and made me feel welcome and a part of his healing.*

Southern Adelaide LHN Carers value effective care coordination and communication

SALHN carers also described the value of coordination between service providers, flexibility and access, and including the person and their carer in care plans and strengths-based solutions that held the person's needs and preferences as the primary focus, as the best things about the service. Their comments align with the Valuing Individuality and Supporting Active Participation Domains, in particular.

> *The skills you gave my daughter to cope.*
>
> *Regular communication and follow up.*
>
> *Had the ability to call or email if I had questions and they were always answered*
>
> *Meetings set up between Mental Health Service, Centacare representative, Housing Trust (Housing SA) Liaison officer, which resulted in positive outcomes, and good follow up. We appreciated being involved in these meetings. We liked the "strength-based" approach which focussed on what the client COULD do, rather than deficiencies. The three of them worked as a TEAM.*

Women's & Children's Health Network (HN)

Women's and Children's HN covers public clinical services provided to children and young people across the whole state, inclusive of metropolitan and rural communities. It includes the Women's and Children's Hospital and Child and Adolescence Mental Health Services in the community. It also covers a dedicated Mothers and Babies unit for women with more severe presentations of mental ill-health.

Fifty-six Women's and Children's HN carers shared what could have been better (19 reported no concerns) and 77 shared what was best about the service. The following themes were apparent from the free-text comments from Women's and Children's HN carers.

Women's and Children's HN carers need more intensive support in the early stages of their carer role

Many comments emphasised the gaps in system access and knowledge by many Women's and Children's HN carers, which is understandable, given their parental role as primary carers of children and also because, for many, this is their first experience of contact with mental health services. Therefore, many comments aligned with the Supporting Active Participation and Providing Information and Support Domains. They said their experience would have been better if:

> *There were more resources allowing us an earlier appointment. Staff are clearly doing the best they can but they're over-stretched and wait times are far too long.*
>
> *The triage waiting time was shorter, particularly with a teenager who was suicidal. The system is a 'one size fits all' system and localising mental health services for under 18s at the WCH only DOES NOT WORK. This service needs to be available locally, not just in the city. Daughter was transported by police due to the huge waiting time in getting an ambulance and could not go to the local hospital (FMC or Noarlunga) as she was under 18.*
>
> *Parents had a meeting first alone to explain circumstances. Time with the treating doctor was not so limited.*
>
> *A mental health professional provided me "the carer" with clear direction about HOW TO RESPOND to unusual behaviours at home...What to say, how to guide, encourage, boundaries to set, carer group to refer to, understanding of terms "psychosis", "DID", etc. I desperately needed guidance to reduce my emotional stress!!*
>
> *There was more funding. My daughter needed to be at self-harming stage to qualify for an appointment. I first tried three years ago but she wasn't bad enough. There simply were not enough resources.*
>
> *More psychiatrists were available to speed up referrals.*
>
> *The wait times for appointments were shorter. My 12yo daughter was very sick (mental health) and the wait for an appointment was 2 months.*

Women’s and Children’s HN carers want better continuity of care

In addition to raising concerns about access, several Women’s and Children’s HN carers raised a range of concerns about the system of care delivery, given this was a new experience and confusing time for many. Whilst not directly aligned with any one Domain, these experiences likely impacted all Domains; the Making a Difference Domain, in particular.

> *There was more continuity of care instead of multiple mental health workers assigned.*
>
> *Better communication with parent. Continuity in treating provider - always changing for various reasons, so feels like you’re always starting again...communication between therapists needs to improve as very confusing to patient and parents.*
>
> *The report letter was not filled with lies and was un-truthful. It was derogatory and abusive. No one deserves to be abused. Mentally, emotionally, physically, or through derogatory of falsely written paperwork. And can be rectified through the courts’ legal channels.*
>
> *Initial triage by CAMHS upon presentation of my child at hospital was inadequate and placed my child in danger of self-harm.*

Women's and Children's HN carers value services that help them find answers and understand mental ill-health

Many Women's and Children's HN carers emphasised their positive experiences of services, as evidenced by the much higher number of carers who responded to this question, compared with the question seeking their views on what needed to improve. In particular, their comments suggest that many have experienced significant bewilderment or distress trying to find help for their young person's emerging mental ill-health and have appreciated finally receiving answers. Their comments suggest that these cares value how many service staff are focusing on building engagement and rapport with the young person and providing intensive support and information to family carers to help them understand the mental health needs of their young person and build their capacity as carers. This aligns with the Providing Information and Support and Supporting Active Participation Domains.

