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Australian Commission on Safety and Quality in Health Care Consultation:

Submitted via Email to:

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our 'friends' include more than 12,000 people with lived experience of mental health concerns across Australia. This includes lived experiences with all parts of the mental health care system, NDIS, psychosocial disability support outside the NDIS, PHN commissioned services, public and private service options, and service provision across urban, regional, rural and remote Australia. All members of our Board and staff have mental health lived experience as either a consumer, family/carer/kin/supporter, or both.

Lived Experience is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities. We advocate for effective policies and systemic change to improve mental health care and psychosocial disability support services and support across the lifespan, across the Australian health and social care system, including within State and Territory jurisdictions.

We welcome the opportunity to provide our feedback to this consultation on the review of the National Safety and Quality Health Service Standards.

Background & Purpose of this Consultation

The Australian Commission on Safety and Quality in Health Care (the Commission) is updating the National Safety and Quality Health Service (NSQHS) Standards. The goal of this consultation is to inform the development of the third edition of the NSQHS Standards.

The NSQHC (2nd Edition, 2021) were developed by the Commission in collaboration with the Australian Government, states and territories, the private sector, clinical experts, patients and carers. The primary aims of the NSQHS Standards are:

- To protect the public from harm
- To improve the quality of health service provision.

They provide a quality assurance mechanism that tests whether relevant systems are in place to ensure that expected standards of safety and quality are met.
The eight NSQHS Standards in the 2021 2nd Edition are:

- Clinical governance
- Partnering with consumers
- Preventing and controlling infections
- Medication safety
- Comprehensive care
- Communicating for safety
- Blood management
- Recognising and responding to acute deterioration

The Consultation questions for this review are:

1. What existing and emerging safety and quality risks should the Commission be considering in the third edition?

2. How can the third edition have a greater impact on driving high performance?

3. How can the third edition support integration of services, within and across health services?

4. How can the third edition support a continuous learning approach and minimise a compliance mindset?

5. What needs to change in the current format and structure of the standards for the third edition to be easier to understand and act on?

6. Are there areas of duplication or redundancies that could be removed from the current standards?

7. Please provide any additional comments you think will assist the Commission with the development of the third edition of the NSQHS Standards.

Our Response

In preparing this submission, we brought together a large focus group of Lived Experience Australia 'friends' drawn from our national representative panel to discuss the review questions. The group focused particularly on the first three consultation questions. They identified several issues from their lived experience, and their de-identified comments are included here with their permission. We thank them for their contributions.

1. What existing and emerging safety and quality risks should the Commission be considering in the third edition?

The use of AI and how that relates to the person's confidentiality and safety, its potential positive and negative impacts of AI on mental health, and also how the current and future mental health workforce might use AI in their day-to-day practice. This included concern for cyber security of health information, more broadly.

There are things that just absolutely should not be outsourced. Where's the security and you know, governance around that? And then also being mindful of the impact that AI can have on people's overall mental health and well-being.

Where like people are having developing relationships with AI avatars and that's all very well and good if they're able to build a sense of connection and, you know, not experience isolation and loneliness. But AI avatars can be manipulated by the software system and can actually then cause harm or encourage the people who are dependent on them to engage in harmful activities. So, it's just trying to balance the role of AI within healthcare and also how patients are interacting with that to meet their healthcare needs and yeah, how healthcare's using AI to try and support patients or provide care to patients.

[Re concern about doctors using AI to help write their consultation notes and the argument that this would allow more time to spend with the person) *What I'm really concerned is it's taking away the*

humanity….and it's so easy for the specialists to stuff up if they relied totally on these AIs because they don't have the human features.
I think cyber security will be a really huge thing and healthcare information being leaked and I don't know what the standards; some kind of minimum set they can have around keeping healthcare information secure and safe.

Some people felt strongly that there need to be separate National Mental Health Standards, particularly in addressing the psychological safety of the Lived Experience (peer) workforce which is likely to grow in number into the future. We recognised that separate standards may not be an option; however, this does not dismiss there being a gap in the current standards in relation to the Lived Experience workforce.

We need separate standards for mental health - I actually think it needs to come back because we've got a very changing landscape and particularly a changing workforce and we know, I don't know that we've got the evidence around it, but there's been a lot of harm done to the lived experience workforce within the settings.

Current and future workforce pressures that impact achievement of the standards and may mean fundamentally changed structures to how services and care are delivered.

