

Care Opinion Australia

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Amplifying the Consumer Voice in the Mental Health Sector

*Submission to the
Mental Health Select Committee's
Inquiry into the opportunities to improve mental
health outcomes for Queenslanders*

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EXECUTIVE SUMMARY

CARE OPINION AUSTRALIA IS A A NOT-FOR-PROFIT PUBLIC ONLINE FEEDBACK PLATFORM PROVIDING AUTHENTIC INSIGHT INTO CARE PROVISION AND ITS IMMEDIATE IMPACT UPON THE CONSUMER.

Now in our tenth year, Care Opinion Australia has partnered with a range of community care and health services across Australia.

As those with mental health illness, problematic substance use and suicidality continue to experience stigma in the community, it is imperative that they are given the opportunity to have their voices heard and responded to, whilst maintaining their anonymity.

This submission addresses the limitations of traditional feedback mechanisms and highlights the absence of consumer voices in service improvement.

In this submission, Care Opinion Australia addresses Terms of Reference 1 (d), (e), (f) and (g) and makes the following four (4) recommendations:

1. Queensland Health adopts a transparent, system-wide, online public **feedback** mechanism. This consumer led platform will enable services to directly hear about the lived experience of service users, their families and carers.
2. Queensland Health adopts a transparent, system-wide, online public **response** mechanism. This process will equip services with the ability to individually investigate and respond to the needs of those at greater risk of poor mental health.
3. Queensland Health utilises the feedback received, to guide consumer-centric service reform. It is expected this will lead to better service outcomes and workplace improvement.
4. Queensland Health and its commissioned services adopt a transparent online public feedback system, such as Care Opinion Australia, to determine a subscription model that best suits the mental health sector.

CARE OPINION AUSTRALIA

Care Opinion Australia (COA) is a not-for-profit organisation that facilitates transparent, independent and two-way communication via an online public platform. COA allows consumers (patients, service users, clients, carers, family members) to share holistic stories (accounts) of their experiences with health, aged and social care service providers without reserve or the confines of survey boxes.

These stories are lived experiences that are being told in order to recognise the exceptional care that was received and/or to highlight the need for change.

COA is committed to supporting subscribers to achieve their mission of facilitating connection and conversations between consumers and service providers. COA enables people to share their experiences of health and care in ways which are safe, simple and leads to change. COA moderates each story to ensure anonymity is maintained, services are protected, and consumers remain safe through the two-way dialogue in the public domain. Anonymity is particularly crucial, in terms of safety, for those at risk of, or experiencing, mental health concerns.

Within health and care services, anonymous feedback is often received, however this anonymity prevents responses. A third party managing the process allows services to respond to the feedback whilst maintaining the storytellers' anonymity.

RECOMMENDATION TO TERMS OF REFERENCE

1. Queensland Health adopts a transparent, system-wide, online public **feedback** mechanism. This consumer led platform will enable services to directly hear of the lived experience from service users, their families and carers.
2. Queensland Health adopts a transparent, system-wide, online public **response** mechanism. This process will equip services with the ability to individually investigate and respond to the needs of those at greater risk of poor mental health.
3. Queensland Health utilises the feedback received, to guide consumer-centric service reform. It is expected this will lead to better service outcomes and workplace improvement.
4. Queensland Health and its commissioned services adopt a transparent online public feedback system, such as, Care Opinion Australia to determine a subscription model that best suits the mental health sector.

(d). The experience and leadership of people with lived experience of mental illness, problematic substance use and suicidality and their families and carers.

The voices of people with lived experience of mental illness, problematic substance use and suicidality are critical in amplifying the consumer voice, be they patient, parent, relative, carer or friend.

COA provides a platform through which the voices of those with lived experience of care provided in health, hospital, aged and community services can be heard. When stories (accounts of a care experience) are told on COA, they influence:

- service improvements and/or policy change
- increase of staff morale (where the experience was positive)
- refocus of organisational culture from organisation-centric to person-centric care.