> *XXX took on my thoughts, views and concerns and she placed it all on the table to be addressed.*
>
> *Dr XXX has been very helpful with our son, for our son to have someone that is not related to talk to about things that he is finding tricky in his life and have a different perspective. Dr XXX was the only psych that our son had eventually warmed to and he has been helpful in listening and responding to our concerns and providing reassurance that we are on the right track. XXX has been a good listener and practical, he spends time building rapport with his patients to establish a connection (which with our son has taken a long time but he persisted through the challenges). I am very appreciative.*
>
> *Getting introduced to and working with a psychologist who understands my daughter's needs and has been able to make great progress and build rapport, allowing her the opportunity to thoroughly engage so she can receive the best treatment.*
>
> *Very good follow up with phone calls and excellent communication where needed.*
>
> *The support and understanding my son and I received, as well as an actual diagnosis after many years of seeing professionals.*
>
> *Our daughter now has the knowledge and skills to be able to deal with her issues and we too are able to support her better knowing what we have learnt along the way. We can't thank you enough for making all our lives a lot better. Thank you Thank you Thank you.*
>
> *Getting advice and feedback. Learning practical things to help. Open lines of communication and contact.*

Women’s and Children’s HN carers value staff compassion as the family learned to cope and adapt

In addition to the above comments that demonstrate Women’s and Children’s HN carers’ strong desire and need for information and knowledge, many commented on the value of care and compassion shown towards them and their young person, as they adapted to their circumstances and becoming involved with mental health services. Their experiences aligned with the Showing Respect and Valuing Individuality, in particular, and the Making a Difference Domain, in general.

> *The amazing talented, kind and knowledgeable staff. The genuine care and hope of client recovery. The external to CAMHS in-house therapy support with school meetings and plans.*
>
> *The accessibility and respectful work of the therapist.*
>
> *They took the time to listen and try to understand to help the best way possible. Kindness and compassion. Respect and empathy for my daughter.*
>
> *A family approach, being able to express difficulties in family dynamics in a safe environment.*

Regional LHNs

Rural mental health services are dispersed across several parts of regional and remote South Australia, with a mix of small local community teams serving large areas, local hospitals available in some regional centres, greater reliance on telehealth, and with the primary inpatient services for more acute care located in Metropolitan Adelaide.

Eleven rural carers shared what could have been better (2 reported no concerns) and 14 shared what was best about the service. The following themes were apparent from the free-text comments from rural carers.

Rural carers wanted more access, practical information and support

Aligned with the Providing Information and Support Domain, rural carers were most concerned about access to support when they and the person they cared for needed it, and better communication and coordination between inpatient and community services, and with them as carers.

> *We have an amazing support team here, but it gets let down/lost at every hospital admission only to leave us and the community mental health team frustrated, confused and quite frankly annoyed. There is a need for more local Psychiatrists and Psychologists.*
>
> *If help was more available when required - after hours. A&E waiting times do not help.*
>
> *There was a contact person assigned to us on the ward. The notes of some staff members - particularly patient support staff - seemed to not work very well.*

Rural carers also wanted more support and inclusion as part of their carer role, aligning with the Supporting Active Participation and Showing Respect Domains.

> *It was identified I was a carer earlier on and mentored/directed to supports. A little more information on help I can get to help my son.*
>
> *Things were better explained. Once in hospital (my son) I was forgotten. I had no idea of my rights as a mother and carer. Information was extremely difficult to get due to “privacy concerns”.*

Regular communication, being involved, effective service coordination, and caring staff had a big impact on the rural carer experience

Rural carers praised services when they were effective at Providing Information and Support and Supporting Active Participation of carers by Showing Respect and including them in care. They particular emphasised the value of coordination of care which they perceived as supporting their caring role and Making a Difference by improving outcomes for the person they cared for. Many emphasised their appreciation for the caring qualities of staff.

> *My knowledge that I can ring any time if I have concerns with my son's condition. I always get help and don't know where we would be without this service! I am forever grateful to XXX on KI for her amazing help. It is helpful that they communicate with the local Drs so that we are all on the same page.*
>
> *I know I can call any time during office hours for an update, chat or even a bit of a vent. XX from the SFMH team has been a life saver in more ways than one. Liaising between the Dr, Counsellor, Support Worker, Psych and ourselves...she has tied it all together and makes things happen moving forward. I have really appreciated her support and care.*
>
> *I really appreciated how quickly and efficiently XXX got things in order so that XXX's mental illness did not spiral out of control avoiding hospitalisation. Appointments and forms were completed within 2 weeks of contacting them, and we were informed of upcoming psychiatrists appt straight away, making me as a carer feel confident that professional help and diagnosis was all in place.*
>
> *That the doctors/nurses took into account what I wanted/needed for my wife's treatment. The staff were always respectful of my "insight" when treating my wife.*
>
> *The nurses were very caring and informed me of any issues.*
>
> *Same doctor here every day. Lovely staff. Wonderful support.*

Older Persons Services (across LHNs)

Across the State-wide system, services for older persons' mental health serve the needs of people 65 years+ (50+ for Aboriginal and Torres Strait Islander people) with first onset of psychiatric; dementia complicating a pre-existing psychiatric illness or severe behavioural and psychological symptoms, and younger consumers with a diagnosed progressive early-onset neurodegenerative disorder with cognitive impairment and behavioural disturbance.

Thirty-eight carers shared what could have been better 6 reported no concerns) and 63 shared what was best about the service. The following themes were apparent from the free-text comments from older persons services carers.

