



Your Experience of Service

What consumers
say about NSW
Mental Health
Services

2017-2018



Health



Acknowledgements

We gratefully acknowledge the support of members of the YES Advisory Committee and colleagues at BEING, the NSW Ministry of Health Mental Health Branch and The Bureau of Health Information. Many thanks to Andrew McAlister for his analysis of free text responses. Most importantly, thank you to the many consumers who have made the time and effort to complete a YES questionnaire, and the BEING and NSW Health staff who have worked together to improve services using the YES feedback.

Report produced by:

InforMH
System Information and Analytics Branch
NSW Ministry of Health

Published October 2018

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

Please check with InforMH for any amendments.

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Foreword

Consumer experience should be at the centre of mental health care. Your Experience of Service (YES) provides consumers of New South Wales mental health services the opportunity to give feedback on their care and support. YES supports services and consumers to work together to improve this care. In 2017-18 more than 24,000 YES questionnaires were completed. There was an 18% increase on the previous year in the number of returns from consumers supported in the community.

This report is produced by the System Information and Analytics (SIA) Branch of the NSW Ministry of Health. SIA's role is to support the data, information and analytical needs of the NSW public health system. We assist services to make better decisions and provide better care.

This third annual YES report focuses on how services use YES feedback. Examples of Action and Change activities have been included as stories throughout the report. These highlight the importance of strong leadership and the commitment to make changes at local, district and state levels.

In 2018-19, NSW will be the first Australian state to introduce an electronic version of YES which allows consumers to complete YES at any time and receive immediate feedback. The Mental Health Carer Experience Survey (MH CES) will also be introduced to ensure that the carer voice is heard alongside that of the consumer. These initiatives underline NSW's commitment to hearing from all people who use our services.

We would like to thank the many consumers who have made the time and effort to complete YES questionnaires and worked with our services to facilitate change. Thank you also to the staff from BEING (the state-wide peak organisation for people with a lived experience of mental illness) and NSW Health, who continue to work together to improve services using YES feedback.



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Summary

Your Experience of Service is a nationally developed questionnaire designed to gather information from consumers about their experience of care. This report summarises the third full year of YES data.

More than 24,000 YES questionnaires were returned in 2017-18

This represents around 34% of hospital consumers and 6% of community consumers. Overall returns increased by more than 1,600 (7%) compared with last year. There were more than 7,800 community questionnaires returned, an increase of 18% since last year.

A broad range of people completed YES

YES hospital returns are highly representative of all NSW hospital consumers. YES community returns include a good balance of men and women, indigenous and non-indigenous consumers, and people receiving involuntary community care. People under 25 and people receiving very brief care are under-represented in the community. Nearly 9% of people completing YES spoke a language other than English at home and more than 130 different languages were reported.

Most people completing YES reported a positive experience of care

Around two-thirds of people completing YES reported that their overall experience was excellent (39%) or very good (28%). In community settings, more people reported that their overall experience was excellent (44%) compared to hospital environments (36%). The most positive experiences were reported for the domains of Respect, Individuality, Safety and Fairness. While still positive, the lowest scores were reported for the Information and Support domain.

Experience in hospitals is improving

The experience of hospital care has improved slightly but significantly in the last three years. The largest increases were for questions in the domains of Making a Difference and Information and Support, which have been the lowest scoring domains in previous years.

Some groups of consumers report a different experience

People treated in hospital settings reported significantly less positive experiences than people receiving community care. In both settings the least positive experience was reported by people who were treated involuntarily.

In community care, young people (under 25 years of age) reported more positive experience, however in hospital settings people aged 18-24 reported significantly less positive experience. In hospital settings older consumers generally reported more positive experience.

Consumers who identify as Aboriginal and/or Torres Strait Islander reported a slightly but significantly less positive overall experience of care than other consumers.

Language results are complex and need exploration by local services

Overall, people speaking languages other than English reported similar or more positive experience of care than people speaking English. However there were different patterns for different regions and languages.

Staff have a large impact on experience

Across all free text responses the theme of "Staff" was mentioned more than any other topic (approximately one third of all comments). Consumers consistently indicated that staff matter most in determining their experience of care. Positive interactions with staff were often identified as the best things about a service. Many consumers reported that faster and easier access to staff would improve their experience.



Your Experience of Service

Your Experience of Service (YES) helps public mental health services to work with consumers to improve their care and support. This national questionnaire was designed and named in partnership with mental health consumers throughout Australia. NSW implemented the paper version of YES in 2015 (see Appendix 1 YES Questionnaire) and the electronic version in 2018.

This report summarises the third year of YES data from NSW services.

For information regarding the development of YES, please see Appendix 2 Technical Information.

When and how is YES offered?

YES should be offered to all consumers of NSW Health hospital, community and community residential services who are aged 11 years or older. If they see more than one team, the YES questionnaire should be offered by each of these teams.

Each Local Health District (LHD) or Speciality Health Network (SHN) offers YES in a way that suits their local needs. Some use a continuous method where YES is offered regularly and is available for consumers to complete at any time. Others use a snapshot approach where people are encouraged to complete YES in a particular week or month of the year. Some services combine both approaches. These different approaches may contribute to differences in results between services, as they affect the number or type of consumers who respond.

Reporting on YES

YES feedback is provided to services using a range of reports:

- monthly reports on return rates and overall experience
- quarterly reports on results for each individual question and all free text responses for individual hospital units or community teams
- six-monthly reports on results for each individual question and all free text responses for long-stay units.

Action and change

Feedback from YES questionnaires is used to support service improvement. The 'Action and Change Framework' helps NSW Health services to involve consumers in planning and implementing service improvements. This process of co-design is an essential component of the YES initiative in NSW.

The lowest scoring YES question across our district was Q18 (*Information given to you about this service*)

To improve this, we are working to develop a wider range brochures and resources. We want to empower consumers with the information they need about their service. Consumers are actively involved in the design of these resources. We are consulting with our District's Health Literacy Committee to make sure that all of the resources are recovery-oriented and written in plain English.

Central Coast LHD Mental Health services





Data Collection

Hearing from people who use the service about their experiences of using mental health services.



Data Analysis

Putting consumers' views together with other people's who are in a similar situation - finding common experiences and feedback.



Reporting and Feedback

Using the information gathered to let services know where they can improve.



Action and Change

Consumers and Mental Health Services to make change happen!



How many consumers completed a YES?



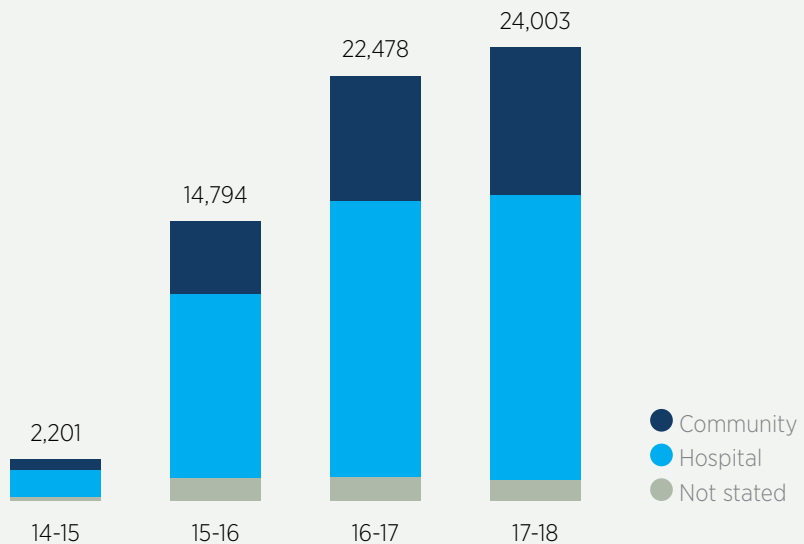
In 2017-18

24,003

YES questionnaires were returned.

This is an increase of 1,525 returns (7%) compared with last year.

Most of this increase was in community returns, which increased by 18%.



Our YES feedback highlighted that consumers wanted better access to their psychiatrist. On the South Coast, psychiatry appointments are limited and are sometimes cancelled due to flight delays. To improve this we have made more appointments available and are offering a mix of face-to-face and tele-psychiatry appointments.

SNSWLHD Bega Valley Community Mental Health and Drug and Alcohol Team

It is difficult to compare YES return rates with other surveys

Most patient experience surveys first select a subset or sample of service users who are then contacted and asked to participate. However, NSW Health has made a commitment that all people using mental health services should have the opportunity to provide feedback on their experience.

YES aims to reach all consumers, not just a sample

YES questionnaires are offered by staff, and available in waiting rooms using displays and "hotboards". YES questionnaires are anonymous so there is no way of knowing how many consumers were offered a questionnaire. In 2017-18 we estimate that the number of YES returns is equivalent to around 34% of all hospital consumers and approximately 6% of community consumers.



YES return rates are sufficient as long as they represent all consumers

The return rate reported by most surveys is the proportion of the sample who return a survey, rather than the proportion of the whole population of service users. The NSW Patient Experience Survey, conducted by the NSW Bureau of Health Information, is an example of a carefully designed and conducted survey with good return rates. The 2016 hospital survey targeted a sample of around 75,000 people from the 1.7 million NSW hospital admissions in that year¹. More than 28,000

people completed to the survey. This was around 38% of the sample, and around 2% of all hospital admissions. Because the sample was carefully selected and was representative of all consumers and services, this provides a reasonable estimate of overall patient experience.

Enough consumers complete YES questionnaires to allow us to draw valid conclusions, particularly for hospital services. The proportion of consumers

completing YES questionnaires is comparable to or greater than patient experience surveys which use a sampling approach. Rather than focusing on return rates, it is now more important to ask

- Are YES returns representative of all people using mental health services, or are some groups not currently being heard?
- Are all services and service types being represented in YES returns?



¹ Adult Admitted Patient Survey 2016. Bureau of Health Information, Sydney, NSW. [online at http://www.bhi.nsw.gov.au/nsw_patient_survey_program/adult_admitted_patient_survey]



Which consumers completed a YES?

