Submission on the draft third edition of the National Safety and Quality Health Service Standards

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Attention: NSQHS Standards (third edition) - Consultation 2

Australian Commission on Safety and Quality in Health Care

Submitted by Emerge Australia

About Emerge Australia

Emerge Australia is the national patient organisation representing an estimated 600,000 people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), long COVID and related energy-limiting conditions. We provide information, support and education; work with clinicians and researchers; and advocate for health and disability systems that are safe, accessible and informed by lived experience.

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Executive summary

Emerge Australia welcomes the strengthened emphasis on person-centred practice, cultural safety, equity and care, free from bias, racism and discrimination in the initial draft of the National Safety and Quality Health Service (NSQHS) Standards.[1] These are essential foundations for high-quality care.

However, stigma is not explicitly named or addressed in the draft. Bias and discrimination describe important attitudes, decisions and conduct by workers and organisations. Health-related stigma is a social process through which people are labelled, stereotyped, devalued or treated differently because of a health condition. Individuals living with stigmatised health conditions often experience bias and discrimination, but stigma also captures the experience and response of the person receiving care: anticipating disbelief or poor treatment, concealing information, doubting their own experience, delaying care, disengaging after harm, or not returning to a service.

> Emerge Australia's central recommendation is that preventing, measuring and reducing health-related stigma be made an explicit, organisation-wide safety and quality responsibility across the Standards.

For people living with ME/CFS and long COVID, stigma is not abstract. Our communities repeatedly report being disbelieved, having symptoms minimised or psychologised, being labelled anxious, deconditioned or unmotivated, and receiving advice that does not account for post-exertional malaise (PEM), a worsening of symptoms and function following activity. The resulting harm can include delayed diagnosis, inappropriate or harmful care, deterioration, avoidance of healthcare, loss of trust and reluctance to disclose symptoms or previous experiences.

Recommendations

- Name health-related stigma in the overarching description of high-quality care and define it in the glossary, including enacted, anticipated, internalised and structural stigma and its relationship to bias and discrimination.
- Require boards and executives to identify, prevent, monitor and reduce stigma across interpersonal practice, organisational systems and structures.
- Require services to measure patient experiences of stigma, including anticipated stigma, non-disclosure, care avoidance and disengagement, and use the findings in risk management and quality improvement.
- Include stigma-informed practice in workforce capability, person-centred communication, clinical assessment, care planning and complaints systems.
- Co-design anti-stigma approaches with people and communities who experience stigma, including people with ME/CFS, long COVID and related poorly understood, contested, fluctuating and invisible conditions.

Why stigma must be explicit

Stigma is not interchangeable with bias or discrimination

The draft appropriately requires care and systems to be free from bias, racism and discrimination. Those concepts do not, on their own, cover the full stigma process. Stigma may be enacted through dismissive treatment or discriminatory decisions; anticipated when a person expects judgement or disbelief; and internalised when repeated negative messages lead a person to feel shame or doubt the legitimacy of their own illness.

A person may therefore avoid a service, withhold information or not return after a harmful encounter even when no current worker commits an observable discriminatory act. If the Standards only examine worker behaviour or completed episodes of care, this patient-level barrier can remain invisible.

Stigma changes access, disclosure and engagement

The consequences arise across the care journey. Fear of being judged can affect whether a person seeks care, what they disclose, whether they feel safe to question advice, and whether a trusting therapeutic relationship can be established. Previous stigma can also shape later encounters: a patient may minimise symptoms, avoid emergency care, decline referrals or disengage from the system because returning no longer feels safe.

These effects directly undermine the draft's aims for respectful and trusting relationships, shared decision-making, care for the whole person, equitable access, safe feedback systems and reduced unwarranted clinical variation. Addressing stigma is therefore an essential enabler of person-centred care and high-quality care.