To date, COA has published 151 stories related to mental health experiences in Queensland. They have been viewed a total of 109,334 times.

When services are subscribed to COA, staff will receive alerts to the stories as they are published on the platform about that service. This real-time feedback benefits the service provider who can influence timely and meaningful change at the service-level based on current patient experiences.

The transparency of the feedback offers multiple advantages:

1. The service can communicate its commitment to learn from storytellers' lived experiences to the consumer and the broader public
2. The service is held accountable to its commitment to learn from consumers' lived experiences, and for the care it provides
3. Members of the public can better understand services' willingness to welcome and act on the consumer voice.

The below excerpts of stories told on the site, demonstrate the qualitative data collected, with detail that is often only revealed in safety and quality, complaints and/or Executive-level discussions.

Story 1 | [Hospital care and mental health](#)

I was admitted to Dysart Hospital because of suicidal ideation... I saw the doctor once for a few minutes the whole time I stayed, almost a full day. The doctor asked me how I was feeling and then didn't wait for the answer. **The doctor gave me back all my meds, including the old meds I'd brought along to show the staff... the ones I'd said I was thinking of overdosing on...** I felt disorientated, like a number, weak, powerless, unconsidered and uncared for.

Story 2 | [Eating disorder \(lack of\) treatment](#)

I believe the treatment they received was a combination of lack of training around eating disorders and stereotypes around what a person with an eating disorder looks like... Additionally, although they had postural tachycardia and blood pressure drops, and they were told on admission they would not be able to walk to the toilet or stand in the shower, they regularly walked to the toilet in front of the nurses I believe. They were able to self-harm despite being in a high vis bed. I'm deeply disappointed with the actions of Ipswich Hospital and the inappropriate treatment has caused distress for myself and my partner, and **caused my partner to feel as though seeking help was the wrong thing to do.**

Story 3 | [Lack of adolescent mental health support](#)

We took our teenage child to the ED due to self-harm. Our child has a history of depression and anxiety. We got there around night time and was not seen by a Doctor until early hours of the next morning in the Short Stay Unit. The Doctor who eventually saw us and treated the wound was exceptional. Extremely kind, compassionate and caring.

The extremely disappointing and concerning problem is that they were the only one to see our child. Not one person from the Acute Care Team or anyone from the Mental Health Team came and saw us... not one. **We were told that because the Acute Care Team classed it as an act of deliberate self-harm, that they wouldn't help us! I believe self-harming**

comes under mental illness and here was the Acute Mental Health Team telling us they wouldn't help because it was deliberate.

Currently, no public mental health services in Queensland subscribe to Care Opinion Australia, and they remain reliant on traditional feedback mechanisms that lack transparency, do not include public accountability, and are typically organisation-centric. This limits services' abilities to engage with consumers about what matters most to them. This is particularly pertinent when consumers prefer the protection of anonymity and are thus limited in their ability to contribute their experience through meaningful two-way narratives.

Lives Lived Well is a not-for-profit provider of support services for people experiencing problematic alcohol and other drug (AOD) use or mental health concerns in Queensland and New South Wales. Since partnering with COA in 2015, Lives Lived Well embedded the use of the platform into their governance systems. This has resulted in hundreds of stories being shared on the platform, enabling consumers' lived experiences to inform quality assurance and service improvements.

The below excerpt from a response to [one consumer's story](#) highlights how the lived experience can be used.

"... you have raised some significant concerns and due to their nature, we are treating your comments as a serious complaint and are investigating the concerns and circumstances you have outlined.

Since receiving your Care Opinion feedback, we have explored the matters you have raised and have identified areas where our service did not meet our standards.

Whilst we cannot change what happened for you, we have addressed these areas with the staff involved and commit to making necessary changes so that this does not happen to another resident."

The stories told about the services provided by Lives Lived Well on the Care Opinion platform, describe the challenging journey experienced by consumers on their recovery.