YES hospital results are highly representative of all NSW hospital consumers. We can be confident that YES is providing an accurate view of NSW hospital consumer experience.

YES community returns include a good balance of men and women, indigenous and non-indigenous consumers, and people receiving involuntary community care.

People under 25 and people with very brief care are under-represented in community YES returns. The online YES application (eYES) aims to help these consumers provide feedback.

These differences are one of the reasons why hospital and community data are mainly described separately in this report.

We need to hear from all consumers

It is important to know if some groups of consumers are less likely to complete a YES questionnaire. Younger people, males and people from different cultural or linguistic backgrounds often don't complete health surveys. This makes it harder to ensure services meet their needs. We compared YES returns with data on consumer characteristics in NSW hospital and community mental health services in 2017-18.

A representative sample of hospital consumers returned a YES questionnaire

YES returns from hospital services are broadly representative of all hospital consumers. People with briefer periods in hospital were slightly under-represented: 69% of hospital episodes but only 58% of YES returns were from people spending two weeks or less in hospital. Females and people receiving involuntary care were also slightly under-represented in YES returns.

Community YES returns miss short episodes of care and some young people

In community YES returns, men and women, indigenous and non-indigenous consumers, and people receiving involuntary community care were all well represented. Of NSW community consumers, 29% are under 25, but only 22% of YES returns were from this age group. Older consumers were slightly over-represented; 11% of NSW consumers were over 65, and they contributed 16% of YES returns.

Each year NSW community mental health services are involved in emergency assessments and referral of many thousands of people. In 2017-18 more than 40% of individuals seen by community mental health services only had contact for 24 hours or less. However, only around 4% of all YES returns were from these consumers. People who have long term contact with services are much more likely to complete a YES: in 2017-18 around 20% of consumers had care for more than 6 months, but they provided more than half (52%) of YES returns.

This means that we need to continue efforts to reach more community consumers. We also need to be cautious in interpreting community findings, because they may not include the voice of some groups of consumers. The launch of the eYES application in 2018 aims to make it easier for all consumers to complete YES, and particularly improve access for community consumers and younger people.

We analysed the YES free text responses from 2015-2017 and looked at the scores for domains and individual questions for all our community teams.

We found common themes such as poor location, building aesthetics, limited parking, difficult to access via public transport and poor cleanliness. The consumer's feedback helped support a change in location – with the exception of one team, all community mental health services in our area have relocated to the purpose built Brookvale Community Health Centre which also houses other community health services.

NSLHD BCHC Community





Community

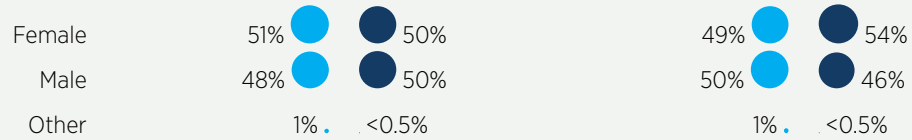


Hospital

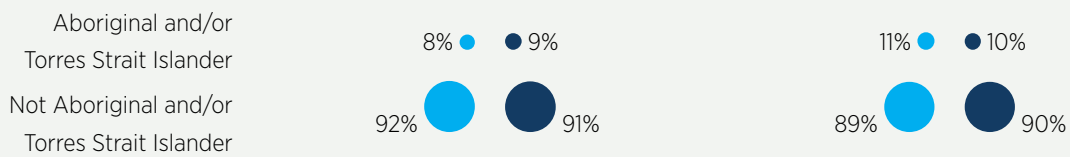
YES Returns NSW consumers

YES Returns NSW consumers

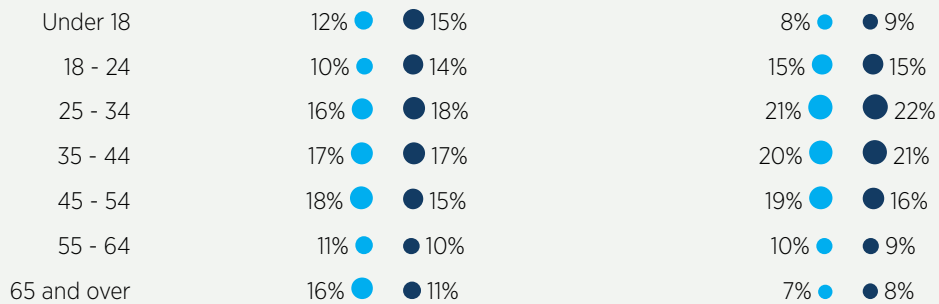
Gender



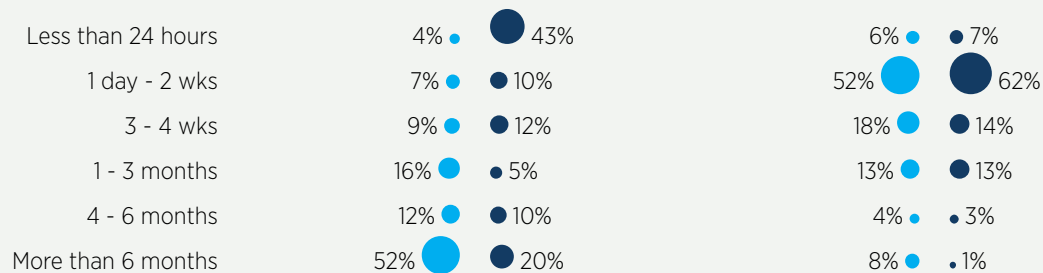
Aboriginal and/or Torres Strait Islander



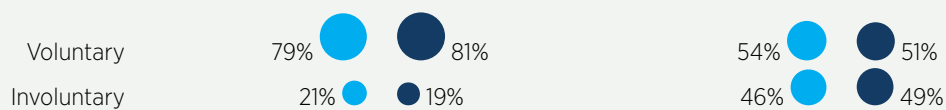
Age Group



Duration of Contact



Legal Status



What did consumers say about their experience?

Two-thirds of people (67%) rated their experience as excellent or very good on a single summary question (Q26).

Using the overall experience score, 73% of consumers reported an excellent or very good experience.

People in community settings report a more positive experience than people in hospital care.

The most positive experiences were reported for the domains of Respect, Individuality, Safety and Fairness.

This section looks at average experience for all consumers. The next section (page 12) explores whether some groups of consumers have different experiences.

Using results from Question 26

Question 26 asks people to summarise their experience in a single question. Around two thirds of people completing a YES described their overall experience as excellent (39%) or very good (28%) on this question.

People in community settings reported a more positive experience than people in hospital care. Nearly three quarters (73%) of people in community settings reported that their overall experience was excellent (44%) or very good (29%) on Question 26. In hospital settings 64% of people reported an excellent (36%) or very good (28%) experience.

Using an overall experience score

A richer way to understand experience is to look at experience over all of the questions answered. By combining the scores of questions 1-22, different areas of consumer experience are included in an overall score. This combined score can be used to measure the percent of people who report an overall excellent or very good experience across all questions.

This year 73% of consumers reported an excellent or very good experience. Experience was more positive in community settings (78% excellent or very good) than in hospital services (69% excellent or very good)

Across the six YES domains the most positive experiences were reported for Respect, Individuality, Safety and Fairness. Fewer people rated their access to Information and Support as excellent or very good.

Question 26
Overall, how would you rate your experience of care within this service in the last 3 months?



Overall experience score

Community

Percent Excellent or Very Good



Hospital

Percent Excellent or Very Good



In their free text responses, many consumers told us that the Pambula Community Mental Health Drug and Alcohol area needed physical improvements. As a result, we are conducting a quality improvement project. We are partnering with Hudson's Coffee at South East Regional Hospital to upgrade the area and make it more inviting.

**SNSWLHD Bega Valley Community
Mental Health Drug and
Alcohol**



Which groups of consumers report a different experience?

People receiving involuntary care reported the least positive experience of care, however around two thirds still described their overall care as excellent or very good.

Young people in community care reported the most positive experience, with many positive returns from youth-focused services.

In hospital care, young adults, indigenous people and people with long hospital stays reported the least positive experiences.

It is important to know if some groups of consumers have a different experience of care, because services should meet the needs of all consumers. Knowing which groups of consumers report a different experience also helps when interpreting other data in this report. Some apparent differences between services may be simply because they see different groups of consumers.

This report tested this issue differently from previous YES reports

Previous YES reports have found differences in experience scores based on gender, age and duration of care. We made two changes to analysis methods in this year's report. First, we used the measure *Percent of consumers with an excellent or very good experience* as the main measure for this analysis, rather than the average experience score. Second, we used a different statistical comparison, which tests whether groups differ after adjusting for all other variables. This is because some variables often occur together.

Involuntary care is linked to less positive experience

People who received involuntary care were much less likely to report positive experiences. Despite this, most of this group still reported that their overall experience was excellent or very good (71% of involuntary community consumers, 63% of involuntary hospital consumers). Around one in six people completing YES said that they were unsure if they had been treated involuntarily, and this group also reported less positive experiences.

In community care, young people reported the most positive experience

People under 25 reported significantly more positive experiences than other community consumers. This is partly because there were many returns this year from specialist youth services, which were rated very positively by consumers. In community care, people with very brief contact (less than 24 hours) reported less positive experiences, however these consumers are very under-represented in YES returns.

In hospital care young adults and indigenous consumers reported less positive experiences

For people receiving hospital care, older consumers generally reported more positive experiences. People aged 18–24 reported significantly less positive experience, and people aged 55–64 significantly more positive.

Slightly fewer indigenous consumers reported an excellent or very good experience in hospital (83% of indigenous consumers compared with 84% of non-indigenous consumers); however, this difference was statistically significant after adjusting for age, gender, legal status and duration of contact.

People with longer stays in hospital reported significantly less positive experience even after adjusting for factors such as legal status.