The extreme labour shortages in the healthcare sector and industry and the impact… I'm not sure what the Commission can do around protective industrial action. But yeah, the labour workforce shortages and ensuring that there's safe patient ratios and healthcare services actually adhering to the minimum rest periods, because you know there are staff who are just so overworked and stressed and having to pull double shifts because there's risk to patient safety because they're so short on staff. But ironically, you're putting, say, patients at risk by having overworked, stressed-out staff who are fatigued and more likely to make mistakes.

And unfortunately, in the mental healthcare space, you know in the acute units per se, there's nursing shortages as well. So you're getting nurses who may not be adequately qualified coming in to work in acute units and are more at risk of using restrictive practices or not using trauma informed care, so I think those nurse to patient ratios across all areas of healthcare, but especially in hospital settings are really critical, but workforce shortages are gonna be really a challenge in the healthcare space, not just mental health, but in general and adequately qualified staff who are actually able to do the job that they're in the casualised workforce… in Adelaide we've got a community rehab centre which you know more than half of the staff were agency staff. That does significant things for the proper operation of a place, let alone the quality of care.

Consideration of the linkages across non-clinical CMO and clinical services, and therefore the Standards for each, especially with the structures of some newer initiatives (such as Urgent Mental Health Centres, Medicare Mental Health Centres) not being as clearly one or the other, but a combination of both, due to the integration of the Lived Experience workforce and shifts in models of care arising from Lived Experience advocacy.

I've been on the end of an accreditation process for a community managed organisation. So it is incredibly complicated… bringing together of those two standards in the health sector is important, CMO and clinical services, because issues of stigma and discrimination always come up across both.

In some of these new services, they seem to start Ok with the promise of centring lived experience and having strong ratios of Lived Experience peer workers, but then I've watched it back-peddling to become all about risk assessment and clinical dominance.

A stronger focus and recognition by services and their workforces of diversity, health literacy and communication needs were emphasised. The revised standards need to acknowledge that this diversity increasingly applies to those who receive services and also those who deliver services.

During a recent hospital stay, they had a shortage of nursing staff and, as a result, my lunch was brought in and put on a tray that I couldn't actually even access, so I couldn't eat it. I'm wondering whether or not we need, you know, staff that deliver meals and things to actually make sure that the people can reach them, cut them up, eat them, those types of things…Similarly, it's no good giving someone a statement of rights without checking that they can read.

There need to be a clear way of guiding people with communication challenges, or people with intellectual disabilities and using health literacy at their level… using verbal communication and cues and pictorials also creating that friendly environment, the safe place and safe space to go to... there has to be some form of mandatory practice for all staff. (Note: Lived Experience Australia is involved in a project / 'Talking Scrubs' which involves co-design of pictorial icons for health professionals in acute and crisis care settings to wear on the scrubs/work uniforms to help communicate with and improve mental health assessment for people with communication needs who present in apparent distress.)

It's not just the people who are the recipients of services; it's actually the people delivering services -it's a very culturally diverse workforce out there, particularly in mental health care.

A stronger focus on feedback and complaints processes was emphasised as needed, and also how services demonstrate the actions they take to respond to adverse incidents and improve service delivery. Ryan's Rule was noted as a helpful process that people felt should be considered and consistently used in all jurisdictions.

The imbalance in power dynamics and the fact that sometimes there can be like an abuse of power within these kinds of settings and so obviously like having like a robust complaints process and like incident reporting that actually does something instead of it just sort of being parked or put away… there's been a lot of just organisations trying to like cover up or just dismissing incident reports or when people raise concerns. Things to make sure that there are timely processes, and governance around making sure that patients are safe, but also the safety of everyone involved in care.

When there's clinical incidents and there's reviewing them… this goes back to the volume of patients and harm and also staff shortages - a timely process for the clinical incident reviews… But then if you're not actually investigating, you know, your clinical incidents in a timely manner, then how are you actually going to learn and have more, you know, safety mechanisms and governance put in place?... the average coroner inquest is about five or six years after an event, which you know is just not on. We have one coroner in Queensland. Our coroner is in Brisbane, so what does that mean for the rest of the state too?

One other point around the clinical governance is that when patients and their families or carers want to raise concerns around care - Queensland, we have Ryan's rule - that escalation pathway.

Ryan's Rule - The Three Steps:

1. Talk to the nurse or doctor: Discuss your concerns about the patient's condition with the treating nurse or doctor.
2. Speak to the nurse in charge: If you are not satisfied with the response, ask to speak to the nurse in charge of the shift.
3. Call 13 Health (13 43 25 84): If your concerns remain unaddressed, call 13 Health to request a Ryan's Rule Clinical Review.

The group also thought that the reviewed standards could make more mention of the NDIS and its interface with healthcare services, given it is now well-established.

