National Mental Health Commission December 2022

Feedback on the National Health Literacy Strategy



Australian Government National Mental Health Commission



About the National Mental Health Commission

The National Mental Health Commission provides cross-sectoral leadership on policy, programs, services and systems that support better mental health and social and emotional wellbeing in Australia. There are three main strands to the Commission's work: monitoring and reporting on Australia's mental health and suicide prevention system; providing independent advice to government and the community; and acting as a catalyst for change.

The Commission's underpinning principle is the Contributing Life Framework. This framework acknowledges that a fulfilling life requires more than just access to health care services. It means that people who experience mental ill-health can expect the same rights, opportunities, physical and mental health outcomes as the wider community.

Vision 2030: Blueprint for Mental Health and Suicide Prevention (Vision 2030) is a blueprint for a successful, connected mental health and suicide prevention system to meet the needs of all people living in Australia. As part of the federal Department of Health and Aged Care's 10-year plan, it takes a long-term approach to change and improvement. Vision 2030 aligns with the National Preventative Health Strategy in recognising the need to address social determinants of health.

In May 2020, the Commission led the development of the National Mental Health and Wellbeing Pandemic Response Plan. The Plan identified specific challenges to mental health and wellbeing associated with the COVID-19 Pandemic and provided a range of measures to address these challenges. Through the Plan it was recognised that there were groups within the Australian community who would experience the social and economic impacts of the Pandemic more negatively than others. The Commission refers to these groups as priority populations. On 30 June 2021, the Commission funded ten organisations to undertake Pandemic Plan Priority Populations Research grants^[1] to help us build a better understanding of the impacts of the Pandemic on some of the priority populations and their communities.^[2] The lack of accessibility of public health information for priority populations was a key challenge revealed through these grants.

Additionally, the Commission has been tasked by the National Federation Reform Council with developing the National Stigma and Discrimination Reduction Strategy. The Strategy is referred to under the 'Promoting and protecting mental health' focus area of the National Preventative Health Strategy 2021-2030. There are several insights from the Commission's work to date in developing the Stigma Strategy that are relevant to the National Health Literacy Strategy. These insights are reflected in the feedback below.

Feedback

Does the Framework capture the important components? If not, please describe what else is needed.

The Commission notes that the Consultation Paper: Development of the National Health Literacy Strategy captures important components that broadly address health literacy needs, however there are some areas that could be strengthened.

Greater focus on mental health and people with lived and living experience of mental ill-health

There are no references to mental health or the needs of people with lived and living experience of mental illhealth in the consultation paper even though people with mental ill-health have poorer physical health outcomes, shorter life expectancy and do not receive the same health care as the rest of the population.

• There is a life expectancy gap of up to 15 years between those with a mental illness and the general population. 80% of people with mental illness also have a serious physical health condition, which is often not diagnosed or treated.

- The life expectancy for severe mental illness is substantially reduced compared with the general population. This reduction is attributed to a 2 to 3 times greater risk of cardiovascular morbidity and mortality, with the prevalence of cardiovascular disease up to 3.6 times greater in people with serious mental illness.
- Contributing to the poor physical health outcomes of those with mental illness are the high rates of diagnostic overshadowing, which refers to discrimination that occurs when a person's physical health needs are overlooked and misattributed as symptoms of their mental illness.
- While limited, research shows people with lived and living experience of mental ill-health have lower health literacy scores compared to other populations1.
- Examples of people who may not identify as having lived or living experience of mental ill-health but would benefit from health literacy efforts include children and young people, those experiencing homelessness, and those experiencing addiction. People experiencing homelessness have a shorter life expectancy and higher rates of morbidity and mortality compared to non-homeless individuals.2
- Individuals with experiences of trauma may have difficulty in accessing health care and engaging with health information. It is vital that health literacy outreach and education reduces access barriers by taking a trauma-informed approach and ensuring that engagement with the health system is safe and trustworthy.

The Commission therefore recommends that people with lived and living experience of mental ill-health be considered a priority population group in the National Health Literacy Strategy. People with lived and living experience of mental ill-health are a distinct group of health care consumers who require a holistic, person-centred approach where they can receive clear and transparent information on services, treatment options, costs, and are informed about the risks and side effects of treatment, including talking therapies, medication and other procedures such as electroconvulsive therapy and transcranial magnetic stimulation.

The National Health Literacy Strategy should also acknowledge that accessing health information can be a frightening, overwhelming and stressful experience. Certain physical health conditions, illnesses and diagnoses can affect a person's mental health, where individuals are often scared and confused and can require more complex self-care, physically and mentally.