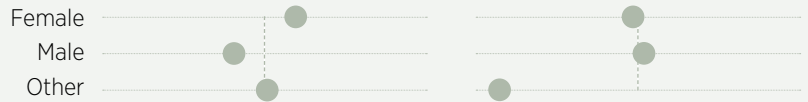


Community

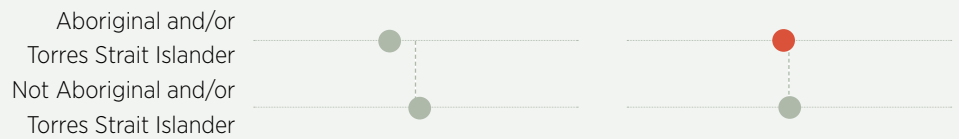


Hospital

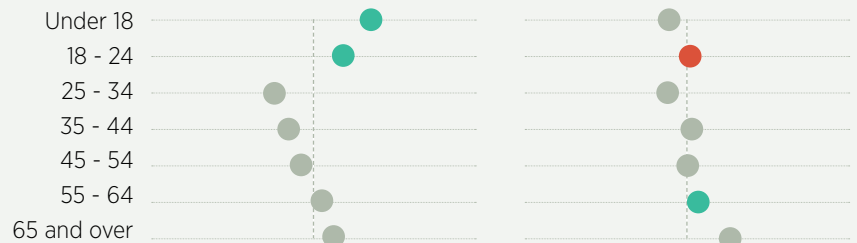
Gender



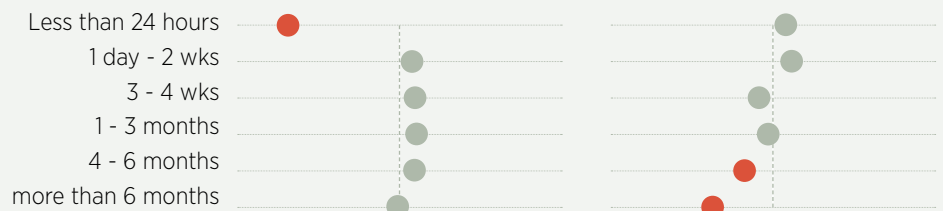
Aboriginal and/or Torres Strait Islander



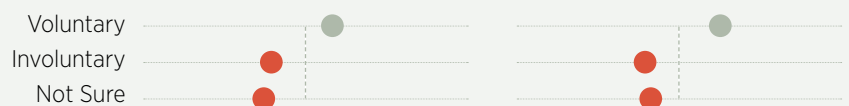
Age Group



Duration of Contact



Legal Status



Assistance Completing



- Significantly better experience
- No significant difference
- Significantly worse experience



Highest and lowest scoring questions

Consumers gave us feedback that they did not know when the Peer Worker was available. We have developed a calendar, and displayed it so that it is visible for all staff and consumers.

NSLHD Ryde Community Mental Health



Q2:
Staff showed respect for how you were feeling

Q1:
You felt welcome at this service

Q6:
Your Individuality and values were respected (such as your culture, faith or gender identity)

Q4:
Your privacy was respected

Q3:
You felt safe using this service



Community

5.0

4.7

4.6

4.5

4.4

Hospital



Q6:
Your Individuality and values were respected (such as your culture, faith or gender identity)

Q10:
Your opinions about the involvement of family or friends in your care were respected

Q4:
Your privacy was respected

Q1:
You felt welcome at this service

Q2:
Staff showed respect for how you were feeling

We identified Q20 (Access to peer support) as one of our lowest scoring YES questions. We discussed this in a YES meeting with consumers and a consumer advocate and together planned for a guest speaker to address this topic. Consumers, staff, carers, local non-governmental organisation and Mental Health and Drug & Alcohol executives were invited to hear the presenter, who spoke from the perspective of a peer coordinator and advisor for the NSW Mental Health Commission. After the presentation we shared a barbecue lunch and discussed the provision of mental health services from different perspectives.

SNSWLHD, Kenmore Hospital, Ron Hemmings Centre, Goulburn



Q21:

Development of a care plan with you that considered all of your needs (such as health, living situation, age, etc.)

Q18:

Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc.)

Q20:

Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc.)

Q16:

There were activities you could do that suited you

Q19:

Explanation of your rights and responsibilities

4.1

4.0

3.9

3.8

3.7

Q16:

There were activities you could do that suited you

Q21:

Development of a care plan with you that considered all of your needs (such as health, living situation, age, etc.)

Q19:

Explanation of your rights and responsibilities

Q18:

Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc.)

Q20:

Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc.)



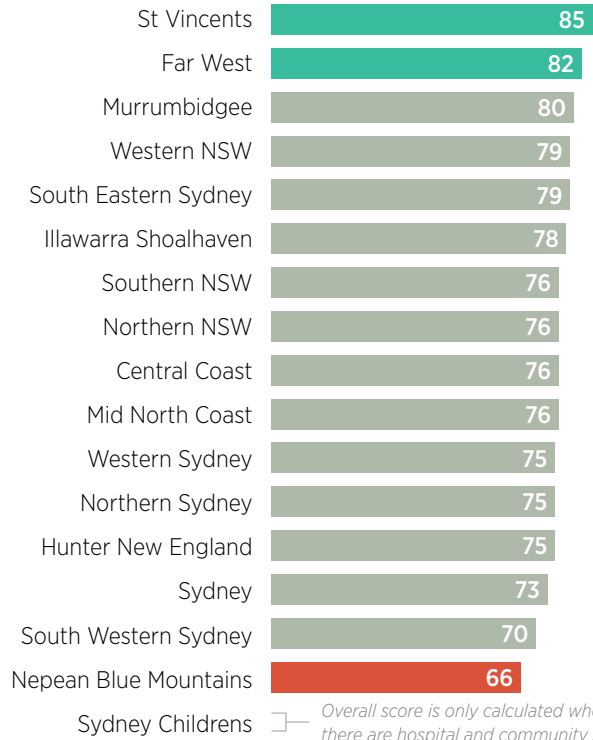
How do LHDs and SHNs compare?

This section looks at the percentage of consumers reporting an excellent or very good experience across LHDs and SHNs. This percentage is first calculated separately for community and hospital returns for each LHD/SHN. The overall percentage is then calculated as the average of community and hospital scores for each LHD/SHN (see the see Appendix 2 for more information for more information). We only present results where there are 30 or more responses for an individual district.

In consultation with consumers and clinicians, initial target ranges have been set for overall YES scores and will be included in reporting to LHDs and SHNs from mid 2018. The initial target is 80% of consumers reporting an excellent or very good overall experience (85% in community care, 75% in hospital care).

Note:

Justice Health and Forensic Mental Health Network results are reported separately on page 8 of the supplement report.



Overall score is only calculated when there are hospital and community scores

- Better than target (≥80%)
- Just below target (70% - <80%)
- Below target (<70%)

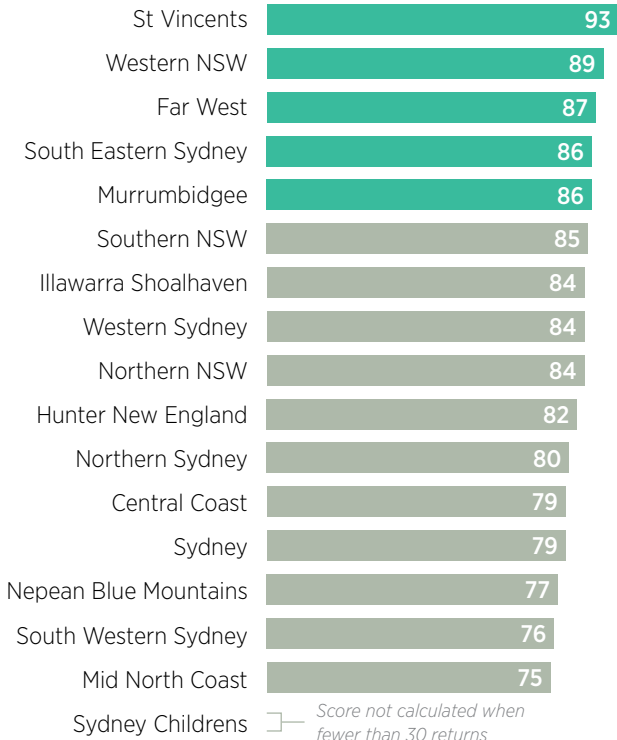
Our YES feedback highlighted the need for more information about the unit, such as the names of team members, leave arrangements, visiting hours, meals and available programs. We developed an orientation booklet to give to consumers upon arrival so that this information is easy to access.

NSLHD Henley Unit Inpatient





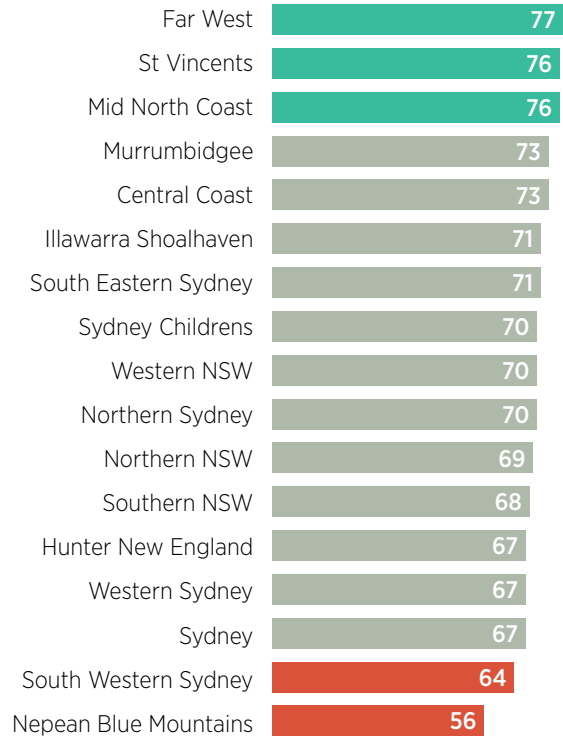
Community



- Better than target (≥85%)
- Just below target (75% - <85%)
- Below target (<75%)



Hospital



- Better than target (≥75%)
- Just below target (65% - <75%)
- Below target (<65%)



What has changed?

The experience of hospital care has improved slightly but significantly in the last three years.

Measuring change is complex, because the mix of consumers and services changes each year as YES collections increase.

All LHDs/SHNs should support clinical and consumer leaders to work closely together to investigate these results and improve care.