The voices of these consumers with lived experience have been used to inform service design and improvement, and when positive, used as evidence of the service's value to its consumers.

This is encouraging for the morale of Lives Lived Well's staff as 90 percent of stories submitted by consumers described and rated their experience as purely positive. They include experiences from regional, rural, and residential settings, demonstrating the adoption of the platform regardless of literacy and access to the Internet.

Recommendation 1: Queensland Health adopts a transparent, system-wide, online public **feedback** mechanism. This consumer-led platform will enable services to directly hear of the lived experience from service users, their families and carers (in near-real time).

(e). The mental health needs of people at greater risk of poor mental health.

Care Opinion Australia continues to collaborate and partner with consumer representative bodies and patient experience leaders around the country and the voices of people with poor mental health are heard through these channels.

COA's National Advisory Group met in November 2021 and discussed the impact COVID19 has had on family centred-care, patient engagement and consumer partnering activities, including:

- System failures in not considering volunteers as part of the essential workforce, thus excluding volunteers from an onsite presence during COVID19 restrictions
- The impacts of limitations around the visiting of those in short-term and long-term care
- Communication with families and carers when they cannot be physically onsite, including:
 - videoconferencing and telehealth contact with medical staff
 - family participation in shared decision-making
 - the ability of families to identify and escalate issues they observe about the care provided.

The pandemic also limited the efficacy of traditional feedback mechanisms that are significantly dependent on face-to-face contact, such as volunteers to solicit feedback through surveys. Infection control practices have also limited the presence of hard-copy feedback forms and information materials. COA's subscriber-base across Western Australia, New South Wales and Victoria all reported a significant drop in feedback received via traditional feedback mechanisms when the pandemic required services to implement contactless methods of collecting feedback.

Traditional feedback mechanisms, such as surveys, tick-boxes and the categorisation of feedback as either compliment, complaint or suggestion are organisation-centric approaches that have been developed for input into databases. They are not person-centric that allow for consumers to share holistic feedback that covers an entire experience. Having a narrative-based, moderated platform such as COA, enables the consumer to be more in control of what and how they share their lived experience of care.

The below excerpts from stories demonstrate occasions where a consumer may find it difficult to express their experience in a number from one (1) strongly agree to five (5) strongly disagree with any meaningful context.

Story 1 | [Poor level of care in a psych ward](#)

Overall, I feel the hospital did do some good things and some nurses and staff were really helpful however, in my opinion, the level of care was not where it should be. And because this is a psychiatric hospital for young people, I believe the level of care was not enough.

Story 2 | [Not being supported when in need](#)

The first PSA was happy to bring the patient down. However, I believe the second PSA was not happy with this as the first PSA knew the patient outside of work. At shift handover the afternoon nurse said that it would be unfair to the other patients for the first PSA to accompany my friend out however, upon waiting outside the hospital, I saw many patients out for a smoke and others coming down to collect belongings from people outside.

I was informed that the second PSA would come to the concierge desk where I was waiting to collect these things however, I never saw them before I believe they reported back to the ward that I was not at the concierge desk. The other PSA was kind enough to actually come to the concierge desk to collect these things and they were in tears, due, I believe, to the way in which the second PSA had spoken to them all day.

Transparent and free-form narratives about care experiences between consumers and service providers can be used to identify the mental health needs of people at greater risk of poor health.

Not being reliant on surveys allows the feedback to be submitted when it suits the patient. Asking patients about feedback at the point of care is not always appropriate, such as when an experience has been traumatic or there are complex discharge instructions to consider. The inclusion of education material about how to leave a story of their care experience with discharge information enables patients to consider giving the feedback when they are ready, and on their terms.

It is equally critical for consumer representative bodies and public interest bodies to access story data that can be collated, analysed, reported on and shared to expediate learning across a broader level.

Recommendation 2: Queensland Health adopts a transparent, system-wide, online public response mechanism. This process will equip services with the ability to individually investigate and respond to the needs of those at greater risk of poor mental health.