The Commission recommends a stronger approach on linking mental health literacy as part of the broader health literacy experience. Mental Health Literacy is a component of Health Literacy that is defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention"³. It focuses on understanding how to obtain and maintain positive mental health, reduce stigma related to mental health disorders, and enhance help-seeking efficacy. However, there is emerging evidence that 'mental health literacy' as it is defined in the literature does not lead to a reduction in stigma. In fact, being able to identify signs and symptoms and attribute them to a diagnostic label predicts that someone is more likely to hold stigmatising views.

Appropriate language is central to building trust and rapport. It is important to recognise that the language used to refer to people with lived and living experience of mental ill-health needs to be cognisant of the ways that people might understand their experiences, including different beliefs and cultural responses. Special care needs to be taken to avoid contributing to stigma and discrimination.

• To address the health literacy needs of those with lived and living experience of mental ill-health and the broader community, it is important to use person-centred and strength-based language. For example, there

¹<u>Health literacy in people living with mental illness: A latent profile analysis - PubMed (nih.gov)</u>

² Seastres, Ramon & Hutton, Jennie & Zordan, Rachel & Moore, Gaye & Mackelprang, Jessica & Kiburg, Katerina & Sundararajan, Vijaya. (2020). Long-term effects of homelessness on mortality: a 15-year Australian cohort study. Australian and New Zealand journal of public health. 44. 10.1111/1753-6405.13038.

³ Mental health literacy | The British Journal of Psychiatry | Cambridge Core

can be negative reactions to the use of the word 'patient' within mental health contexts and people may not identify with being described as a 'patient', particularly when focusing on preventative care.

- Evidence from the development of the Commission's National Stigma and Discrimination Strategy suggests that overly simplistic messages about mental ill-health can be stigmatising. For example, homogenised understandings of mental ill-health, and focussing on higher prevalence diagnoses such as depression and anxiety, may have had the unintended consequence of increasing stigma and discrimination towards people with more complex needs. Explanations of mental ill-health which focus on biomedical approaches alone can also contribute to stigma.
- It is therefore an important principle that information should distinguish between different experiences across the spectrum of mental ill-health, from supporting general wellbeing, to responding to distress or shorter-term experiences of mental ill-health, through to understanding and supporting more complex, episodic or longer-term mental health needs (e.g. ongoing or severe experiences/diagnoses of depression, severe anxiety disorders, psychosis, schizophrenia, personality disorders and eating disorders, among others).
- While people may be eligible for and access psychosocial supports, for example as provided under the National Disability Insurance Scheme (NDIS) or be able to avail themselves of protections under the Disability Discrimination Act, it should be noted that not all people with lived and living experience of mental ill-health identify as 'disabled' or as a person with a disability.

Transparency of health treatments, delivery and options

The National Health Literacy Strategy would be strengthened by including a need for greater transparency as part of health information about treatment delivery and options. This is important in the mental health context in relation to the historical and continued use of potentially coercive practices.

This would help to ensure and allow for a clear understanding of health choices. There is a need for the health workforce and service providers to utilise supportive decision-making approaches so that people are not coerced into making decisions they would not otherwise have agreed to and to maximise the opportunity for individuals to make their own health decisions.

The Pandemic Plan Priority Populations Research grants highlighted how limited accessibility of public health information worsened physical and mental health outcomes for priority populations during the Pandemic. This included a lack of accessibility for people with disability (e.g., inconsistent use of Auslan interpreters during federal Government announcements) and people of culturally and linguistically diverse backgrounds (e.g. public health information not being available in multiple languages in the first instance). A lack of digital capability for some groups, such as older Australians, also presents challenges to accessing and interpreting important health information. Health literacy will not be improved for priority populations unless information is equitably and consistently accessible for these groups.

Addressing health literacy information overload

The National Health Literacy Strategy would be strengthened by including the need to address and manage information overload as part of the health literacy environment for all consumers, recognising that the sheer magnitude of health information available can overwhelm people and result in anxiety even when individuals have the skills and abilities to understand the health information.

Recent research highlights a range of negative impacts from information overload:

- Effects from the increase in health information during COVID-19 increased feelings of powerless, anxiety and depression4.
- Online searches for health information can increase health anxiety resulting in body vigilance and people can misinterpret information and may catastrophise about the possible causes of their symptoms that results in significant increase in healthcare use when it may not be required5.
- Caregivers and people with significant health conditions, such as cancer6, may receive health information at a rate far higher than they are able to process resulting in experiences of information overload. 7
- In relation to mental health literacy information, information overload has been shown to influence attitudes and behavioural intentions that is, it can diminish interest in learning about mental health, which in turn reduces likelihood of help-seeking or encouraging others to seek help when needed.8

Aim 3 of the framework speaks to all Australians having the skills to find and use reliable health information across the varied media they use, but could also outline how to mitigate the risk of this action resulting in people feeling overwhelmed and anxious by helping people to understand how to critically evaluate this information.