NSW average results appear stable

To test for change we looked at the percent of consumers with excellent or very good experience over the last three years. Overall results appear fairly stable (see table below). Community results decreased slightly in 2017-18, but hospital results have increased slightly each year.

Percent of NSW consumers with excellent or very good experience			
	2015-16	2016-17	2017-18
Community	79%	79%	78%
Hospital	67%	68%	69%
Overall	73%	73%	73%

A simple average may be misleading because of changing consumer and service mix

A simple average may be a misleading measure of change. Changes from year to year may be caused by a different mix of consumers or services, rather than by true changes in the experience of care. For example, older consumers tend to report a more positive experience. Therefore, more YES responses from older people in one year would increase the state average. Alternatively, if a LHD/SHN with less positive results returned many more YES questionnaires in one year, that could reduce the state average.

It is important not to create a false impression or hide a true change. These risks are greatest for community YES data, because community returns are increasing each year and some consumer groups are still under-represented. To reduce these risks, we used a statistical technique to adjust for three factors which influence YES results and which have changed in frequency from year to year: the age of the consumer, the length of contact with the health service, and the LHD or SHN. We did not adjust for involuntary legal status, because if differences between services or over time were due to differences in the use of involuntary care, we did not want this to be hidden by statistical adjustment.

Our YES feedback told us that consumers felt there were not enough activities and in particular they wanted more outdoor activities. We have since introduced pet therapy and a sensory garden. Consumers have been positive about the changes and have told us that their experience of the ward has improved as a result.

















NSLHD PECC RNSH



Experience in hospital is improving, after adjusting for consumer and service mix

For hospital consumers there was a slight but significant increase in the likelihood of reporting an excellent or very good overall experience. The largest increases were in the domains of Making a Difference and Information and Support, which have been the lowest scoring domains in previous years.

For community consumers, there was a trend towards more positive overall experience. This was not statistically significant for overall experience, but improvement in the Information and Support domain was significant.

	 Community	 Hospital
Overall Experience	1.07 (0.98 - 1.17) 	1.05 (1.00 - 1.10) 
Respect	1.10 (0.99 - 1.23) 	1.03 (0.98 - 1.09) 
Safety	1.01 (0.91 - 1.13) 	1.05 (1.00 - 1.10) 
Individuality	1.12 (0.99 - 1.26) 	1.03 (0.98 - 1.07) 
Participation	1.09 (0.99 - 1.21) 	1.04 (1.00 - 1.09) 
Info & Support	1.08 (1.00 - 1.17) 	1.07 (1.02 - 1.11) 
Impact	1.05 (0.99 - 1.13) 	1.07 (1.03 - 1.12) 

Odds of change in likelihood of reporting an excellent or very good experience, over the last 3 financial years (July 2015 – June 2018), after adjusting for consumer’s age, duration of contact and LHD/SHN of service. Figures show Odds Ratio and 95% confidence interval. Odds ratios greater than 1 indicate more positive experience. Statistically significant improvements are shown in green.



There are differences between Health Districts and Networks

We used the same statistical technique to compare health districts and networks, but only adjusted for the the consumer's age and their duration of care. There was a significant improvement in experience for hospital care at seven LHDs/SHNs (Far West, Illawarra Shoalhaven, Mid North Coast, South East Sydney, Southern NSW, South West Sydney and St Vincent's).



Community consumers reported significant improvement in experience in Southern NSW and Western NSW LHDs. Some LHDs/SHNs have smaller numbers of community returns, which makes it difficult to show significant change. There was a slight but significant reduction for community consumers in Far West LHD, however, this analysis is based on a small number of questionnaires. For more details see Appendix 2.

Differences between LHDs/SHNs need local investigation and change

These statistical trends do not prove that services are improving or deteriorating in those LHDs/SHNs. YES provides services with an important screening tool. There may be many reasons why YES results differ between services or over time. All services should establish processes for clinicians and consumers to work together to investigate these results, and develop the best responses to their situations.

	 Community	 Hospital
Central Coast	-	-
Far West	✘	✔
Hunter New England	-	-
Illawarra Shoalhaven	-	✔
Murrumbidgee	-	-
Mid North Coast	-	✔
Nepean Blue Mountains	-	-
Northern NSW	-	-
Northern Sydney	-	-
Sydney Children's	-	-
South East Sydney	-	✔
Sydney	-	-
Southern NSW	✔	✔
South West Sydney	-	✔
St Vincent's	-	✔
Western NSW	✔	-
Western Sydney	-	-

Change in likelihood of reporting an excellent or very good experience over the last 3 financial years (July 2015 – June 2018), after adjusting for consumer's age and duration of care. Only significant trends are shown.

-  significantly better experience
-  significantly worse experience
- no significant difference

We analysed the YES free text responses from 2015-2017 and identified that consumers wanted more group activities such as art, yoga, mindfulness and education on healthy lifestyle. To support this change we added an exercise physiologist and art therapist to the team. A variety of extra weekly activities are now run with consumers. Yoga mats have been purchased and wall and table murals have been painted on the unit.

**NSLHD East Wing Inpatient & NSLHD
OPMHS Inpatient - Manly**

We used our YES feedback and further discussions with consumers to make a number of important changes in our service. Consumers told us that they sometimes forget their appointment details or travel a long way only to find the doctor is not available. To assist we now use SMS reminders and schedule appointments for consumers with greater distances to travel later in the day so that there is time to contact them should the doctor not be available.

**NSLHD Ryde Community
Mental Health**



Information about physical health

More than half of consumers recall being provided with information on exercise, diet, medication side effects and alcohol and drug use.

Just over half of hospital consumers recall receiving information about medication side effects, including just under half (48%) of young people in hospital.

Mental health services need to find ways to make health information more relevant and memorable for young people.

Only half of older consumers in hospital recall being given information about medication side effects.

The physical health of people using mental health services is a critical priority. NSW has added questions to the YES questionnaire which ask whether consumers remember being given information about six aspects of physical health care. These questions were based on the Healthy Active Lives (HeAL) Declaration (for more information see www.iphys.org.au).

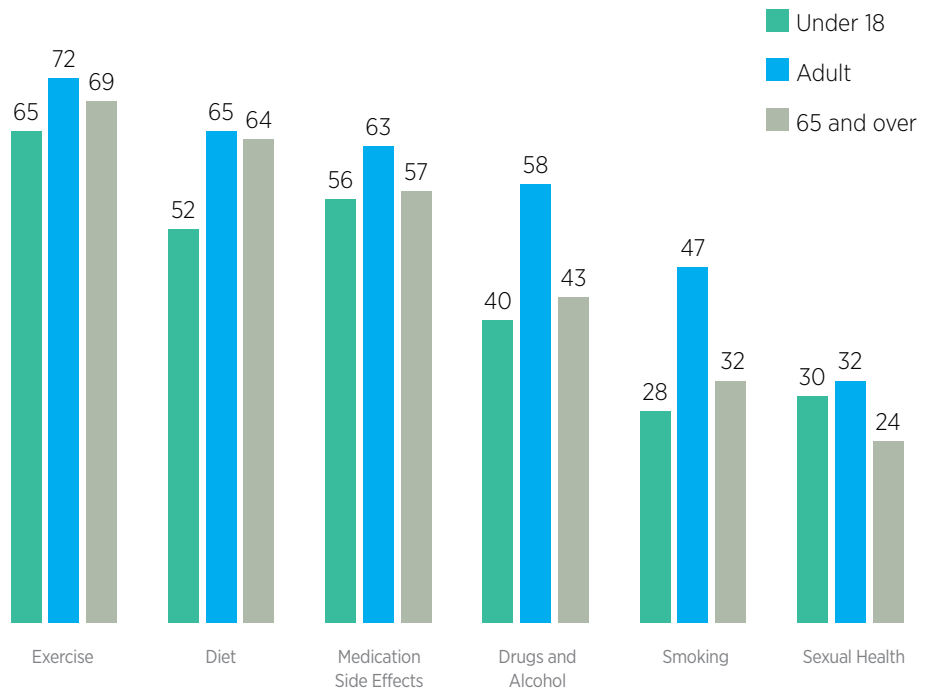
Most people receive information about diet, exercise, medication side effects and drugs and alcohol

More than half of people who completed the HeAL questions recalled receiving information on exercise, diet, medication side effects or drug and alcohol use. People were less likely to recall information on smoking or sexual health. People might not recall receiving information for many reasons. Not all information is relevant for all people. For example, a non-smoker may not need information about smoking. Services may provide information, but if it is not provided at the right time or in the right way for that individual then it may not be remembered.



Community

Percent of people who recall being given information



Percent = Number answering "Yes" divided by total valid answers ("Yes", "No", "Unsure").

Around half of hospital consumers recall information about medication side effects

Medications are an important component of treatment. Many psychiatric medications have short and long-term side effects that require careful monitoring and adjustment of medication. Just over half of hospital consumers recall receiving information about medication side effects, including just under half (48%) of young people in hospital.

Less young people recall information on physical health

Prevention of long-term health problems should ideally start, from the earliest contacts with health services. Younger people were less likely than adults to recall being given information on all issues. In community care only half (52%) recalled being given information on diet, and less than half recalled information on drugs and alcohol (40%) or sexual health (30%). These figures suggest that hospital and community mental health services need to find ways to make health information more relevant and memorable for young people.