(f). How investment by the Queensland Government and other levels of government can enhance outcomes for Queenslanders requiring mental health treatment and support.

The Care Opinion Australia platform enables stories (accounts of consumers' experience(s) of care) to be told anonymously, and moderated by a professional team, enabling consumers and staff to remain safe in the storytelling process.

Health services subscribed to COA encourage their consumers to tell their story on the platform which they then respond to online. The experienced team of moderators facilitate closed but transparent online conversations between consumers and service providers; conversations that constructively share what went well, what could be improved upon, and how their feedback is being used for change.

This format of feedback is distinctly different from traditional feedback mechanisms because:

- The conversation between consumers and service provider is more relational than transactional.
- The responder is ideally close to where the care was provided and will respond specifically to the concerns raised by the consumer.
- Consumers may hear back from more than one person, including Executive staff.
- The dialogical nature of the platform allows for the loop to be closed on the feedback.

The below excerpts are from a single story published on the COA platform that resulted in a change being made. This change not only benefited the storyteller's child, but enhanced outcomes for all young people admitted for the treatment of an eating disorder to this Ward.

Story 1 | [Mirrors in the bathroom](#)

Story excerpt: My adolescent has been an inpatient on 4A multiple times, and also in another hospital. On my child's first admission to 4A, I was so shocked and confused as to the size and location of the mirror directly opposite the shower.

I feel that anyone with any clue about eating disorders would know how extremely inappropriate this is. In my opinion, any other child or adolescent that uses the bathroom does not need a mirror of that size, especially not opposite the shower. When showering

(naked naturally), I believe the patient is able to stare and glare and focus on every part of their body.

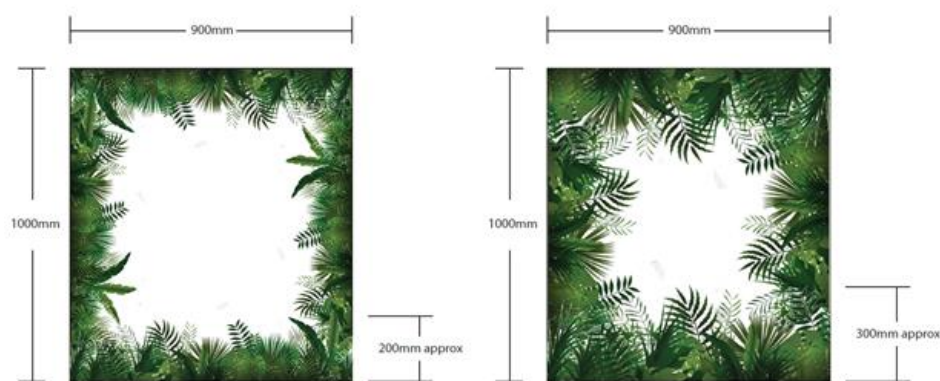
Service response excerpt 1: *I understand how confronting mirrors can be for patients with eating disorders and body dysmorphia and very much appreciate your feedback. I am happy to advise that we are currently organising for decorative decals to be placed around the mirror to reduce the size of the reflective screen and this should occur at beginning of March 2020.*

Author response excerpt: Thank you for listening. I am so grateful that I have been heard. So many of us parents now feel hopeful that we have a voice.

Can I ask that you pretty please involve Kara, the ED nurses on the ward, the Psychologists and Drs and Desley from the EDC with your decisions about the stickers and how much of the mirror to leave?

Response excerpt 2: *Following previous feedback received through Patient Opinion [now Care Opinion Australia] we had arranged for a border decal to be fitted onto the mirrors to reduce the size of the reflective screen. Before applying the decal, we have consulted with a number of families and staff and due to further feedback, we have reviewed the decal size again and have updated the design and artwork to include a much larger design which will be 300mm x 300mm around the whole mirror – all the effect of this can be seen on the attached design drawing. [See figure 1].*

Figure 1: Image of a service improvement made related to a story told



Author response excerpt 2: This is so brilliant. I am so happy. I think this idea is fabulous. Thank you for listening and taking this seriously. It will make a big difference. Yay:)

In 2015, the Western Australia Department of Health mandated the use of the Care Opinion Australia platform for all its public hospital services.