Older Persons Services carers wanted more communication and support

Older Persons Services carers expressed a variety of views that centred on the need for communication and involvement to ensure quality of care for the person. This aligned clearly with the Providing Information and Support and Supporting Active Participation Domains. It included more communication about the care being provided to their loved one, more involvement in the day-to-day plans around care, and more communication about the whole service pathway and navigation of the complex aged care supports system, including supports post-discharge for those individuals who would be returning home.

Their comments were not surprising given, unlike other services, the vast majority of carers in these services (almost 60%) identified as spouse carers with likely long-term intimate relationships with the person they cared for, one third were carers of an aging parent and concerned for the person's later and end-of-life needs, and almost 40% were 65 years or older themselves. They said the services would have better if:

> *I had more support when my husband was acutely unwell. It was difficult to speak to his Psychiatrist and the Community Visitor was also hard to contact at times. I realise everyone is overstretched, but when you are alone caring for someone with psychiatric issues it can be very stressful.*
>
> *Possibly if I had also been present when person was admitted as may have gained more information at that time, however that opportunity wasn't offered.*
>
> *My concern regarding my wife's health and ongoing care is when is it the right time to move on. With a high level of dementia and the ongoing deterioration of her mental and physical health, moving to a private care facility may not be the right move. Question!! Where do we go when the near future is death? When is palliative care right?*
>
> *My mum's treatment was completed in hospital rather than being sent to a respite bed in a nursing home and coming in 1x week for treatment (even though she was still feeling unwell on discharge). Medication changes on day of discharge. Mum feeling very unwell whilst in respite (side effects of medication). No access to psychiatrist, doctor, impacting recovery. No contact number supplied on discharge if mum became unwell. Family meeting prior to discharge was not held.*
>
> *Has been limited communication or updates on mum's care, strategy or planning. Phone calls have been returned, but no contact has been to provide update.*
>
> *I would like more accurate information of how my dad is going. ie when I ask how is dad going beside "well", "unsettled" etc, would like to know if he has been aggressive, soiling himself, in the face of staff. Not just the good stuff.*

Older Persons Services carers were concerned about the care environment

Older Persons Services carers wanted better quality of the physical environment in which care was provided. This did not align with any CES Domain but again highlighted a strong desire for ensuring the person's needs were met, given their life-stage.

> ***I was disappointed that Mum's personal effects were misplaced after transferring to the mental health ward in a different hospital. Apparently, her things were taken for safe keeping and never found - including a family photo book that would have been helpful to her (dementia). These things were never recovered or returned.***
>
> ***Mum wasn't allowed to lie on her bed to nap in the afternoon, something she always does. It was difficult to feel comfortable and happy in the visitors' room. A nice outdoor area with shade would make this nicer. Her personal items -knitting, photos etc went missing.***

Related to this, of all service types, the impacts of COVID-19 were particularly noted by this group as a concern because of how it restricted visiting, especially where their family member had dementia or where very elderly couples were now separated near the end of life (n=5 carers noting this as their primary concern but understood why it was necessary).

Friendly and engaged staff were valued by Older Persons Services Carers

Many Older Persons Services carers said they valued friendly staff who took the time to engage with them about the care needs of their family member. They particularly noted the friendly nursing staff and medical staff. This also supported them as carers and aligned with the Making a Difference, Showing Respect and Supporting Active Participation Domains.

> ***Staff kept me informed of any changes with my brother - multi-disciplinary meetings were excellent. Drs made regular contact with me regarding changes to medication.***
>
> ***Caring staff, not treated as a number and pushed out quickly.***
>
> ***The team were always approachable from psychiatrist to the RN case worker and Dr at Southern Mental Health Services for Older People. Great support for me as a carer as well as the patient.***
>
> ***My mind was at ease knowing the staff were giving my mum the best holistic care. XXXX at Northgate was in my world the most engaged but all staff were good. XXXX the admin lady at Northgate was also beautiful, great with communication and update.***

Emotional support, compassion and empathy were valued by Older Persons Services carers

Underpinning the friendly support and engagement, many Older Persons Services carers spoke about the kindness, compassion and empathy shown towards them by individual staff and whole teams. They described staff who were responsive to their requests and concerns. This gave them peace of mind that their family member was safe and receiving quality care, and that they were being shown dignity and respect, particularly as part of end-of-life care. This provided them with important emotional support as carers. Their comments aligned particularly with the Valuing Individuality and Supporting Active Participation Domains.

> *… the empathetic staff who expressed insight and demonstrated experience in dealing with the specific issues my family member faced. …the proactive primary care person who is able to check in, respond, and make recommendations quickly.*
>
> *The kind staff that supported my mental health and encouraged me to physically stay away until mum was settled. I appreciated and need this push.*
>
> *I think one of the most critical treatments when someone is dying, is treating the person with respect and dignity. I thank the facility, the manager, doctor and all involved as they definitely ticked both boxes!*
>
> *All staff on the ward genuinely care about the patient and their recovery. They display empathy!*

Supporting the family/couple, not just the individual, was valued by Older Persons Services carers

Several Older Persons Services carers described feeling that were also the focus of care and support alongside the person receiving care; that staff and the services took the couple’s or whole family’s needs into account as part of care provision. Their comments aligned particularly with the Making a Difference and Showing Respect Domains.