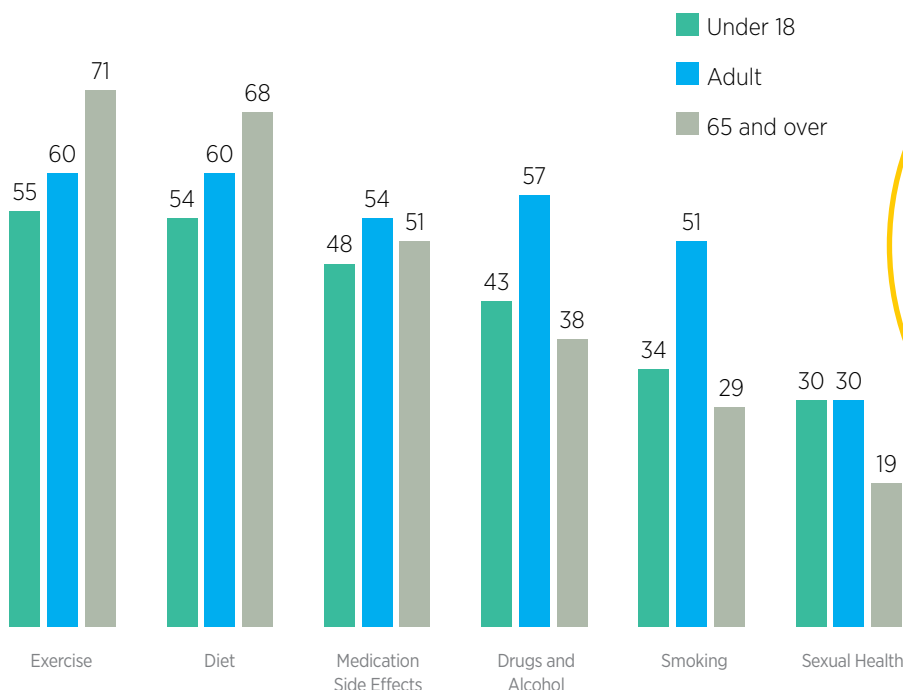
Older people recall less information on medication side effects

For older people with mental health and other health problems, managing medications safely is a high priority. Many older people who completed YES recalled being given information on exercise and diet, including around 70% of older consumers in hospital. However, older consumers recalled less information about medication side effects when compared with adults. Only half (51%) of older people in hospital recalled being given information about medication side effects.



Hospital

Percent of people who recall being given information



Our service scored low on Q32 (informing people about possible side effects of medications). Many YES free text answers also mentioned medications and side effects. In response, we have arranged regular face-to-face discussions with our hospital pharmacist to discuss medication needs. Since making this change, consumers report feeling more respected and informed.

NSLHD Bridgeview Inpatient



A focus on language

Around 9% of people of people completing YES spoke a language other than English at home. More than 130 different languages were reported.

Overall, people speaking languages other than English at home reported similar or more positive experience of care than people speaking English.

Consumers from Southern and South/Central Asia (including speakers of Bengali, Nepali and Arabic) reported significantly more positive experiences.

Speakers of Auslan, German, Maltese and Dutch reported significantly less positive experiences.

Language results are complex and need to be further explored by local services.

NSW has one of the most culturally diverse communities in the world, with more than 215 languages spoken². The YES results reflect this diversity. Over the last three years nearly 9% of people answering YES spoke a language other than English at home, and more than 130 different languages were reported.

² <http://multicultural.nsw.gov.au/>

YES can be completed in English or 21 community languages

The YES questionnaire asks people to identify the language that they usually speak at home, even when they are completing YES in English. Some people also completed YES in one of the 21 translated versions.

For this section we have included data from all years of YES collection, to provide enough numbers to examine as many languages as possible. We grouped languages into regions using standard Australian Bureau of Statistics groupings. We examined community and hospital results separately, and only reported on individual languages when they had at least 30 valid YES returns in either hospital or community care. To look for overall differences we combined hospital and community results for each language, and used a statistical adjustment in case differences between languages were due to differences in age, sex, type of service (hospital or community) and LHD/SHN. For more information, see appendix 2.

Non-English speakers reported similar or more positive overall experience

Overall, most people speaking languages other than English at home reported equivalent or more positive experience of care than people speaking English. The most positive experiences were reported by consumers from Southern Asia (81% excellent or very good experience overall, compared with 73% for English speakers) and South/Central Asia (77% excellent or very good). Both of these differences were statistically significant. This trend was consistent for most languages within those regions. Speakers of three individual languages (Bengali, Nepali and Arabic) reported significantly more positive experiences.

Some individual language groups reported significantly different experiences

Language results varied significantly between and within regions. More positive experiences were reported by people speaking Spanish, Samoan, and 'Other South East Asian' languages (these included, Filipino, Khmer, Malay, Burmese, Cambodian, Bahasa, Hakka, Lao, Malagasy, Bisaya, Chakma, Chamic and Rohingya).

Significantly less positive experience was reported by speakers of German and 'Other Southern European' languages (Maltese, Dutch).

A small number of people (25) indicated that they spoke Australian Sign Language (Auslan) at home. This group reported significantly less positive experience.

The language results are complex and need to be further explored by services

Overall, the results are complex, suggesting that it is important not to make broad assumptions. Language and nationality do not automatically align; many Spanish speakers are from South America, and some French speakers may be from Canada or Africa. It is possible that there are cultural differences in the way in which people respond to surveys such as YES. The number of speakers of some languages is small and, despite the statistical adjustments used, it is possible that the results reflect experiences in one or two services, where many people from one language group are receiving care in the same LHD/SHN or service.

Services should explore these results with their local consumers and communities.

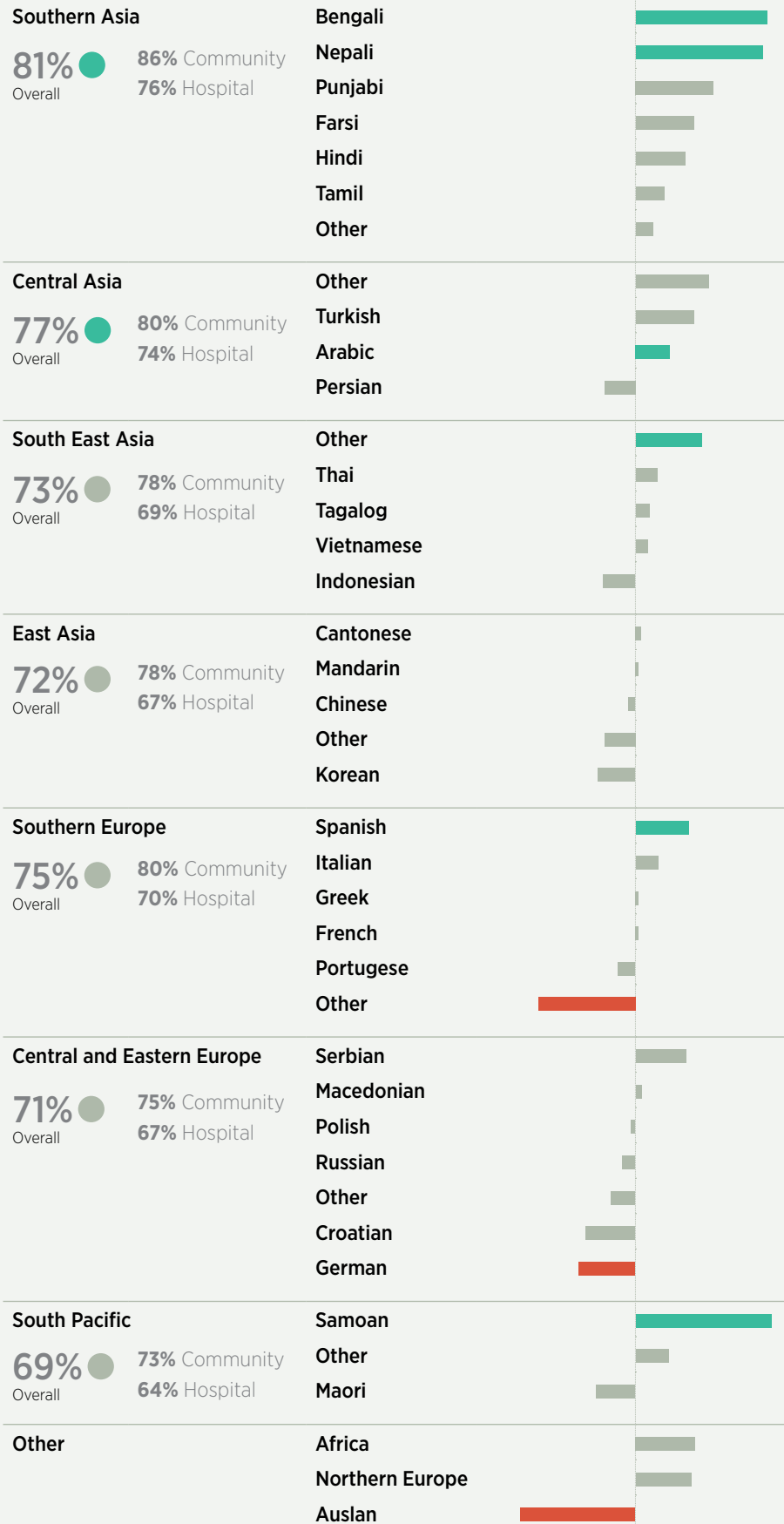
English

73% Overall
79% Community
68% Hospital

Length and direction of bar shows likelihood of excellent or very good experience for each language compared to English. Colours show significant differences, after adjusting for age, sex, hospital/community setting and LHD/SHN.

Excellent or very good

< Less Positive More Positive >



A focus on younger and older people

Across all age groups, more than two-thirds of people reported an excellent or very good overall experience.

In community care, younger people were most likely to report positive experiences. Of young people using Child and Adolescent Mental Health Services (CAMHS), 92% reported an excellent or very good experience.

In hospital care, older people using specialist Older Persons Mental Health services reported the most positive experiences.

Younger and older people receiving care in Adult or General services reported less positive experiences than people in age-specific services; however, most felt safe and treated with respect. These services may need a wider range of age-appropriate activities and information.