Stigma is a systems and quality-of-care issue

A substantial evidence-base shows that health-related stigma impedes care-seeking and engagement, contributes to inequitable experiences of care and worsens health and social outcomes across a wide range of conditions. Cross-condition frameworks identify enacted, anticipated and internalised stigma, operating through interpersonal, organisational and structural processes. This supports treating stigma as a quality-of-care issue addressed through established safety and quality-improvement systems.[2]

Stigma is produced not only through individual attitudes but through policies, clinical pathways, documentation practices, service design, workforce education, resource allocation and organisational culture. For people with ME/CFS and long COVID, structural stigma can occur when services treat symptoms or disability as primarily psychological because the conditions lack a single definitive diagnostic test; fail to make reasonable adjustments for invisible or fluctuating disability; or impose attendance, assessment or rehabilitation requirements that are unsafe for people with PEM.

Because accreditation standards shape what services measure, report and improve, explicitly naming stigma would make visible what has historically been invisible, and ensure it is an accountable quality-improvement responsibility. It would also support the Standards' move beyond minimum compliance towards organisational cultures that consistently deliver high-quality care.

The experience of people with ME/CFS and long COVID

ME/CFS

ME/CFS is a serious, disabling, multisystem illness. Its hallmark feature is post-exertional malaise (PEM): a delayed and sometimes prolonged worsening of symptoms and function following physical, cognitive, emotional or social activity that exceeds the person's limited capacity. Symptoms and capacity can fluctuate, and the disability may be invisible. Many people with moderate ME/CFS are largely housebound, while an estimated 25% are severely or very severely affected and may be completely housebound or bedbound.[3] These features are often poorly understood in healthcare and can make patients especially vulnerable to disbelief.

A 2024 scoping review of healthcare system barriers found that long-standing stigma, disbelief and sexism were prominent barriers to care for people with ME/CFS. It described patient testimony being discredited, symptoms being psychologised, distress and humiliation, withdrawal from healthcare, inadequate workforce education and difficulty obtaining accessible care.[4] Australian qualitative research has likewise identified stigma and misunderstanding, negative interactions with health professionals and difficulty finding appropriate services as barriers to participation and care.[5]

A qualitative study of people with ME/CFS similarly identified not being believed or taken seriously, lack of knowledge, fragmented care and being left without appropriate services as major sources of dissatisfaction.[6] The US Centers for Disease Control and Prevention also recognises that some clinicians do not accept ME/CFS as real, and that negative healthcare experiences and limited professional education can complicate and delay diagnosis.[7]

Emerge Australia hears the practical consequences of this pattern from our community: people delaying or avoiding care; preparing extensively to prove their illness; concealing the severity of symptoms; losing confidence in clinicians; and being advised to increase activity without adequate recognition of PEM. Emerge Australia's 2019 Health and Wellbeing Survey, completed by more than 1,000 people, identified lack of practitioner knowledge as the greatest barrier to appropriate health services and documented continuing stigma and misunderstanding in healthcare.[8] For patients who risk prolonged deterioration simply by attending an appointment, a dismissive encounter carries an especially high cost.

Long COVID

Long COVID has inherited many of the stigma mechanisms associated with other poorly understood, invisible and fluctuating conditions. This can include symptoms being attributed to anxiety or deconditioning, patients feeling pressure to prove that their illness is genuine, and services failing to accommodate fluctuating capacity or deterioration following exertion.

In a UK community sample, a validated Long COVID Stigma Scale found that 95.4% of respondents experienced at least one form of stigma at least sometimes and 75.9% experienced stigma often or always. Anticipated and internalised stigma were more common than enacted stigma.[9] Because convenience sampling limits generalisability, these findings demonstrate the nature and potential scale of the problem rather than providing an Australian prevalence estimate.

More recent qualitative research found that people with long COVID experienced stereotyping, dismissal and self-stigma that affected help-seeking and access to care, with layered impacts for people from minority ethnic communities.[10] The evidence reinforces why a standard focused only on overt conduct is insufficient: fear of poor treatment can prevent the clinical encounter from occurring or limit what is disclosed during it.

Intersectional and compounded stigma

ME/CFS and long COVID are often invisible and fluctuating, and both disproportionately affect women. Condition-related stigma can interact with gender bias, disability discrimination, racism, poverty, mental health stigma and other identities or circumstances. A stigma-informed approach would complement, not dilute, the draft's strong focus on cultural safety, racism and equity. It would help services identify how different sources of stigma compound one another and create distinct barriers to safe care. The culturally specific purpose of requirement 2.10 should be retained, with guidance acknowledging how condition-related stigma may intersect with racism and culturally unsafe care.