> *I felt like I too was being carried and cared for by this service.*
>
> *External support, now I have a better understanding of what is involved in admission and of ongoing aftercare at home. Has helped us to investigate and experiment with respite. Respite was/is a great help.*
>
> *My husband was looked after exceptionally well. Staff were very friendly, helpful and caring to both of us. It is the best facility my husband could have been in. I am very grateful for the way the staff looked after both of us.*

Forensic Services

The person's entry to forensic mental health services can be a particularly daunting experience for families and carers, with additional legal requirements and physical structures and routines, unlike other parts of the system.

Eight forensic carers shared what could have been better (3 reported no concerns) and 11 shared what was best about the service. The following themes were apparent from the free-text comments from forensic carers.

Forensic carers wanted more information and involvement to understand this specialised system

Forensic carers said their experience would have been better if there was more information and support earlier when the person who they cared for entered the forensic system, and more communication and involvement once there. This aligned strongly with the Providing Information and Support Domain. Forensic carers emphasised the importance of the environment being as humane as possible for their family member.

> *The doctors had more time to speak to the family; explain what my son suffers; how long he will stay here in JNH for; the medication he is on.*
>
> *Lots of confusion in the very beginning, so more information on things "allowed" would have saved some frustrations and emotions.*
>
> *Sometimes it would have been nice to have a bit longer visiting time than a strict 30 minutes. Also, it would be better for XXX if he could talk to us in private without an open door. It inhibits him from telling us what is bothering him.*
>
> *I wonder if having therapy animals might be of benefit to patients.*

Safe and effective support by caring staff had a big impact on the forensic carer experience

Forensic carers placed significant value on the felt benefits of mental health care for their family member, as the main influence and impact on their carer experience; that the person was now in a safe, respectful and caring environment receiving the care they needed. Their comments align with the Making a Difference and Valuing Individuality Domains, in particular.

> *All staff are very caring and very respectful of my family member. I feel he is very well looked after, not just as a patient but as a human being.*
>
> *Friendly staff, always happy to chat and inform about the patient. Willingness to engage with me about progress and treatment, and my deep knowledge of the patient. KNOWING HE IS IN A SAFE PLACE!*
>
> *Amazing staff! They work with the patients and family and have a patient centred approach. They have been incredibly kind and supportive.*
>
> *As my son says, the beautiful and friendly people that have helped him...and for this I will forever be grateful.*

Veteran Services

The Jamie Larcombe Centre (JLC) is a specialist mental health inpatient service primarily for veterans (and also more recently for emergency services first responder personnel). It is located in metropolitan Adelaide and serves the needs of veterans across metropolitan, regional and rural South Australia. It is complimented by follow-up outpatient services in the community, dedicated to veterans and first responders.

Ten veteran carers shared what could have been better (4 reported no concerns) and 12 shared what was best about the service provided by the Veteran services. Whilst 16 of the 18 carers who completed the CES survey were from Veteran community services, several of their comments also related to their JLC experience. The following themes were apparent from the free-text comments from veteran carers.

Veteran carers wanted more knowledge, partnership and continuity of care

Veteran carers said their experience would have been better if there was more information and support to understand the unique mental health needs of their veteran family member. Many veteran carers were spouses, and their focus was also on the wellbeing of the family unit surrounding the veteran. Hence, they emphasised the need for close communication and involvement with those providing mental health treatment and care during inpatient stay and in relation to discharge planning. This aligned strongly with the Providing Information and Support and Supporting Active Participation Domains.

> *There is communication with me as the carer with all Drs involved in treatment and aftercare. Of three visits over 12 months, I was only invited on one occasion to speak with a part-time junior training Dr.*
>
> *When needed, help would have been helpful as weekends no staff available.*
>
> *Dr XXX hadn't rotated to her next assignment before my partner left. It would've helped to have a conversation with her prior to my partner discharging. The new doctor was not yet familiar.*
>
> *If I could have had more chances to discuss treatment for my partner at home…how I am feeling and what I can do better to help not only my partner, but also myself.*
>
> *On discharge/coming out of JLC would have been nice to know "the plan". I knew there were appointments, but I felt very uncertain about what would happen next.*
>
> *More time for partners to chat in separate sessions with treating doctor.*

Trust and being listened to, respected and included was valued by veteran carers

Veteran carers framed their positive experiences of services as a ‘couple’. They expressed their carer role as highly connected to and impacted by the mental health and wellbeing of the person they supported. They therefore emphasised the value of knowledge and learning ongoing strategies to effectively support their family member’s veteran-specific mental health needs. Whilst their comments aligned with all CES Domains, the Making a Difference and Supporting Active Participation Domains were noted, in particular.