Nearly one-quarter of YES returns were from people under 18 or over 65

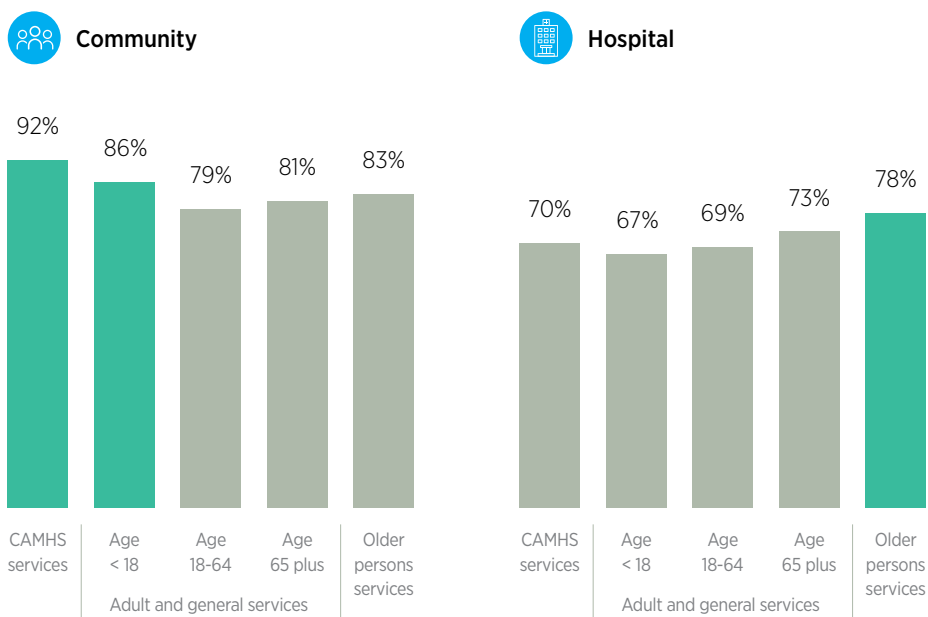
Mental health services provide care for people across the lifespan. This year there were more than 2,600 returns from people under 18. This included more than 500 returns from young people who received care in “adult or general” mental health services. This term is used in national mental health reporting to refer to services that cater for adults or for a mixed age group. These include community assessment and emergency teams, and community teams in some rural areas who care for all age groups. They also include adult hospital mental health units or units with a wider age range such as Psychiatric Emergency Care Centres (PECCs). There were more than 2,400 returns from people aged 65 and over, including more than 500 from adult or general services.

In community care, younger people report the most positive experiences

Of young people using Child and Adolescent mental health services, 92% reported an excellent or very good experience. YES questionnaires were returned by many consumers of specialist adolescent and youth-focused teams, and most reported a very positive experience. More than 95% of consumers reported an excellent or very good experience at three specialist community teams for younger people (headspace Bondi Junction, Nepean Blue Mountains CYMHS Assessment and Therapy, and Hornsby Early Psychosis Intervention Service (EPIS)).

In hospital care, older people report the most positive experiences

More than three-quarters (78%) of YES questionnaires from specialist older people's services reported an excellent or very good experience, compared to 70% of responses from child and adolescent mental health hospital units.



Percent of people with excellent or very good overall experience. Green indicates at or above target performance

People in age-specific services report more positive experiences

Most young or older people treated in adult or general services reported positive experiences. The graph on the previous page shows that scores were more positive when people were treated in services that specialised in care for that age group.

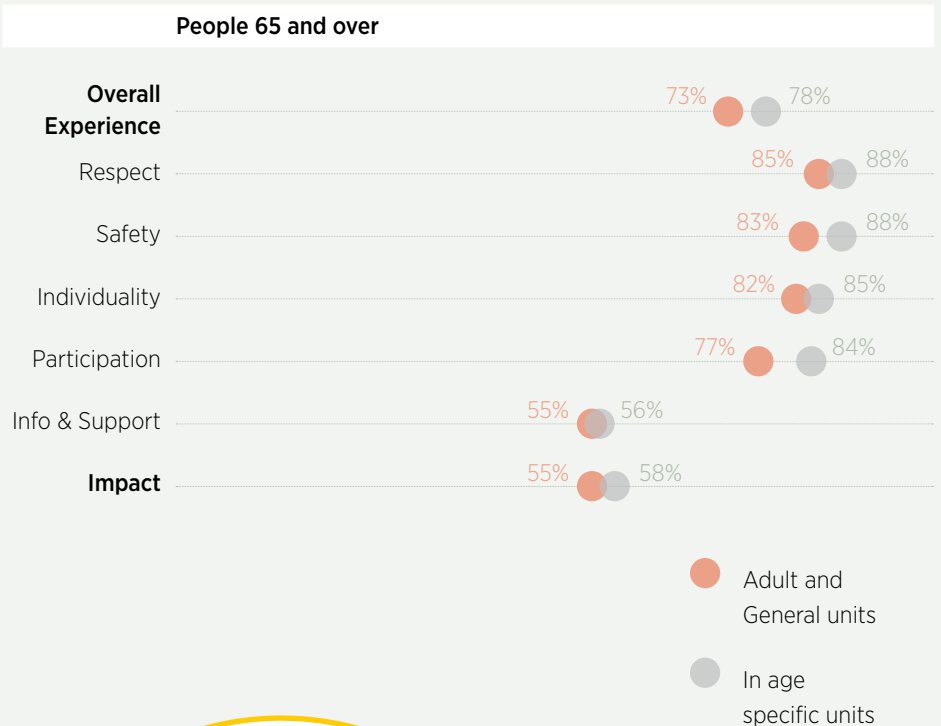
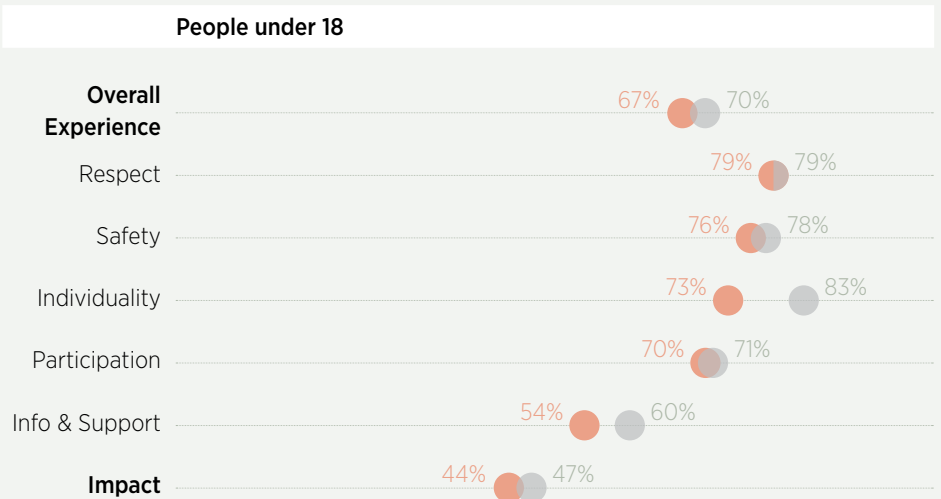
In specialist older person's hospital units, 78% of people reported excellent or very good care, compared with 73% of people over 65 cared for in adult or general services. The biggest differences were in the domains of Participation (7% lower) and Safety and Fairness (5% lower), and the smallest difference in the domain of Information and Support (1% lower).

People under 18 reported slightly more positive experience when cared for in specialist CAMHS units (70% excellent or very good) compared with adult or general units (67%). Respect and Safety were the most positive domains for young people in adult or general units, with very similar ratings to those in specialist CAMHS units. The biggest differences were in domains of Individuality and Information and Support. Young people were 5-10% less likely to rate these as excellent or very good when they received care in adult or general hospital units.

Together these findings suggest that when mental health hospital units care for younger and older people they need a range of age-appropriate information and activities. They also need strategies to ensure that people of all ages feel safe during care.



Percent of people with excellent or very good overall experience



Using feedback from YES reports and discussions with consumers and carers, we started a consumer-carer communication and recovery focused group. In the group we discuss educational topics and goals for care planning. Consumers tell us that this group has increased their confidence in directing their own recovery.

WNSWLHD Specialist Older Persons' Community team



A focus on free text responses

People's experience and interactions with staff were often highlighted, as a positive as well as an area for improvement.

Faster and easier access to staff was highlighted as something that would improve experience.

Consumers want more recreational and diversionary groups that involve physical activity and being outdoors.

When completing YES, consumers are asked to provide more detailed comments about areas for improvement (Q33 "My experience would have been better if ...") and things that went well (Q34 "The best things about this service were ..."). These comments are provided directly to services to be used in service improvement. This year we have also explored options for statistical analysis of these questions.

Analysing free text responses

Analysis of free text responses is complex: this section presents the results of preliminary analyses conducted in early 2018. The frequency, expression, sentiment and structure of comments were analysed using Natural Language Processing techniques and statistical software. For more information on these methods please see Appendix 2 Technical Information.

What was analysed?

We examined all free text responses from more than 37,000 YES questionnaires received between 2015 and 2017.

Just over half of people completing YES (19,759 responses) answered Q33 "My experience would have been better if ...".

More than two thirds of people (25,468 responses) answered Q34 "The best things about this service were ..."

Consumers supported by hospital and community services were equally likely to provide a written comment. People who speak a language other than English at home were equally likely to provide a written comment.



Staff are mentioned more often than any other topic

Across all free text responses, the theme of “staff” was mentioned more than any other individual topic.

Positive interactions with staff are often the best things about a service

Comments about staff occurred most frequently (in around a third of responses) when consumers described the best things about the service. Many consumers highlighted friendly, approachable, courteous and supportive staff as the best things about their experience of care.

Better access to staff will improve experience

Where staff were mentioned in response to things that could be improved, comments often indicated that consumers didn't feel that they had sufficient access to staff. Faster and easier access to staff was highlighted as something that would improve experience. Less frequently, some comments identified negative attitudes or inconsistency among staff.

Consumers want more groups and activities

Groups and activities appear to be highly valued. The types of activities mentioned frequently as positives included Dialectical Behaviour Therapy (DBT), craft, pets, dogs, yoga and mindfulness.

Consumers want more recreational and diversionary groups that involve physical activity and being outdoors. Comments and requests from consumers seemed to focus on a greater variety of stimulating activities, rather than on greater access to specific therapy groups or programs.

Food needs to be more nutritious, fresh and healthy

The quality of the food was raised by some consumers as something that could have been better, with requests for more nutritious, fresh and healthy meals. However, some consumers also identified food as a one of the best things their experience, often along with shelter and accommodation.

Making changes to medication is often a positive experience for consumers

Many consumers said that having their medication changed or adjusted was a positive experience. However, a number of consumers felt that their experience would have been better if their medication was reduced.

