Productivity Commission Inquiry into: *Delivering quality care more efficiently*.

Submission from:
Carla Treloar
Scientia Professor, Centre for Social Research in Health
UNSW Sydney

Submission:

Thank you for the opportunity to provide comment on the interim report of this inquiry.

I wish to comment on draft recommendation 1.1:

> The Australian Government should pursue greater alignment in quality and safety regulation of the care economy to improve efficiency and outcomes for care users

I support this recommendation and want to provide an argument for the development of aligned quality and safety regulations which feature the provision of stigma-free care. I have provided details regarding two aspects related to regulatory standards: (1) the importance of stigma-free care for better quality outcomes; and (2) a review of existing international quality standards with respect to the inclusion of stigma.

The evidence presented below focuses on the importance of stigma as a concern for many people. US research identified 93 different identities, practices and conditions that are stigmatised and estimated that 95% of the population lived with at least one over their lifetime (ref 4 below). To avoid experiencing stigma, people might wait longer to get tested, be cautious about disclosing information, or not go ahead with treatments. Hence, stigma has been recognised as a fundamental cause of population health inequalities (ref 9 below).

For delivery of quality care in any system, addressing stigma should be recognised as a key aspect of operations, and be explicitly written in to quality standards.

I note that the importance of stigma-free care will also impact on the Commission's interest in a new approach to prevention investment. The impact of stigma affects every step of the care continuum, and investments in prevention will not be optimised if barriers associated with stigma are not recognised and dismantled.

1. the importance of stigma-free care for better quality outcomes

a. Defining stigma

Stigma is a social process whereby people are excluded or treated differently by others based on health conditions, identities, and practices that are judged or viewed negatively by members of society.

- Health conditions could include things like depression, diabetes, HIV, autism, facial scars, eating disorders;
- Identities could include things like gender, race, socio economic class, sexuality, religion;
- Practices could include things like smoking cigarettes, having sex with multiple partners, engaging in sex work, using illegal drugs.

Stigma may result in discrimination, which can take the form of negative words or actions directed at a person. Stigma can also be expressed as unfair organisational policies and procedures, laws, media representations, and social norms.

Individuals can experience multiple, intersecting forms of stigma, when they are being excluded based on their social identities related to multiple things such as race, gender, sexuality, and class. For example, a woman of colour who identifies as lesbian may experience stigma related both to her gender, sexuality, and how these intersect (1,2,3).

Stigma can occur at multiple levels:

- Structural stigma: Examples include lower funding for mental illness research or women's health research or fewer mental health services relative to other health care. Another example is the criminalisation of substance use, resulting in over-policing of people who use and inject drugs.
- Organisational stigma: Examples include procedures that ask people questions that are not relevant to their care or make assumptions about them (such as their gender, or access needs). Additional examples include policies that direct staff to undertake excessive practices such as calling security based on a person's identity or double glove when examining people living with HIV, or procedures that display HIV status in ways that breach the patient's right to privacy.
- Interpersonal stigma: Examples include negative words or actions taken by one person against another person such as asking inappropriate questions ("how did you get HIV?"), reacting in ways that send the message that a person isn't welcome (including non-verbal signals) and indicating that a patient is less worthy of care or which diminishes their experience ("you just need to try harder").
- Individual level stigma: Examples includes thoughts leading to lowered self-esteem and self-efficacy: "Why try? Someone like me is not worthy, or unable to work, live independently, or have good health."

b. Stigma can affect just about everyone

At some point in their lives anyone might be concerned about how they will be received when seeking care.

Research from the United States identified 93 different identities, conditions, and practices that might be the target of stigma. The researchers found that most of a sample of the general population lived with one or more of these in their lifetimes (4).

c. Stigma undermines quality health care

Stigma prevention in health care is particularly important because this is where people turn when they feel unwell and vulnerable (5).

Quality health care is the goal of every health system: stigma has been highlighted as a key contributor that undermines the delivery of quality care (6).

d. Stigma is a core barrier to health care access and results in poorer health outcomes

Stigma is one of the biggest barriers to healthcare. To avoid experiencing stigma, people might wait longer to get tested, be cautious about disclosing information, or not go ahead with treatments (7). They might do so because of their own past experiences of stigma or from hearing stories from

other people about being treated poorly (8). This means that stigma can result in poorer health outcomes for physical and mental health for many people (9).

For example, in a sample of more than 20,000 people who were overweight or obese, perceived weight discrimination was associated with significantly increased risk for obesity-related chronic medical conditions even after adjusting for BMI, physical activity and sociodemographic variables. The authors concluded that public health and policy interventions are needed to reduce the the negative impacts of stigma on health and the costs of care (10).

e. Stigma costs

When people don't feel like they can come forward to receive care, their health may decline or become more complex to manage or treat. This impacts their future health and quality of life and can make providing care more complex for health workers because of a greater burden on the system as a whole. There is also substantial personal cost involved – to self-esteem, to quality of life, to health and wellbeing (11).

For example, research from the UK found that individuals who reported experiencing any discrimination in a healthcare setting had £434 higher costs associated with health service use over six months compare to those who had not reported experiencing any discrimination. These costs were a result of costs in inpatient care, emergency presentations, and primary care (12).