Roles of those delivering health information

While the framework for the National Health Literacy Strategy is strongly focused on empowering individuals to seek out health information (Aim 2 and Aim 3), there are risks in shifting information seeking responsibility onto individuals that could result in health professionals not providing health information to individuals effectively or supporting individuals in their health decisions. The consultation paper prioritises improving the health literacy of Australians but has less focus on those who play a role in delivering and supporting decisions around health information. The Commission suggests the inclusion of General Practitioners and the primary care workforce in playing a key role in advancing health literacy as they are best placed to build trusting relationships within which to deliver health information. Capacity building for GPs to ensure this information is delivered free from stigma may also be necessary, given data from the BETA team that indicates that people with mental ill-health who experience stigma in their interactions with health professionals most frequently experience this from GPs.

While the framework for the National Health Literacy Strategy has a heavy focus on digital health literacy, consideration should be given to the importance of how health information is communicated in face-to-face interactions with health professionals and people in the community. These interactions are critical to people's understanding of how to approach health decisions and manage their health. Evidence also shows that these are the kinds of interactions where people frequently experience stigma and there is an opportunity to ensure these interactions are compassionate and free from judgement.

While digital mechanisms are of course important, health information is sometimes best conveyed within the bounds of a trusting relationship. While there is mention of person-centred and community-centred approaches, there could be greater focus on the optimal conditions for engaging people in conversations about their health, whether that be in-person or through virtual/digital tools and ensuring a balanced approach between empowered individual health information seeking and receiving support from health professionals to help guide people in their health decisions.

⁴ <u>COVID-19 Information Overload, Negative Emotions and Posttraumatic Stress Disorder: A Cross-Sectional Study - PMC (nih.gov)</u>

⁵ How online searches fuel health anxiety: Investigating the link between health-related searches, health anxiety, and future intention - ScienceDirect

⁶ <u>Health information overload among health consumers: A scoping review - ScienceDirect</u> ⁷ Carenivers' Information Overload and Their Personal Health Literacy - PubMed (nih gov)

 ⁷ <u>Careqivers' Information Overload and Their Personal Health Literacy - PubMed (nih.gov)</u>
⁸ Bink, A. B. and Corrigan, P. (2022). "The impact of mental health information overload on community education programs to enhance mental health-care seeking". Journal of Public Mental Health, Vol. 21. No. 2, pp. 174-178. https://doi.org.10.1108/JPMH-062021-0077

Is the proposed vision appropriate for the National Health Literacy Strategy?

The Commission recommends the overarching vision for the National Health Literacy Strategy be expanded to include supported decision-making. Supported decision-making is fundamental to enabling people to exercise their human rights as citizens, and self-determination. Beyond simply informing people of their treatment options, supported decision-making ensures that people are provided with all necessary tools and information to make their own decisions. Specific to people experiencing mental ill-health, the supported decision-making approach respects a person's will and preferences and recognises that decision-making approach is important because it shifts the responsibility from individuals to locate and respond to information and places requirements on the health care system itself to actively support decisions being made by individuals. This enables health literacy to lead to lasting improvements by using a social ecological model that extends beyond an individuals' own role to instead build in processes that support people in their decision-making processes.

Are the key principles captured? If not, what is missing?

The Commission considers that the key principles are captured.

Are the aims the right ones for achieving the vision of the National Health Literacy Strategy?

The Commission suggests that the aims could include more detail on where health literacy efforts are likely to take place. For example, alongside community-based interventions, health literacy-building opportunities could intersect with those that already exist in acute settings such as hospitals and rehabilitation facilities:

- Encouraging health literacy skills during periods of hospitalisation and leading up to discharge from hospitals and rehabilitation facilities allows for the provision of meaningful and accessible information on maintaining and promoting good health.
- This could also be a chance to facilitate easy access and referral to a variety of resources that can be used once they leave hospital.

The Commission suggests that the aims should provide an opportunity to consider enhancing health literacy for carers/caregivers. The role of carers/caregivers can include difficulty communicating with health care professionals and navigating services. Low health literacy in caregivers also can have impacts on adequate care provision and health outcomes⁹.

Do you have any example actions that could be considered under each aim?

Aim 1: Systems, policies and practices within and across sectors support an effective health literacy environment.