> ***The holistic care for Caree both when in and outpatient care.***
>
> ***My husband and I were treated with respect and our opinions noted.***
>
> ***The staff. Exceptional people who made us both feel valued and important and that their contribution would involve greater hope and beneficial outcomes…The other thing is honesty. Totally trust all at the JLC. Lastly, Dr XXX is so good at explaining things and knows both of us so well…JLC is our safe place and that’s because we/I trust them to find the best way forward for my partner and, in consequence, me.***
>
> ***Getting to find out more about PTSD and ways to support my partner and myself. Involving partners with Trauma Recovery Programme. I have learnt extremely useful tools.***

Overall Summary of Qualitative Comments

Across the LHNs, carers said their experiences with services would have been better if staff worked more collaboratively with carers, were more accessible, helped with more practical support issues, and alleviated information barriers for carers. NB. Across all LHNs, some carers said they had no concerns or that they were very happy with the service.

Carers across all of the LHNs consistently said the best things about the services were how the service made carers feel – respected, included, valued, listened to, and supported in their role. Staff being helpful, friendly, caring and compassionate were noted as what was best about services. Carers emphasised the importance of compassionate care for their family member.

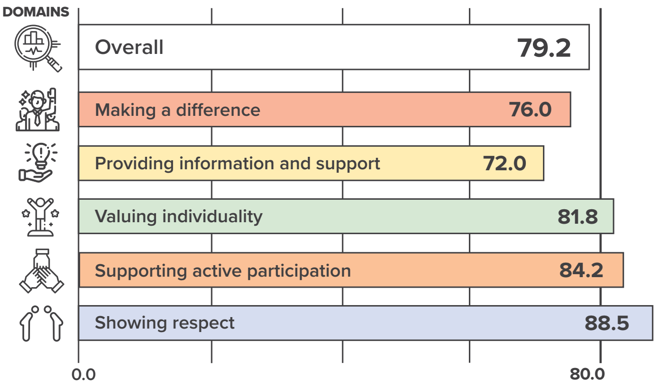
Across the five Domains, different emphases were apparent according to service type. For example, whilst all carers emphasised the importance of Providing Information and Support, this was particularly noticeable in the comments made by Women’s and Children’s HN carers. Veteran carers emphasised the importance of trust and Supporting Active Participation as part of working with the family/couple as a unit. Rural carers emphasised access and the importance of communication and coordination between service providers and the family.

Appendix 4: Carer Gender, Age and Role Duration

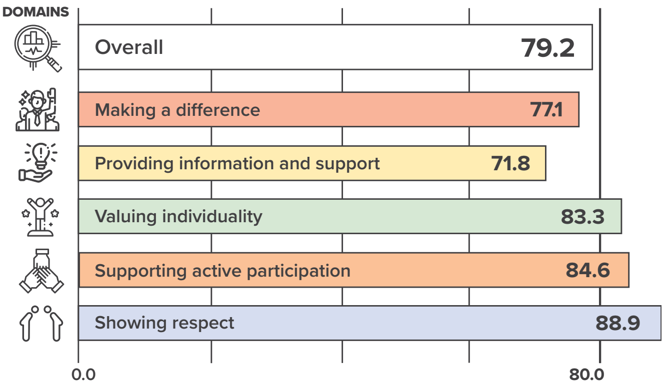
No statistically significant differences were found across these variables.

Carer Experience by Gender

Mean scores for female carers (N = 335)

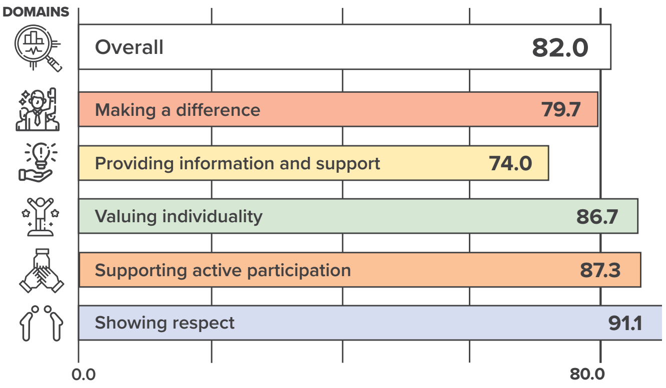


Mean scores for male carers (N = 113)