“The excellent staff, who were very professional while still being warm and compassionate. The facility feels very calming and clean”

“The exceptional people, I honestly feel hopeful about my future. All the nursing staff were so empathetic and showed true compassion”

“The different activities, BBQs, music groups, outings, art groups and the animated movies”

Q34 The best things about this service were...





Your Experience of Service

Service:

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

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

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

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

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

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

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

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

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

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



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

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

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

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

.....

.....

.....

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

.....

.....

.....

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

What is your gender?

Male Female Other

What is the main language you speak at home?

English Other

Are you of Aboriginal or Torres Strait Islander origin?

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

What is your age?

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

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

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

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

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

Did someone help you complete this survey?

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

Thank you for your time and comments

Please place the completed questionnaire in the envelope provided and return by mail

InforMH
Reply Paid 3975
Sydney NSW 2001

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

Appendix 2 - Technical Information

YES development and validation

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

<http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-conexp>

YES NSW collection method

NSW protocols are based on the national “YES Guide for Organisations”, available at <http://mhsc.aihw.gov.au/committees/mhssc/YES-survey/>

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

- Distribution to services: LHDs/SHNs order blank YES questionnaires and pre-addressed envelopes using the same online ordering process as other NSW Health forms.
- Sampling periods: NSW Health recommends that YES is offered to all consumers on discharge from a service and at least annually for people in ongoing contact with services. LHDs/SHNs differ in their approach, and some focus on periodic (annual or six-monthly) census periods.
- Identifying services: Before distribution, services enter a four-digit unique service code in the service identification box on page 1 of the YES questionnaire.
- Offering: Services are encouraged to promote the availability of YES through posters and the display of collection boxes, and to include offering of YES in service discharge protocols. Services are encouraged to use peer workers to promote and support YES collection wherever possible.
- Returning: Consumers place completed YES questionnaires in a sealed, reply-paid envelope or collection boxes provided.
- Completed questionnaires are collated and scanned by a commercial scanning organisation under contract to NSW Health.
- Data is provided monthly to InforMH, System Information and Analytics Branch, NSW Ministry of Health, within two weeks of the end of the reporting period.
- Data received by InforMH is checked, validated and stored in a secure, purpose-built SQL (structured query language) database on password-protected NSW Health servers.
- Data analysis and reporting is conducted by InforMH.

Identification of NSW services

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

All NSW Mental Health Services are registered in a central database, the Mental Health Service Entity Register (MH-SER), and have a unique four digit numerical code. This four digit code is used in YES reporting because (i) it can be more accurately scanned than a handwritten service name, and (ii) it allows data on YES questionnaire return rates or responses to be accurately compared to other data on the same service.

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

Services are provided with a monthly report showing the number of returns with missing service identifiers, and the details of any handwritten names. The rate of service identification error has declined when compared with previous years.

In 2017-18, of 24,003 completed YES questionnaires received, 22,923 (96%) had a valid 4-digit service identifier entered.

Analysis

Initial data manipulation for this report was conducted using SAS and statistical analyses were conducted using Stata SE v15. Missing, invalid or duplicate answers were recoded as null. YES returns with less than 12 of the first 22 questions completed were excluded from analysis. Overall scores and domain scores were constructed following the methods used in the national YES development.

YES questions use two scoring scales:

Frequency Scale	Performance Scale	Numerical Score
Always	Excellent	5
Usually	Very Good	4
Sometimes	Good	3
Rarely	Fair	2
Never	Poor	1

Estimation of return rates

To estimate return rates the following denominators were used:

For hospital episodes: the number of episodes of hospital care ending in the year (separations), including same-day episodes, plus the number of people remaining in hospital on June 30 2018.



For community episodes: the number of episodes where an individual had at least one face-to-face contact with a community mental health team within the year. In the current report people whose only service contact in the year occurred by telephone were excluded. The availability of an electronic version of YES in 2018-19 may make it easier for these people to have an opportunity to complete the questionnaire.



Analysis of Change

To examine change in experience over time, a logistic regression was conducted using *Overall Experience Excellent or Very Good* as the binary dependent variable. Only records with a valid Experience Index score and valid service setting (Hospital or Community) were included. Selection of covariates was based on previous analyses of factors influencing experience. For NSW, age group, duration of contact and LHD/SHN were included as independent variables. All were entered as categorical variables, with missing or invalid answers included as a separate category rather than excluded. A numerical dummy variable was constructed to represent year of return (2015-16 = 0, 2016-17 = 1, 2017-18 = 2). A complex survey design was used, with all analyses stratified on service. Significant trend was defined by significantly increased or decreased Odds Ratio (OR) for year of return. Sydney Children's Hospital Network was excluded from community analysis due to insufficient numbers.

ORs and 95% confidence intervals (CIs) are shown in the following table. OR represents the change in likelihood of an excellent or very good overall experience for each additional year since 2016-16. An OR of 1 represents no change. If 95% CIs overlap 1, then OR is not significant. For example, Central Coast OR of 1.10 represents a 10% increase in the odds of an excellent or very good experience each year after adjusting for consumer and care differences. However, the confidence interval (0.91-1.33) shows that this is not statistically significant.

	 Community			 Hospital		
	N	OR	(95% CI) *	N	OR	(95% CI) *
CCLHD	900	1.10	(0.91 - 1.33)	1,939	1.11	(0.91 - 1.37)
FWLHD	154	0.83	(0.78 - 0.90) ***	316	1.35	(1.18 - 1.55) ***
HNELHD	1,995	0.89	(0.74 - 1.08)	4,325	0.88	(0.77 - 1.02)
ISLHD	621	0.79	(0.58 - 1.06)	2,192	1.12	(0.94 - 1.34)
JHLHD	769	0.80	(0.51 - 1.24)	517	1.16	(0.96 - 1.39)
MLHD	614	1.28	(0.97 - 1.68)	1,180	0.91	(0.77 - 1.07)
MNCLHD	542	1.22	(0.87 - 1.69)	2,161	1.17	(1.14 - 1.21) ***
NBMLHD	901	1.15	(0.76 - 1.75)	604	0.78	(0.58 - 1.05)
NNSWLHD	226	1.44	(0.78 - 2.63)	749	1.09	(0.87 - 1.38)
NSLHD	2,621	1.04	(0.89 - 1.23)	6,236	1.05	(0.94 - 1.17)
SCHN				211	1.24	(0.79 - 1.94)
SESLHD	1,298	1.06	(0.83 - 1.34)	2,896	1.15	(1.02 - 1.30) *
SLHD	1,952	1.19	(0.90 - 1.58)	3,010	1.02	(0.92 - 1.12)
SVHN	151	1.31	(0.72 - 2.39)	1,541	1.21	(1.05 - 1.40) *
SNSWLHD	994	1.24	(1.04 - 1.48) *	1,872	1.09	(1.03 - 1.16) **
SWSLHD	361	1.09	(0.66 - 1.82)	1,300	1.19	(1.01 - 1.40) *
WNSWLHD	750	1.60	(1.08 - 2.36) *	3,484	1.02	(0.89 - 1.17)
WSLHD	2,725	1.07	(0.83 - 1.36)	3,691	1.07	(0.84 - 1.36)

Note p * < 0.05, ** < 0.005, *** < 0.0005

Comparison of subgroups

For subgroup comparisons, multivariate logistic regression was conducted using Overall Experience Excellent or Very Good (Yes/No) as the binary dependent variable. Records from 2017-18 with a valid Experience Index score and valid setting (hospital or community) were included. A survey design was used, stratifying data by service. Gender, indigenous status, age group, duration of contact, legal status and assistance were included as independent categorical variables. Missing or invalid answers were included as a separate category rather than excluded. There was no testing or adjustment for multi-collinearity.

	Community				Hospital			
	Valid N	Excellent or Very Good %	Odds Ratio	95% Confidence Interval	Valid N	Excellent or Very Good %	Odds Ratio	95% Confidence Interval
GENDER								
Female	3,714	84%	1.00		6,667	68%	1.00	
Male	3,500	72%	0.56	(0.30 - 1.06)	6,870	70%	0.66	(0.38 - 1.13)
Other	51	78%	0.62	(0.30 - 1.29)	111	45%	1.03	(0.88 - 1.22)
Missing or invalid answer	258	77%	0.34	(0.12 - 1.03)	925	68%	1.99	(1.35 - 2.94)**
ABORIGINAL AND/OR TORRES STRAIT ISLANDER STATUS								
Not Aboriginal and/or Torres Strait Islander	6,547	79%	1.00		11,979	69%	1.00	
Aboriginal and/or Torres Strait Islander	597	73%	0.79	(0.52 - 1.19)	1,412	68%	0.75	(0.61 - 0.92)*
Missing or invalid answer	379	73%	0.69	(0.51 - 0.93)*	1,182	66%	0.82	(0.65 - 1.04)
AGE GROUP								
Under 18	857	89%	2.69	(1.50 - 4.83)**	1,145	66%	0.96	(0.85 - 1.09)
18 - 24	723	83%	1.79	(1.31 - 2.45)**	2,014	69%	0.86	(0.77 - 0.95)**
25 - 34	1,129	70%	0.92	(0.70 - 1.21)	2,878	66%	1.01	(0.90 - 1.14)
35 - 44	1,187	73%	1.00		2,663	70%	1.00	
45 - 54	1,305	75%	1.12	(0.86 - 1.47)	2,488	69%	1.07	(0.91 - 1.25)
55 - 64	784	80%	1.35	(0.94 - 1.95)	1,275	71%	1.40	(1.09 - 1.80)*
65 and over	1,141	82%	1.44	(0.87 - 2.38)	975	76%	1.10	(0.82 - 1.47)
Missing or invalid answer	397	76%	1.48	(0.94 - 2.34)	1,135	67%	1.16	(1.06 - 1.27)**
CONTACT DURATION								
Less than 24 hours	244	57%	0.41	(0.27 - 0.62)***	802	71%	1.18	(0.97 - 1.42)
1 day - 2 wks	500	80%	1.03	(0.61 - 1.73)	6,817	72%	0.94	(0.79 - 1.11)
3 - 4 wks	611	81%	1.11	(0.73 - 1.66)	2,377	67%	0.85	(0.66 - 1.09)
1 - 3 months	1,141	81%	1.00		1,722	68%	1.00	
4 - 6 months	862	81%	1.08	(0.85 - 1.37)	479	64%	0.69	(0.53 - 0.90)*
More than 6 months	3,645	77%	0.94	(0.67 - 1.32)	1,021	59%	0.57	(0.51 - 0.64)***
Missing or invalid answer	520	75%	0.91	(0.66 - 1.24)	1,355	66%	1.16	(0.90 - 1.51)
LEGAL STATUS								
Voluntary	4,494	83%	1.00		5,873	76%	1.00	
Involuntary	1,199	71%	0.57	(0.43 - 0.77)***	4,908	63%	0.61	(0.54 - 0.69)***
Not Sure	1,253	70%	0.47	(0.34 - 0.67)***	2,212	64%	0.67	(0.56 - 0.80)***
Missing or invalid answer	577	74%	0.59	(0.47 - 0.74)***	1,580	67%	1.20	(0.91 - 1.57)
ASSISTANCE COMPLETING								
No assistance	5,781	78%	1.00		11,976	69%	1.00	
Family/friend	608	82%	1.22	(0.73 - 2.06)	500	73%	1.10	(0.64 - 1.91)
Staff	344	82%	0.75	(0.47 - 1.20)	722	72%	1.25	(1.01 - 1.55)*
Peer worker	215	73%	1.10	(0.76 - 1.61)	102	68%	0.25	(0.10 - 0.62)**
Interpreter	87	83%	1.36	(0.56 - 3.31)	17		0.91	(0.57 - 1.43)
Other assistance	88	70%	0.81	(0.52 - 1.26)	97	65%	0.85	(0.69 - 1.06)
Missing or invalid answer	400	72%	0.71	(0.51 - 0.98)*	1,159	67%	2.80	(2.25 - 3.47)***