Figure 2 depicts a visual representation of the numbers of stories told, responses received, and changes planned or made related to the stories tagged with 'mental health' within **Western Australia**. The chart shows that across the 287 stories published, 368 responses were received. 8.3 per cent of these stories also resulted in a change being planned or made.

Figure 2: Visualisation report: How stories have been heard or responded to in WA

This report summarises **287** stories and **368** responses

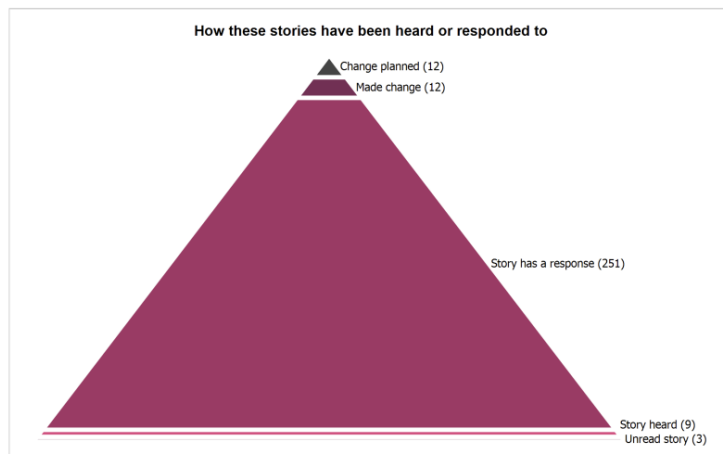
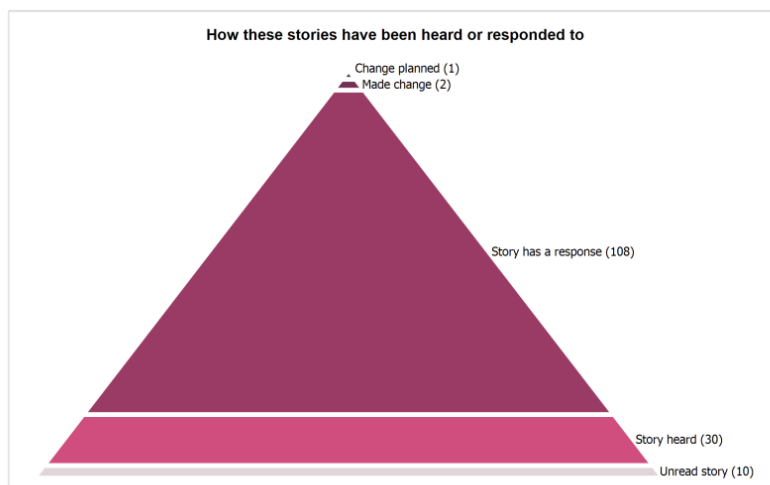


Figure 3 depicts visual representation of the numbers of stories told, responses received, and changes planned or made related to the stories tagged with 'mental health' within **Queensland**.

Figure 3: Visualisation report: How stories have been heard or responded to in QLD

This report summarises **151** stories and **118** responses



The data shows that with no government investment, financial or other, the response rate in Queensland is significantly reduced with few changes indicated (see Table 1).

Table 1: Comparative story data between Western Australia and Queensland

Data	Western Australia	Queensland
Stories told	287	151
Responses received	268	118
Changes planned	12	1
Changes made	12	2
Stories with no response or not read by the service	10	40

Care Opinion Australia not only allows feedback to be submitted online at a time that suits the consumer, but can also be submitted by patients, service users, friends, relatives, carers and advocates, along with volunteers and staff on behalf of patients/consumers.