As a further example, a 2017 modelling study from South Africa showed that 35-50% of infections among newborns of women with HIV were attributed to the cumulative effect of stigma at each step of the care cascade, with significant individual and societal costs (13).

f. The negative impacts of stigma last a long time

Stigma can have long lasting effects (14). People may have had negative experienced in the past – months, or years ago, or have seen negative commentary about people like them in news or on social media today.

These experiences accumulate to impact a person's sense of worth and their trust in health care – they may feel like they won't be treated the same as other people, or they won't been seen as legitimate patients in a health service (15).

g. People who experience stigma are key to developing responses to it.

Having those who have experience of stigma and discrimination involved has been identified as a best practice for addressing stigma in health care (16).

People who have experience of stigma and discrimination hold critical knowledge and diverse expert perspectives that can benefit the design and delivery of services. They need to be included as equal partners in all efforts to reduce the negative impacts of stigma.

Consumer involvement is already embedded as a central aspect of national quality standards (17).

2. a review of existing international quality standards with respect to the inclusion of stigma.

The detail under this heading is taken from a paper currently under review (18). Further detail from this paper can be provided on request. I have included some pertinent information from this paper below.

Our paper examined whether (and how) stigma was present in quality health standards using an international sample. This was an important question to research as a literature review regarding structural stigma developed for the Mental Health Commission of Canada, notes the importance of accreditation processes by which healthcare organisations are assessed on their implementation of safety and quality standards (19). These accreditation processes can 'have a role to play in ensuring that health-care organisations establish and implement policies that respect people's rights, guard against coercive practices, reduce inequalities and disparities, provide access to quality care, and promote the participation of people with lived experience'. Other authors have emphasised the possibilities of stigma-focussed quality and safety standards to facilitate actions to address and reduce stigma in healthcare settings (20, 21, 22, 23), including the development of quality and safety standards for stigma reduction by accreditation organisations. Authors argue that 'greater traction could be gained through a view that understands the problem of stigmatisation in health-care settings, at least in part, as a core attitudinal and behavioural barrier to quality of care' that can be addressed by 'established quality-of-care standards and processes through which to assess, measure, and improve patient care' (20).

For this study, we conducted a policy review of quality standards for how healthcare providers might monitor and reduce instances of stigma. For this review, and due to language barriers, we limited our search to six majority English-speaking countries that make up the 'core Anglosphere': Australia, the United Kingdom, Ireland, the United States, New Zealand, and Canada. In each, we examined the quality standards developed by the national healthcare standards agencies, listed in Table 1.

Table 1: National healthcare standards agencies, by country

Australia	Australian Commission on Quality and Safety in Health Care
United Kingdom[1]	National Institute for Health and Care Excellence
- Scotland	Healthcare Improvement Scotland
Ireland	Health Information and Quality Authority Mental Health Commission[2]
United States	Agency for Healthcare Research and Quality
New Zealand	Standards New Zealand / Ministry of Health
Canada	Health Standards Organisation

In brief, the results of this review indicate:

- Healthcare quality standards typically focus on language and communication as strategies to reduce interpersonal stigma, with enjoinders to be mindful of the stigmatising potential of certain language or terms.
- Many of the healthcare quality standards include training as a strategy to reduce and eradicate stigma, recognising the importance of training to counter stigma. Some healthcare quality standards also include engagement and advocacy strategies, targeted interventions, and consideration of service user preferences.

[1] There is not an equivalent national healthcare standards agency in Wales or Northern Ireland.

[2] The equivalent bodies in other jurisdictions – National Mental Health Commission (Australia), Care and Quality Commission (United Kingdom), National Institute of Mental Health (United States), Mental Health and Wellbeing Commission (New Zealand), and Mental Health Commission of Canada – do not set healthcare quality standards.

- The relatively low profile of complaint as an action to redress stigma within the reviewed healthcare quality standards. This may be because complaints mechanisms can sometimes be difficult, ineffective, or inadequate for people who experience stigma
- Limited consideration of structural stigma
- The involvement of affected communities is identified as best practice in stigma reduction but did not feature in the standards reviewed here.
- A lack of measures in the healthcare standards to monitor stigma and its reduction

Additional suggestion for stigma-focused standards include:

- Adopt this more holistic approach that engages the service user in reflections on their own experiences rather that purely enjoining healthcare providers to be mindful of their language and to take stigma into account when interacting with service users.
- Address organisational stigma through efforts to make health services visible to stigmatised communities through presence at community events or forums and employing people from these affected communities in healthcare services especially in peer work roles as well as including stigma reduction as a priority in healthcare services' strategic plans, updating organisational policies, incorporating stigma reduction into staff recruitment and career development and performance review processes, and documenting instances of stigma in risk management systems
- Incorporate legal and policy interventions and rights-based approaches to reduce stigma.
- Explicit reference to the important role of lived and living expertise in identifying, combatting, and measuring experience of stigma
- Develop approaches to measure and monitor stigma and the effectiveness of strategies to reduce stigma within healthcare services

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