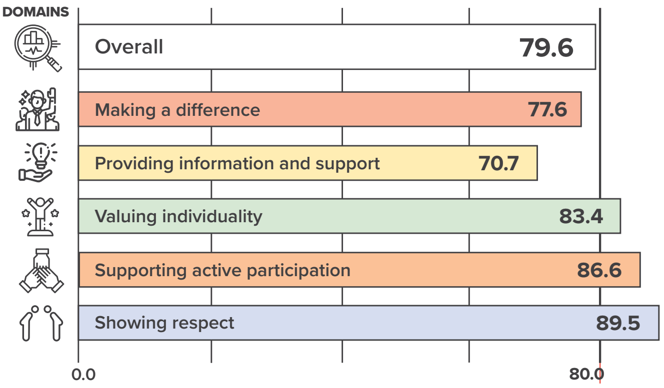


Carer Experience by Age

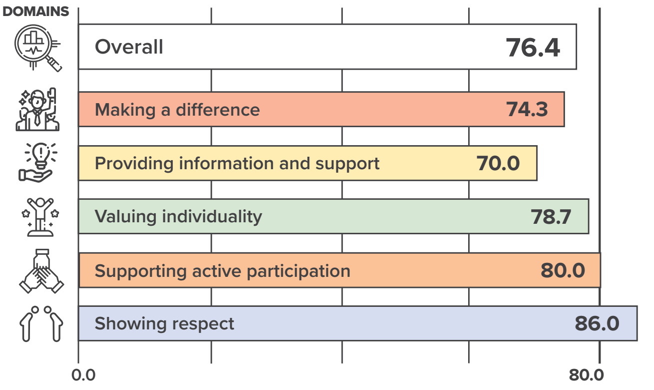
Mean scores for carers aged 18-44 (N = 112)



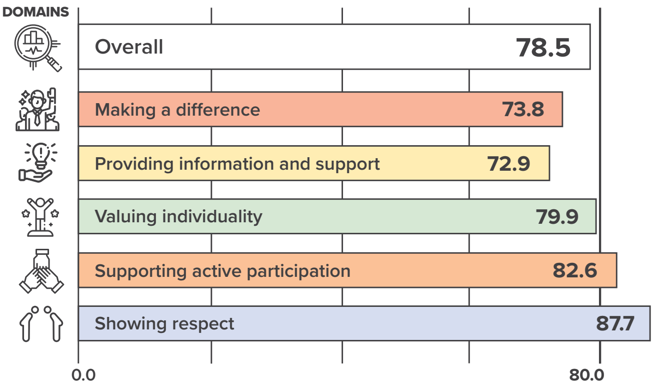
Mean scores for carers aged 45-54 (N = 117)



Mean scores for carers aged 55-64 (N = 90)

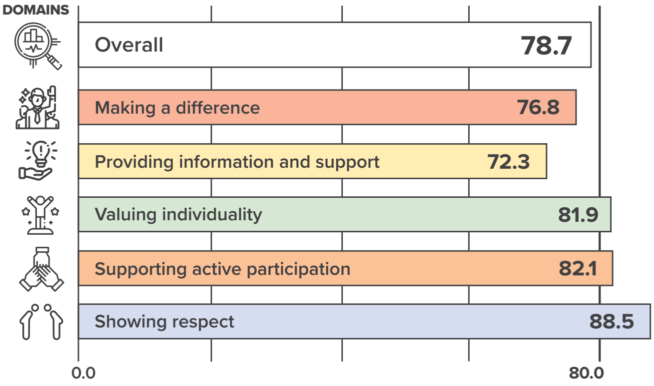


Mean scores for carers aged 65 and above (N = 128)

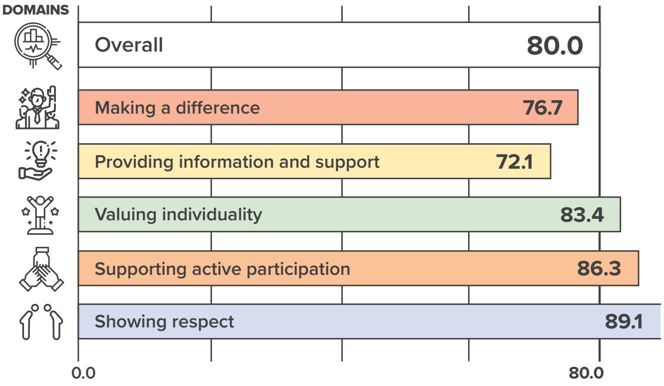


Carer Experience by Role Duration

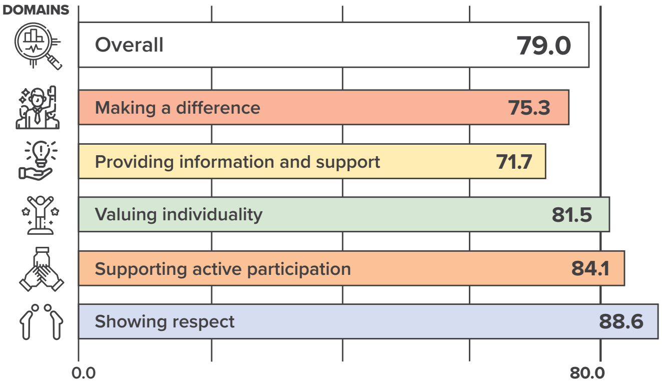
Mean scores for carers of up to two years duration (N = 105)



Mean scores for carers of two to ten years duration (N = 137)



Mean scores for carers of over ten years duration (N = 197)



Appendix 5: Making a Difference by LHN and Subspecialty Service

How the Service Contributed to Outcomes (Domain - Making A Difference) – CES questions by LHN