The Commission recommends that this aim be strengthened to clearly outline the approaches that create an effective health literacy environment. For example, effective means of communicating health information and promoting health literacy include:

- Using a trauma-informed approach to establish trust between the provider and consumer
- · Using supported decision-making approaches
- · Using strength-based, recovery-oriented language
- Using a holistic, person-centered approach
- Providing meaningful choices
- · Not pushing for immediate decision-making

⁹ <u>Health literacy of caregivers of adult care recipients: A systematic scoping review - Yuen - 2018 - Health & amp; Social</u> Care in the Community - Wiley Online Library

- · Delivery of information at an appropriate speed
- · Allowing time and space to ask and answer questions
- Ensuring people are aware of their rights and responsibilities, including the opportunity to make complaints.

These elements are relevant to all consumers of health information and are particularly important for those with lived and living experience of mental ill-health. It is vital that health literacy efforts are underpinned by an understanding of the most effective ways to deliver health information and engage with people. For those with lived and living experience of mental ill-health, the health system is not always seen as trustworthy, and it is vital that health information and literacy efforts promote safety and autonomy if they are to be effective.

Aim 2: All Australians can access health information that is easy to understand, trustworthy, and culturally appropriate.

Aim 2 could expand upon the need to upskill community leaders, providers etc. as well as recognise that while digital mechanisms and tools are important means of communication, there should also be opportunities for in-person health literacy efforts. The Commission supports the example action of embedding health literacy into pre-service education and training for a range of professionals, as well as ongoing professional development. As part of this, we would recommend this training be embedded into relevant curriculums and include a specific component around opportunities to reduce and prevent experiences of stigma and discrimination through the way in which information is communicated.

The Commission also recommends these training requirements be extended to other professional educational settings such as vocational education and training and for professionals working adjacent to the health sector (e.g. in aged care and disability support), as well as in schools, communities and adult education. There may be additional roles for whom such training is important - for example the way in which police spokespeople provide reports on alleged criminal acts that involve someone with experience of mental ill-health can influence (either positively or in a way that undermines) accurate public understanding around mental ill-health. It is noted that broadening the range of roles and settings for which health literacy education and training is relevant would also align with the social determinants of health focus of the National Preventive Health Strategy, under which this Strategy is being progressed.

An important component of what is discussed above is ensuring health literacy information is trustworthy. While the consultation paper mentions the importance of trust, this appears to be limited to content available via digital platforms. The Commission recommends this concept is broadened and included as underpinning the 'enabling environment' for health literacy. Importantly, trust in information would encompass a range of factors, including the context in which information is communicated; the content, tone and form of published information; as well as aspects involved in interpersonal interactions. Action to build trust through these mechanisms may require systemic supports (for example, to enable adequate time for health professionals to understand a person's circumstances and individually tailor health information that may be required). It is also noted that building trust is likely to deliver benefits in other areas, including in service quality, satisfaction and reductions in experiences of stigma and discrimination.

The Commission also recommends that the promotion, strengthening and facilitation of easier access to health literacy that is culturally appropriate also responds to the effective means of communicating health literacy, as listed under Aim 1.

Aim 3: All Australians have the skills to find and use reliable health information across the varied media they use.

Aim 3 puts the responsibility on Australians to locate and use health information across media and assumes there will always be a level of understanding when accessing health information. The Commission suggests

it would be more appropriate to assume that everyone is at risk of misunderstanding information, no matter how skilled or how reliable health information is.

Aim 3 could be strengthened by including the provision of health literacy strategies to address potential misunderstandings of health information to improve Australian population health both online and face-to-face. Health literacy strategies include actions like the use of visual aids and pictures, following up with individuals, creating personalised action plans, and helping individuals to manage their medications.

The Commission also suggests a greater recognition of equity concerns, strengthening the point that digital information is not accessible to all. There are many who may be responsive to health information delivered through in-person and/or digital means who may not actively be seeking out information. This aim could be expanded to speak to the value of face-to-face engagement and outline outreach activities and projects that would have broad impact across communities and priority populations, including those with lived and living experience of mental ill-health.

Are the categories for the leaders and partners who will mobilise health literacy action appropriate?

The Commission notes that the categories for leaders and partners are not mutually exclusive in practice. For example, embedding health literacy into professional education and training should include lived and living experience leadership in the design and delivery of these curriculum components. We suggest consideration of how the categories might be visually presented to emphasise the ways in which they might interact.

The Commission recommends partners including:

- The Equally Well Alliance, responsible for implementing Equally Well and the National Consensus Statement on the physical health of people living with a mental illness.
- The EveryMind Words and Images Matter project which develops guidelines and web-based resources to support image and language use that is safe, inclusive, hopeful and non-stigmatising when communicating about mental health and wellbeing, mental illness, suicidal behaviour, and alcohol and other drugs.
- Lived Experience Australia which represents and promotes the interests of consumers, families and carers in all mental health settings.
- State and Territory Peak Bodies for mental health consumers and carers, families and next of kin, which represent, promote and advocate for their interests in all mental health and carer settings.