Languages

Languages were identified using (i) answers to Q36, Language spoken at home, and (ii) whether a translated YES version was used. Any language identified was included, whether spoken alone or in addition to English. Text entries on language spoken were screened for misspellings. Some improbable responses (e.g. Latin, Esperanto) were deleted and counted as English only.

Languages were grouped according to the ABS Australian Standard Classification of Languages³. All years of YES data were included. Scores were calculated for YES returns with sufficient questions completed, using the same definitions as in other analyses. Languages were analysed individually if they had at least 30 valid YES returns for at least one setting (hospital or community). All other languages were grouped into an 'Other' category within their region.

For community and hospital settings, the percent of persons with an overall Experience Index score in the excellent or very good range was calculated, and targets for each setting applied as for other analyses in this report. It was not possible to combine inpatient and community for many languages, because there were insufficient community responses. A logistic regression model was constructed using overall excellent or very good score as the binary dependent variable, and examining the effect of language group after controlling for age, sex, setting (hospital or community) and LHD/SHN. Confidence intervals were adjusted by stratification for individual unit or team. Odds ratios were calculated using English as the reference group.

³ <http://www.abs.gov.au/AUSSTATS/abs@nsw/DetailsPage/1267.02016?OpenDocument>



		Community	Hospital	Overall
English		15,186	33,482	48,668
Language Not Specified		1,204	3,206	4,410
Australia	Auslan	6	19	25
	Aboriginal languages	1	3	4
South Pacific	Other	23	59	82
	Maori	10	33	43
	Samoan	9	31	40
South East Asia	Vietnamese	96	116	212
	Other	39	66	105
	Tagalog	34	58	92
	Thai	18	36	54
	Indonesian	9	38	47
East Asia	Chinese	139	188	327
	Cantonese	134	191	325
	Mandarin	100	157	257
	Korean	45	99	144
	Other	25	40	65
Southern Asia	Hindi	36	76	112
	Farsi	42	52	94
	Other	30	58	88
	Bengali	35	52	87
	Tamil	19	42	61
	Nepali	15	36	51
	Punjabi	8	31	39
South/Central Asia	Arabic	206	218	424
	Other	66	78	144
	Turkish	62	56	118
	Persian	17	34	51
Southern Europe	Spanish	98	161	259
	Greek	71	146	217
	Italian	94	122	216
	French	25	76	101
	Portuguese	11	52	63
	Other	16	41	57
Eastern Europe	Croatian	73	50	123
	Other	37	72	109
	German	25	66	91
	Serbian	20	60	80
	Polish	24	51	75
	Russian	25	46	71
	Macedonian	17	50	67
Northern Europe	Other	4	35	39
Africa		34	55	89
Americas		-	3	3
Total	TOTAL	18,188	39,641	57,829

Languages included in 'other' categories

Languages are grouped according to the Australian Bureau of Statistics standard classification of languages. Individual languages with fewer than 30 valid returns in at least one setting were grouped as "Other" within their region.

Counts of individual languages are not shown when less than 5.

Languages in "Other" groupings		Returns
SOUTH PACIFIC:	Tongan	44
	Fijian	24
	Cook islander, Bislama, Creoles, Niuean, Pidgin Tokelau	≤5 each
SOUTH EAST ASIA:	Filipino	43
	Khmer	18
	Malay	9
	Burmese, Cambodian	8
	Bahasa, Hakka, Lao, Malagasy, Bisaya, Chakma, Chamic, Rohingya	≤5 each
EAST ASIA:	Japanese	47
	Manchu, Shaghainese, Teochew, Taiwanese, Hokkien, Mongolian, Nuer	≤5 each
SOUTHERN ASIA:	Urdu	35
	Sinhalese	20
	Malayalam	12
	Telugu	11
	Marathi, Oriya, Gujarati, Indian, Kannada, Tajori	≤5 each
SOUTH/CENTRAL ASIA:	Dari	42
	Armenian	36
	Assyrian	24
	Hebrew	12
	Kurdish	6
	Aramaic, Iranian, Lebanese, Chaldean, Egyptian, Pashto, Afghani, Syriac	≤5 each
SOUTHERN EUROPE:	Maltese	29
	Dutch	28
EASTERN EUROPE:	Hungarian	33
	Slovak	19
	Bosnian	13
	Romanian	12
	Yugoslav	10
	Czech	6
	Ukrainian, Albanian, Lithuanian, Slavic, Slovenian, Austrian, Chechen, Georgian	≤5 each
NORTHERN EUROPE:	Swedish	13
	Finnish	10
	Irish	6
	Norwegian, Celtic, Norse, Danish, Faroese	≤5 each
AFRICA:	Dinka	23
	Swahili	15
	Afrikaans	12
	Amharic	8
	Krio	7
	Somali, Shona, Tamashek, Tigrinya, Afrihili, Akan, Algerian, Grebo, Igbo, Kikuyu, Kinyarwanda, Lingala, Sengalese, Sudanese, Zulu	≤5 each



Free text analysis

Free text analysis was carried out using natural language processing techniques and statistical software programs. Methods used to explore free-text themes included;

Analysing the word frequency inverse to comment frequency

The term frequency inverse to the document frequency score (TF-IDF) is used in information retrieval and text mining. This analysis was performed using the qanteda package in R² and is calculated using two measures.

Normalised Term Frequency (TF) is the number of times a word appears in a comment divided by the total number of words in that comment.

Inverse Document Frequency (IDF) is a logarithm of the total number of comments divided by the number of comments where the specific term appears.

Exploring the expression of key words in context

This can be achieved through identifying the semantic overlap (hyponymy) between co-occurring words in the comments and ranking terms by the number of hyponyms.

A hyponym is a word or phrase whose semantic field is more specific than its hyponym and for which the word inherits meaning or semantic intent from another term in a hierarchical relationship.

To explore this, the natural language platform GATE was used to identify the 'head' nouns of each comment. Once identified these were mapped to co-occurring terms within each comment.

Where a hyponym word was identified, it was validated against a threshold and weighted against the head noun TF-IDF score. This created a new and augmented TF-IDF described as the Kyoto Domain Relevance Score which was used for ranking.

Analysing the co-occurrence of key words per comment

N-gram analysis provides an approximation of language by analysis of a sequence of words. A unique aspect of this type of analysis is a focus on the relationship between words in sequence rather than the statistical frequency of their occurrence.

A bigram model algorithm was run on the text using the n gram statistical package in R6. The results were then plotted as a node diagram using the GGplot package in R7.

Analysing the sentiment that the comments expressed

Sentiment analysis or opinion mining is a classification process aimed at determining peoples opinions, attitudes and emotions towards an entity. Sentiment analysis was performed using the tidy text package in R9. A subset of consumer comments corresponding to question 26 (overall experience) scores of 'excellent' and 'poor' were validated against two sentiment lexicons and the total of individual terms scored.

Measuring the structural and language features of comments

Measures of lexical diversity attempt to benchmark the complexity of text by considering the ratio or spread of word use. A common measure is the type token ratio. This is calculated by dividing the types (total number of different words) by its tokens (total number of words). These were calculated using the Qantedea and Lexdiv function package in R.

In the comments little difference was found for lexical diversity in responses completed by people who indicated that they speak a language other than English .

A readability index is an estimation of how difficult a text is to read. The estimation is made by measuring a text's complexity by looking at attributes such as word lengths, sentence lengths and syllable counts.

Skip gram probability

Skip grams are a technique where n-grams are formed but in addition to considering adjacent sequences of words, the associated words within a defined window around a chosen text is analysed. This allows words or tokens to be 'skipped'.

Skip gram probabilities were derived from the comments by first calculating the raw term frequency (how often we see each word occur). This was performed using the dplyr package in R13, which converted all comments to a single column containing every word (4.5 million entries). To calculate the skip gram probability, a fixed size moving window of 10 words was defined around each chosen word (for example 'activity'). The probability of the chosen word being associated with other words (in the defined window) was then weighted against the probability of each word occurring on its own.

Appendix 3 - YES Domains

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

Overall Experience Score (100*Average of validly completed questions 1-22)/5

Note: Question 22 was removed from the domain structure however continues to contribute to the overall score