> *My son was in hospital and his NDIS workers weren't allowed to visit him in hospital and take him out of hospital. He was in a secure unit, but also what I found interesting and maybe this is something for the standards that like well he got the NDIS for when he was admitted to hospital and the hospital seems to have an NDIS liaison person.*

2. How can the third edition have a greater impact on driving high performance?
3. How can the third edition support integration of services, within and across health services?
4. How can the third edition support a continuous learning approach and minimise a compliance mindset?

We believe that inclusion, improved monitoring, and action on each of the above areas will contribute to driving high performance within health services. Several of the ideas below are relevant to more than one of the questions posed above. Therefore, we have not separated the responses.

The third edition should include human rights as underpinning the national standards.

> *The human rights issue as a core thing… the everyday skills really that should be just part of core good performance in practice.*
>
> *Embedding of human rights throughout the whole standards especially in mental health care, like locked wards are still very much a thing here in Queensland in mental health facilities. So, just I think more emphasis on human rights and, you know, throughout the whole Standards.*

This includes greater focus on First Nations and cultural diversity.

> *Promoting safety for Aboriginal and Torres Strait Islander communities… people from like CALD backgrounds. They're fundamental things. They're not optional, given the diversity of people that are actually using services.*

The third edition should consider the interface between CMO [NGO] and clinical services, given there has been more progress in how they collaborate to deliver services and communicate with each other.

> *Why is the public health sector not having stakeholder engagement with the NGO services because these people go through NGO services, then come to tertiary care as well. So, everyone's working in siloes.*

Ensure co-design is core to how services operate, and in how they review and develop all existing and new models of care to meet national standards.

> [Recounting a recent experience in a Lived Experience Advisory Group within a clinical service] *But the model of care, the executive director did the model of care and it's approved, didn't even go through us. So are we sitting here just ticking the box because we have to be here? We're just head counts… the model of care should be co-designed with us and you didn't do that. You did that with your staff and you put it through and you gave it the tick of approval. That model of care can control us severely. So where are the human rights in it? So, this is a safety issue.*

Improved standards for response to people with mental health challenges in Emergency Departments and crisis care are needed. Please also note reference to the integration of peer workers in these settings, and mental health services more broadly, could be more explicit in the revised standards.

> *Ramping's one thing, but people with mental health issues who do go to EDs and particularly in regional areas, that's probably the only choice they've got sort of after hours. There seems to be the triage that they end up on the bottom of the list because they're not considered to be life threatening. And so, the hospital doesn't kind of engage with them because the moment they engage with them, they have responsibility for actually managing their duty of care. So, they sit in the waiting room for hours and they can actually just get up and walk out. I'm not saying that we should actually try and keep them there, but I actually think we need - emotional pain is as bad as physical pain, and that person needs to actually speak and engage with someone much sooner. So, we need to see it as a priority rather than the last priority, and even if that is only going into an area, talking to a peer worker, having a cup of coffee, it needs to be moved through the system.*
>
> *Everything become a Code Black when the staff goes too hard to handle Code Black, which is terrible because now they're brought in Code Grey in children's hospitals because of the disabilities and the Code Grey became a part because the occupational therapist and the allied health said we can manage these cases well because we know what's going on, which has reduced a lot of stressful stuff. There's a culture of just running to code blacks. Code black means a threat. Code grey means a disturbed person.*

A focus on health workforce training is also essential, but it also needs to include a focus on how that training is demonstrated in practice.

> *Disabilities are a missing module for people that go on to work in clinical services. There are things that should be core things on that issue of education and ongoing professional development.*
>
> *I think it's not just training, but it's understanding the reason why these things are important and actually putting it into practice, because it's one thing to actually receive the training, but then if you don't do anything with the training, then it's practically useless. So, it's kind of like there should also be a bit of governance and team regulation in keeping each other accountable when you receive this kind of training and like maybe, staff debriefs. Like, you know, we did this training, how did you apply this in your work? Making sure that staff are trained properly.*
>
> *And I think that people need a refresher as well. I think that it can't just be like one training and that's it. I think there needs to be ongoing training available for staff because people forget things And it definitely shouldn't just be a one-off situation. It's like, tick that box.*

Consideration could be given to strengthening the standards in relation to care planning processes undertaken by health services.

I reckon the standards would have the ability to drive innovation by mandating safety plans for all patients who come in with a mental health diagnosis. And that safety planning needs to be done with a person with lived experience of suicide so that we could actually try to prevent and connect people to some self-support places.