Carers' voices are easily missed when requests for feedback are made directly to the person receiving the care. Yet their role as carer is also blended with that of advocate; particularly when the patient is too young or unable to articulate the experience for themselves. This platform enables issues around these processes to be highlighted and better outcomes to be collaboratively developed.

Facilitating the voices of others impacted by a care experience through a feedback mechanism that is not dependent on face-to-face contact, enables continuous communication from and about those who are most vulnerable in the community.

This information is vital for services and their staff to understand the expectations of the community to better meet clinical needs, improve service delivery aspects and respond to those sharing their story, hearing their voice and validating their perspectives drawn from lived experience.

Recommendation 3: Queensland Health utilises the feedback received, to guide consumer-centric service reform. It is expected this will lead to better service outcomes and workplace improvement

(g). Service safety and quality, workforce improvement and digital capability.

The Care Opinion Australia platform has a comprehensive reporting functionality that can be used to measure the efficacy of the process that the health service organisation uses for encouraging consumer feedback against predetermined performance measures, particularly around service safety and quality.

Each published story is assigned a rating based on how critical it is of the service provider, rating from zero (0), being purely positive, to five (5), being severely critical. These ratings influence the publication process, with publication delayed when stories are rated as a four (4) or five (5). This enables services to collaborate with colleagues and the Executive before developing a considered response to be published concurrently with the more serious story.

Reports that can be drawn from story data include:

- quantitative data
 - story and response numbers
 - stories that have led to a change being planned or made
 - services with ratings (see Figure 4)
- qualitative data
 - story content
 - stories broken down by criticality rating (see Figure 5)
 - response quality
- visualisations (drawn from polarised tags added to the story by the consumer and Care Opinion Australia)
 - tag bubbles (popular tags shown as ‘bubbles’ according to what was good and what could be improved) (see Figure 6)
 - story swarm (how stories are spread over time, showing patterns (including criticality ratings)
 - sunburst (how stories progress from being read, responded to, and leading to change where appropriate)
 - tag clouds (most-used tags according to what was good, what could be improved and how the storyteller felt).