CES Questions #		CALHN	NALHN	SALHN	WCH	Regional LHNs
Q23	Your relationship with the person for whom you care	**2.94**	**3.33**	**2.94**	**3.92**	**3.50**
Q24	Your hopefulness for your future	**3.24**	**3.10**	**3.49**	**4.20**	**3.62**
Q25	Your overall wellbeing	**2.81**	**3.00**	**2.74**	**3.78**	**3.21**
Q26	Overall, how would you rate your experience as a carer with this mental health service over the last three months?	**2.79**	**3.40**	**2.75**	**3.65**	**3.62**

#-Ratings (5=Highest, 1= Lowest)

How the Service Contributed to Outcomes (Domain - Making A Difference) – CES questions by Subspecialty Service

CES Questions #		Older Persons	Forensic	Veterans
Q23	Your relationship with the person for whom you care	**2.78**	**3.46**	**3.00**
Q24	Your hopefulness for your future	**3.00**	**3.23**	**3.44**
Q25	Your overall wellbeing	**2.90**	**3.67**	**2.65**
Q26	Overall, how would you rate your experience as a carer with this mental health service over the last three months?	**3.65**	**3.75**	**2.67**

#-Ratings (5=Highest, 1= Lowest)

Appendix 6: Providing information and Support by LHN and Subspecialty Service

Positive Results (Domain - Providing Information and Support) – CES questions by LHN

CES Questions #		CALHN	NALHN	SALHN	WCH	Regional LHNs
Q1	You understood what you could expect from the mental health service for yourself and your family member, partner or friend	3.18	3.58	3.41	4.25	3.33
Q2	You were given an explanation of any legal issues that might affect your family member, partner or friend	2.60	2.80	2.46	2.47	2.38
Q3	You understood your rights and responsibilities	3.48	4.09	3.68	4.26	3.39
Q15	You were given information about services and strategies available if your family member, partner or friend became unwell again	3.39	3.59	3.75	3.95	3.60
Q17	A brochure or other material about your rights and responsibilities	61.54	61.73	55.76	50.00	69.23
Q18	An explanation of how to make a compliment or complaint about the mental health service	47.62	45.33	38.60	43.88	64.00
Q19	Information about carer support services (such as local groups, carer consultants, counsellors)	68.96	64.47	62.10	55.44	72.73
Q20	Information on opportunities to participate in improving this mental health service	47.83	38.57	42.98	37.11	47.06
Q21	A number you could call after hours for the service	72.41	66.26	64.80	65.76	82.76
Q22	Information about taking a support person to meetings or hearings if you wished	64.00	56.06	47.22	57.83	55.55

Q1-Q3 & Q15 ratings (5 = Highest, 1 = Lowest); Q17-Q22 (% of carers providing 'Yes' responses)

Positive Results (Domain - Providing Information and Support) – CES questions by Subspecialty Service

CES Questions #		Older Persons	Forensic	Veterans
Q1	You understood what you could expect from the mental health service for yourself and your family member, partner or friend	**4.02**	**3.53**	**2.94**
Q2	You were given an explanation of any legal issues that might affect your family member, partner or friend	**3.18**	**3.23**	**2.31**
Q3	You understood your rights and responsibilities	**4.19**	**4.12**	**3.12**
Q15	You were given information about services and strategies available if your family member, partner or friend became unwell again	**4.06**	**2.86**	**3.53**
Q17	A brochure or other material about your rights and responsibilities	**71.05**	**64.28**	**66.67**
Q18	An explanation of how to make a compliment or complaint about the mental health service	**47.14**	**50.00**	**56.25**
Q19	Information about carer support services (such as local groups, carer consultants, counsellors)	**68.49**	**53.85**	**78.56**
Q20	Information on opportunities to participate in improving this mental health service	**44.64**	**36.36**	**58.33**
Q21	A number you could call after hours for the service	**62.34**	**50.00**	**76.47**
Q22	Information about taking a support person to meetings or hearings if you wished	**51.52**	**36.36**	**60.00**

Q1-Q3 & Q15 ratings (5 = Highest, 1 = Lowest); Q17-Q22 (% of carers providing ‘Yes’ responses)

Appendix 7: Involvement in Care (Q27)

Did the Person want Carer involved in their care? - CES questions by LHN

CES Questions #		CALHN	NALHN	SALHN	WCH	Regional LHNs
Q27	Overall, during the last three months, did your family member, partner or friend want you involved in their care?	**3.79**	**4.16**	**4.12**	**4.21**	**4.00**

#-Ratings (5=Highest, 1= Lowest)

Did the Person want Carer involved in their care? – CES questions by Subspecialty Service

CES Questions #		Older Persons	Forensic	Veterans
Q27	Overall, during the last three months, did your family member, partner or friend want you involved in their care?	**4.24**	**4.37**	**4.12**

#-Ratings (5=Highest, 1= Lowest)