I think the federal government is mandating that hospitals move to an electronic comprehensive care plan. Use of this electronic comprehensive care plan is something that needs to be addressed a bit more in the new standards.

The care plan - You're supposed to sit with the person and give it to them and print it off from the E comprehensive care plan. …how many of us have walked out of a hospital where, you know, the nurse will at the last minute give you their nurses discharge plan and then then you'll get the other copy of the actual doctor's plan and you're thinking, well, why are there 2 and why are they saying different things?

The group emphasised the need for the accreditation process to be strengthened, particularly how visits to and monitoring of services occurs.

I really struggle with the way that accreditation's done and they pull in a group of consumers and you're sitting there and you know that if you, if you say something bad, you're not gonna get a very good service next time, particularly in regional, rural areas. I wonder if you know it would be better to have an app where we could actually score our service and and those that don't get good scores come under some sort of, you know, investigation processes.

You know, a tour by the accreditors that would come out and do their tick boxes and talk to people; services would line up the right people for them to talk to and they'd all scurry for two or three months beforehand, getting all their ducks in a row…I think the SNAP accreditation is definitely a good start towards that so, you know, healthcare services don't have a lot of time to prepare and get their ducks in a row, so that means, you know, when the assessors are coming out… they're probably going to be more likely to see the reality of what you know it is.

I think the Commission probably needs to be more proactive in that they're doing like spot checks … actually walking into a health service waiting room and just being a fly on the wall and just seeing, you know, is there information here about patient safety? …And also getting actual healthcare service users to share their experiences…patients and carers reporting to the Commission about their experiences or even a review site or something where you can see how it's tracking and making that process more transparent. But I also think the Commission has a responsibility to be more actively engaging with the healthcare services… the Commission being kind of more on boots on the ground actually more regularly.

Communication within and between services must be improved in order to improve their performance, to ensure that people don't fall through gaps in systems due to poor communication, errors, and service siloes, as exemplified by the following examples.

One of the biggest issues with the transitions between health services, even when you're in the same kind of healthcare service or hospital, is that there's such a lack of communication and there's such an emphasis on the patient actually doing some kind of follow-up. So, a recent example I had is that I had to get emergency surgery about 8 weeks ago…. I presented to the hospital ED, triage category two was in surgery by 6 hours later…So it was great in that perspective….I don't know who, but I was just told that they were going to refer me to the XXX department of the hospital… I had my overnight stay in hospital,

was discharged the next day with a four-week phone call follow-up…that date came and my appointment was at something like 11:00 AM on a telehealth appointment phone call and by 4:00 PM I still hadn't had a call, tried to call, couldn't get through…then I tried to call on Monday. Still no one had called me…It's been four weeks since my appointment because I can't get through. Every time I try and call the surgery unit, I get to some appointment confirmation centre line and then I've waited on hold for an eternity and I've just given up. So, I've tried multiple time. And then like the kind of final crux in all this was that I received a letter in the mail saying that it's from the XXX department saying that they are unable to categorize me for the wait list because there's not enough information and it's a letter saying like, please ask your doctor and the doctor's name… I don't know who that is. So, it's obviously someone from the hospital who works in the hospital who referred me as a result of that ultrasound… I don't even know how to contact this person… You didn't do my referral properly… So, I've just thought I'm just gonna have to go to my GP and show the letter to my GP… he'll have my discharge summary, but he won't have the ultrasound. So it's just like, how can a system be so like, how can it be so dysfunctional?

My family member broke a bone in a fall late last year when we were away. We got back to here, saw the specialist. He was sitting next to the physio OT people at the next desk. He said 'Yes, you'll hear from someone to give you an appointment in two weeks' time for you to come back for the rehab. That was six months ago. We haven't heard from them yet.

But they never gave me the confidence that I can look after myself, that I can look after the baby. I can go home and I can live a normal life. At least something that seemed, you know, because I shouldn't use the word normal. But they never gave me the skills. They did it for me. So I felt safe. So after two weeks I go home. Now I feel I can't do this because I was never given those skills. Yeah, and no follow up. And that's why it's important for them when they're discharged, they have to find out what are the safety, who, how can this person, what can you know, where can they go, who can they connect with?... Once you're out of their field of vision, you don't exist.

The care I received in the ED [for an acute physical health need] was amazing. And the surgery team are amazing, like constantly checking. I had to check, say my name and date of birth about 5 million times throughout the whole process. That's good. That's patient safety being followed, asking me if I knew what I was actually getting surgery for. So, all those like compliance things like hand washing, everything within the ED experience. Communication was amazing. I just wish it was like that for mental health and then even my care overnight in the ward and then the discharge the next day. As soon as I've left the hospital, it's been with these appointments like that follow up appointment and then the specialist referral… it's been so inadequate… while I was in the hospital, it was great. I was being cared for and looked after. As soon as I was discharged, I'm like, not their problem.