Figure 4: Services with ratings report

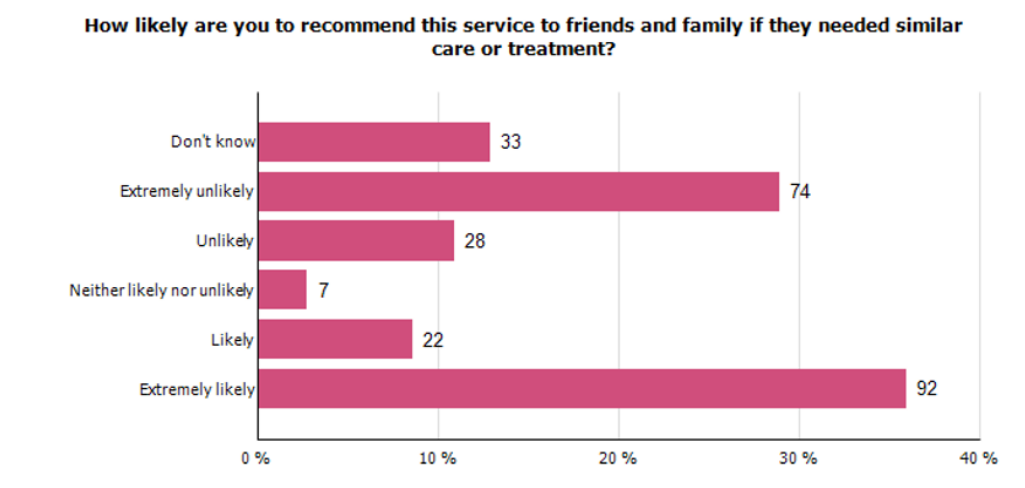


Figure 5: Criticality rating breakdown report

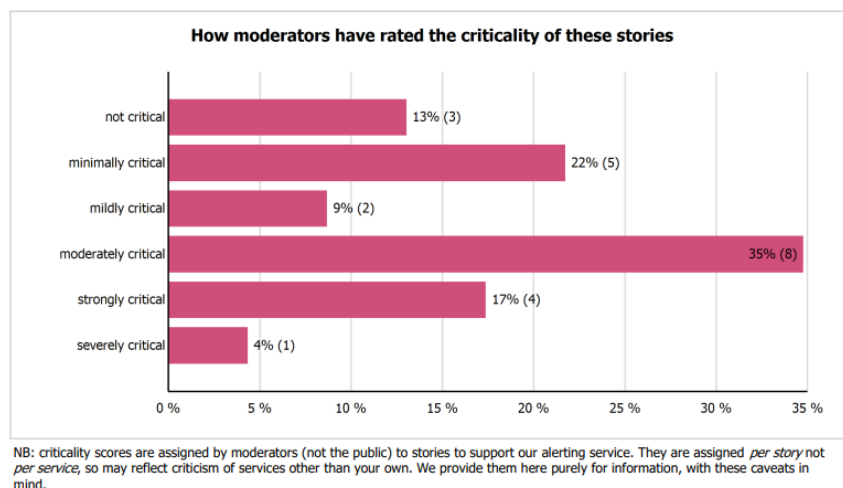
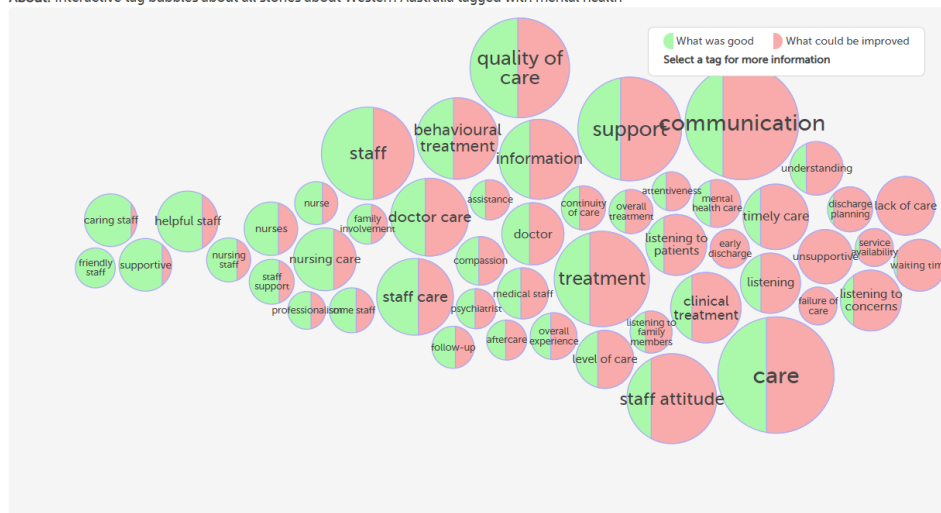


Figure 6: Tag bubble for stories across WA

About: Interactive tag bubbles about all stories about Western Australia tagged with mental health



Care Opinion Australia recognises that the care relationship and environment is different in the mental health setting to other sectors, and that patient reflections of their experience can be distorted under some circumstances, including but not limited to:

- heightened emotions
- comorbidities
- cognitive impairment
- involuntary admission to a mental health service under the Mental Health Act 2016

There are some circumstances in which stories cannot be published on the Care Opinion Australia platform, including:

- if the story raises issues of current abuse or gross negligence
- if the moderators suspect the account is untruthful
- where the story is subject to current legal action
- where the story may negatively impact a very vulnerable person.

Care Opinion Australia identifies the need to amplify the consumer voice in the mental health sector.

Recommendation 4: Queensland Health and its commissioned services adopt a transparent online public feedback system, such as, Care Opinion Australia, to determine a subscription model that best suits the mental health sector.

CONTACT

Please direct any questions regarding this submission to **Assoc. Professor Michael Greco**, Founder and Chief Executive.

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