Suggested amendments to the draft Standards

Emerge Australia recommends a targeted set of amendments rather than a separate stand-alone standard. The wording below illustrates how stigma can be integrated into the existing architecture.

Draft location	Recommended change
Overarching language and glossary	State that high-quality care must be free from health-related stigma, bias, racism and discrimination. Define health-related stigma, including enacted, anticipated, internalised and structural stigma, and explain its relationship to bias and discrimination.
1.01(d) – governance and culture	Amend to: 'identify and eliminate systemic, structural and institutional stigma, bias, racism and discrimination'.
1.03(c) – organisational culture	Amend to 'require leaders to prevent and respond effectively to stigmatising conduct, alongside the existing zero-tolerance approach to bias, discrimination and racism.'
1.07(d) – unwarranted variation	Require investigations of unwarranted clinical variation to consider whether stigma, bias, racism or discrimination contributed to differences in investigation, treatment, access, outcomes or harm.
1.25(c) – clinical and organisational risk	Amend to: 'recognise, monitor and report stigma, bias, discrimination and racism as clinical and organisational risks, and act to improve stigma-informed, anti-discriminatory, anti-racist and culturally safe practice'.
1.09 and 1.12 – consumers and feedback	Co-design stigma-reduction strategies with affected communities. Require feedback systems and patient-reported experience measures to capture whether people felt believed and safe to disclose, anticipated judgement, avoided or delayed care, or disengaged after a negative experience.
2.01(b) – trust and communication	Amend to require stigma-informed, respectful and non-judgmental communication. Clinicians should listen to and take the person's account seriously, avoid diagnostic overshadowing and unsupported assumptions, and support disclosure without fear of adverse treatment.
2.04(e) – assessment and planning	Require assessment and clinical reasoning to consider how stigma or prior negative healthcare experiences may affect presentation, disclosure, trust, access and engagement. Require fluctuating, delayed, invisible or poorly understood functional impacts to be elicited and documented rather than dismissed because they are not visible during one encounter or because they lack a single definitive diagnostic test. This is particularly important for people with ME/CFS, long COVID and related energy-limiting conditions, including where post-exertional malaise (PEM) is present.
2.09 – care environment	Make stigma-free, psychologically safe care an explicit feature of respectful and inclusive care environments, supported by workforce education, reflective practice and patient partnership. Retain 2.10's specific focus on culturally respectful practice and Aboriginal and Torres Strait Islander peoples.

Implementation and measurement

The Standards should make clear that stigma reduction is not satisfied by a one-off awareness module. Health service organisations should use a continuous improvement cycle that includes:

- co-design with communities who experience stigma, including people with ME/CFS, long COVID and related illnesses that are poorly understood, invisible or fluctuating
- workforce education that combines evidence with meaningful contact and lived-experience input
- review of policies, pathways, records, complaints and incident data for stigmatising assumptions or unequal outcomes
- patient-reported measures covering feeling believed, safety to disclose, anticipated judgement, care avoidance and disengagement
- accessible ways to participate and complain, including remote options and reasonable adjustments for people who are housebound, bedbound or cognitively impaired
- transparent reporting of findings and actions taken, with evaluation over time.

This approach would align stigma reduction with the draft's existing systems for consumer partnership, clinical risk, patient experience, workforce capability, feedback and organisational learning. It would strengthen implementation without creating a parallel compliance structure.

Conclusion

This draft third edition of the NSQHS Standards is an important opportunity to make patient experience a genuine driver of safety and quality. The draft recognises bias, discrimination, cultural safety and equity, but it does not yet name the process that makes many people fear, avoid or disengage from healthcare.

For people with ME/CFS and long COVID, stigma can determine whether they seek care, whether their account is believed, whether PEM and fluctuating capacity are recognised, and whether they return after harm. These are core safety, quality, access and equity concerns.

> Emerge Australia therefore recommends that the Commission explicitly embed the prevention, measurement and reduction of health-related stigma throughout the NSQHS Standards (third edition).

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