NOTES

1. Svendsen, M.L., Ellegaard, T., Jeppesen, K.A. et al. Family involvement and patient-experienced improvement and satisfaction with care: a nationwide cross-sectional study in Danish psychiatric hospitals. BMC Psychiatry 2021, 21:190. https://doi.org/10.1186/s12888-021-03179-1
2. Pharoah F, Mari JJ, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev 2010, Issue 12. Art. No.: CD000088. DOI: https://doi.org/10.1002/14651858.CD000088.pub3.
3. Aldersey HM, Whitley R. Family influence in recovery from severe mental illness. Community Mental Health J. 2015;51(4):467–76. https://doi.org/10.1007/s10597-014-9783-y.
4. In order to test for statistically significant differences between multiple (>2) subgroups, we used the non-parametric alternative to an Analysis of Variance (ANOVA) which was the Kruskal-Wallis test. We used the non-parametric alternative because the outcome variables did not meet the statistical assumption of normal distribution. In order to test for differences between just two subgroups, we used the non-parametric alternative to t-tests, which was the Mann-Whitney U test. By default, we used a significance level of .05; but, when multiple comparisons were made, we used the Bonferroni adjusted significance level.
5. Carers had a better experience of community mental health services, compared with their experience of inpatient settings. Community setting scored higher than inpatient setting on Valuing Individuality (U = 21743.5, p = .02), Supporting Active Participation (U = 20828.5, p = .005), and Showing Respect (U = 21530, p = .021).
6. Dharampal, R., Cornelius, A. The emotional and mental health needs of young carers: what psychiatry can do. BJPsych Bull, 2020;44(3):112–20. DOI: 10.1192/bjb.2019.78
7. Hill, T., Broady, T. (2019). Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19). Sydney: Social Policy Research Centre, UNSW Sydney. http://doi.org/10.26190/5c59202697201
8. Carers of clients with service duration less than one year scored higher than carers of clients with service duration of more than five years on Overall (U = 6321, p = .001) and all domain scores: Making a Difference (U = 5741.5, p < .001), Providing Information and Support (U = 6777.5, p = .009), Valuing Individuality (U = 6597, p = .004), Supporting Active Participation (U = 5974.5, p < .001), and Showing Respect (U = 6649.5, p = .006).
9. Carers of clients with service duration of one to five years scored higher than carers of clients with service duration of more than five years on Overall (U = 3083.5, p < .001) and all domain scores: Making a Difference (U = 3009.5, p < .001), Providing Information and Support (U = 3289, p = .003), Valuing Individuality (U = 3358.5, p = .005), Supporting Active Participation (U = 2902, p < .001), and Showing Respect (U = 3428.5, p = .010).
10. Community Central LHN (n=16) scored significantly higher than the overall sample on Overall (U = 2517.5, p =.044) and Providing Information and Support (U = 2519.5, p = 0.44).
11. Southern LHN scored significantly lower (using Bonferroni adjusted significance level of .008) than the overall sample on Valuing Individuality (U = 19460.5, p = .002) and Supporting Active Participation (U = 18179, p < .001).
12. Community Southern LHN (n = 89) scored significantly lower than the overall sample on Overall (U = 14217.5, p =.032), Valuing Individuality (U = 14072, p = .027), and Supporting Active Participation (U = 12962, p = .003).
13. Women's and Children's HN scored significantly higher (using Bonferroni adjusted significance level of .008) than the overall sample on Overall (U = 19149, p = .003), Making a Difference (U = 18685, p = .007), Valuing Individuality (U = 17560, p <.001), Supporting Active Participation (U = 14854.5, p < .001), and Showing Respect (U = 16812, p < .001).

14. Community Women’s and Children’s HN (n = 138) scored significantly higher than the overall sample on Overall (U =18266.5, p = .002), Making a Different (U = 18228.5, p = .001), Valuing Individuality (U = 16564, p < .0001), Supporting Active Participation (U = 13743.5, p < .001), and Showing Respect (U = 15973, p < .001).
15. Community Regional LHNs (n = 21) scored significantly lower than the overall sample on Supporting Active Participation (U = 3249, p = .48).
16. Older Persons Services (n = 96) scored significantly higher than the overall sample on Supporting Active Participation (U = 14977.5, p = .049.
17. Women’s and Children’s HN scored higher than Regional LHNs on Supporting Active Participation (U = 1223, p <.001) and Showing Respect (U = 1510, p = .004).
18. Women’s and Children’s HN scored higher than Northern LHN on Supporting Active Participation (U = 4971, p <.001) and Showing Respect (U = 5268.5, p < .001).
19. Women’s and Children’s HN scored higher than Southern LHN on Overall (U = 8708, p < .001), Making A Difference (U = 8618, p = .004), Valuing Individuality (U = 8018.5, p < .001), Supporting Active Participation (U = 6757.5, p < .001) and Showing Respect (U = 8072.5, p < .001).

For more information

SA Health
Office of the Chief Psychiatrist
Department for Health and Wellbeing
email: health.statewidelivedexperienceregister@sa.gov.au

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