As soon as they don't have governance over you, follow-up can be really, really hard. And that's one of the big challenges in the mental healthcare space. But even for people with long-term chronic, complex physical health conditions, once that governance shifts, and I think it's a real risk when your governance is shifting between healthcare departments and things like even within the health same healthcare service, but as soon as you go from one hospital to another needing to be transferred, who actually has that governance… they're all responsible and no one ends up being responsible.

How health services collect and respond to feedback by people who receive services needs to improve so that system performance also improves.

There's also the issue of the cycle and the feedback. You know what happens to feedback the whole process.

The use of the YES and the CES, the your experience of service survey and that carer version where some states do that like a census once a year… other states do it continuously and it's live. You can go on a website to have a look and see where it's tracking. And so, there's a bit of inconsistency even around some of those things.

I think with all the hospitals and the websites -there's that huge gap between the IT people who do the website, right? Not the people who actually own the content. And half the time the content needs updating. But it's so many hurdles to get through and yet in terms of communicating with …it's all out of date and really the staff know it's out of date. But it's just so, you know, half the time they're battling to get it updated. So, I mean, and that's a system thing, isn't it? …when they come in and do their quality audit or whatever for accreditation.

5. What needs to change in the current format and structure of the standards for the third edition to be easier to understand and act on?
6. Are there areas of duplication or redundancies that could be removed from the current standards?

The format and structure of the third edition of the standards could consider ways to condense and humanise the information. The group offered a number of suggestions.

I feel like having a document with easy read and plain language is essential. I'm not too sure if we already have something like that, just to improve accessibility so that consumers know what their rights are when accessing certain services, especially for those who have lower literacy levels. I think another thing is just seeing whether or not those are available in different languages as well, especially knowing that there could be language barriers from the CALD community.

Some of the action items in even the same standard read quite similarly… if you have these standards and then you have so many action items, how is a healthcare service realistically meant to perform amazingly at every single action item when there's so many? It's just not feasible and possible… condensing…I think it's always going to be a challenge and is it really doing its intended purpose if there's just yoo many action items. One thing that I would like to see is case examples or case studies… more of that actually embedded into each of the standards… really highlighting like real world examples of how this actually looks in practice.

I think making it more like real and making it have more substance to it from a real-world capacity or even like consumer / carer quotes or something to humanise it.

Video it and people could just watch it.

I'd like to see some training videos with consumers and carers in them that highlight what happens if those standards aren't followed, because it gives a human element. So, when someone goes to do something that's not within the standards that they have a thought about… it makes it real. The other thing I'm wondering is if they could use little icons for the repetitive things like management or organisation or just to make it a bit more visually appealing and perhaps even flow diagrams to sort of highlight, you know, which bit comes first in each of those sections.

7. Please provide any additional comments you think will assist the Commission with the development of the third edition of the NSQHS Standards.

In all of these systems, there's a lack of independent advocacy.

The strong view from the group we consulted was also that the standards should make explicit reference to family, carers and supporters, rather than this group being subsumed within the term 'consumer'.

> *I personally don't like that because I think that it's not going to be well understood and you're more at risk of siloing. And I think it places people who have those dual experiences or identify as having those dual experiences in a really tricky dynamic having to navigate that…I personally think it needs to be stipulated as consumers or patients, whatever the language is, parents slash carers, grandparents like, you know, at a bare minimum, consumers, carers.*
>
> *I think you're never going to reach a consensus on this, but I think there's too much risk just having it as consumers.*
>
> *I think it needs to be differentiated more because carers have different needs to the consumer…how do we encourage people to work together well and address those needs of carers if we don't actually highlight it within the document and if you swallow it up all into one, then how do we identify the different needs of both people? Because they're not the same. Yes, they're human factors, but they're different… And then it's hooked into the safety aspects where, you know, crazy silly stuff happens where you know people are discharged home and, you know, family are not even told or not even given a sense of, you know, things that arise that they were never even informed about, but which then impacted them too.*
>
> *It's a bit like safety planning when a person identifies their carer, but the carer may well not be up to it. They could be unwell. They don't know what they're committing to…Perhaps even the opposite where people who are inadvertently brought in and confidentiality and privacy is broken and so it works both ways.*

Contact

We thank you for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our Lived Experience perspectives to any future discussions about this important topic.

Your sincerely

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