National Mental Health Commission
December 2021

Submission on the Draft National Healthcare Interoperability Plan

Australian Government
National Mental Health Commission

Contents

Introduction

The National Mental Health Commission (the 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.

The National Suicide Prevention Office (NSPO) was established in the 2021-22 Budget and sits within the Commission. The NSPO will focus on the coordination of whole-of-government capability to deliver a national approach to reducing suicide rates in Australia, ensuring the voice of lived experience is at the forefront.

The Commission acknowledges the purpose of the Draft National Healthcare Interoperability Plan (Draft Plan) to support safe, secure, efficient, and quality care through an ecosystem of connected providers that conveniently and seamlessly share high-quality data with easily understood meaning. The Commission believes that the Digital Health Agency (the Agency) has an important leadership role to play in ensuring that available and emerging technologies are fully used to transform the mental health system into services and information systems that are person-centred.

In 2019, the Commission released the Vision 2030 Blueprint Consultation Report. This Report was informed by the Commission's Connections Tour in 2019, which provided an opportunity for those with lived experience of mental ill-health and those providing care and support, to provide strategic input into the design of Vision 2030. Over 3,000 participants from across Australia identified that the mental health system continues to present barriers to identifying needs and providing safe, quality, and effective care that is accessible to all.

These barriers are evident at the individual, service, and system level. At an individual level, there is a lack of understanding about experiences of psychological distress and the role of trauma in the development of mental illness. Negative attitudes and behaviours towards people who experience mental ill-health and suicidality contribute to the self-stigma and shame which create barriers to seeking help. Consumers have poor service experiences and are often not afforded a voice in their own care. Services are not well coordinated or easy to navigate.

The Vision 2030 Blueprint proposes a person-centred system, where social and emotional wellbeing is front and centre of every decision, and where consumers and carers partner and have a choice in shaping and delivery of care and support. The Vision 2030 Blueprint highlights a national, consistent system comprising all elements of primary, tertiary, and community-based care.

In the Final Advice of the National Suicide Prevention Advisor, evidence from people with lived experience of suicidality revealed that poor integration and communication across services is a major barrier to seeking help. Individuals having to tell their story multiple times to multiple health care providers, receiving a non-compassionate response, or decisions being made without consulting other appropriate members of their health care team, create feelings of isolation and stigma. Developing an integrated, seamless system for the sharing of health data, as well as a common and respectful healthcare language for suicidal behaviour, will enable providers to deliver compassionate responses that meet people 'where they are' and make it safe to seek help.

The Commission notes that the Draft Plan would be strengthened by placing a greater emphasis on trauma-informed person-centred care and being led by the insights and experiences of people with lived experience of mental ill-health and suicidality. We would also like to see further articulation of the full range of providers that will be incorporated into the Plan, including social services, drug and alcohol services, and peer-led, peer-run community care providers. The

Commission would also encourage the inclusion of proposed mitigations to address risks to consumers associated with greater interoperability, including the risk of stigma and discrimination to people experiencing mental illness.

The Commission and the NSPO would like to work with the Agency to provide further advice and ongoing support related to mental health and suicide prevention considerations across language, standards, privacy, governance, complaints, training and oversight, and evaluation, with a focus on addressing the risk of stigma and discrimination to people experiencing mental illness and suicidality. The voices of lived experience can guide this work and should be at the centre of the Draft Plan.

Should you wish to discuss this submission in further detail, please contact Dr Alex Hains, Executive Director, Policy via alex.hains@mentalhealthcommission.gov.au.

Interoperability Principles

1. Does the National Mental Health Commission support the Interoperability Principles in section 3.1, or should some principles be amended, added or removed?

NMHC Response

The Commission supports the National Health Interoperability Priorities of Identity, Standards, Information Sharing, Innovation and Benefits.

The Commission recommends amendments to Interoperability Principle 2. Use of health information supports individual choice and access to information. The Commission recommends this principle be rephrased to *Interoperability supports a person-centred approach to care by enabling individual ownership, choice, and access to information.* The Commission further recommends a sentence be added to highlight that Australians should have ownership over data held about them, real choices in managing their own health and be empowered to choose the treatment and supports that are right for them. This may include consumers giving consent for their health information to be exchanged with various health professionals or services to support integrated care. Rephrasing to emphasise the importance of a person-centred approach supports good practice and aligns with the final report from the Productivity Commission Inquiry into Mental Health, finding 4.1- *A person-centred mental health system.*

Implementation Actions

2. Are there any key actions missing to promote the objectives of this Plan? (A consolidated list of actions can be found in section 10 – pg. 68)

NMHC Response

The Commission supports the key actions listed in the Draft Plan. It further recommends that the Draft Plan prioritise, and be led by, the insights and experiences of people with lived experience of mental ill-health and suicidality. To enable this, the Commission recommends an additional action be included to convene a lived experience working group to co-design the planning, development, and monitoring of the key actions in the Plan.

The Commission's understanding is that different states have different data and milestones for newborns. The Agency could also consider including an additional action to work across jurisdictions to achieve uniformity in identification and data capture.

3. Would you like to see any changes to the scope or timeframe of the proposed actions?

NMHC Response

The Commission recommends the following changes to scope and/or timeframe of the proposed actions:

- Action 6.9 Agreement for use of personal health information.
  The Commission recommends this action specifically considers the sharing of information for the purposes of insurance and legal processes, and what protections need to be in place for individuals, particularly for people with experience of mental ill-health and suicidality. The Commission understands that requests in relation to mental ill-health and suicidality are often unnecessarily broad in scope and disclosure can lead to prejudicial treatment. The Commission further recommends that agreements for use of personal health information consider arrangements for data sharing and use following an individual's death.

- Actions 8.1 Survey of hospital, pharmacy, and GP organisations to provide a benchmark for the level of interoperability, and 8.2 periodic interoperability survey.
  The Commission recommends the scope of this survey be expanded to include allied health, community care, human services, and private providers such as psychologists and psychiatrists. Scope should also explicitly include tele-web health services. This would ensure any baseline study adequately encompasses the full scope of interoperability required across Australia's complex system of service delivery across the health and mental health system. The Commission further recommends that the survey should also be expanded to include individuals receiving services, in order to understand the experience of consumers and carers of the benefits or unintended consequences from interoperability.

4. Are there any actions that your organisation would like to be involved in progressing, and what would that involve?

NMHC Response

The Commission is currently working in partnership with people with lived experience of mental ill-health who have been directly affected by stigma, along with people with other forms of expertise across the health sector and broader community to deliver the National Stigma and Discrimination Reduction Strategy.

The Commission welcomes the opportunity to be involved in progressing the following actions, to ensure these reflect the perspective of people with lived experience of mental ill-health and suicidality, and reduce the experience of stigma and discrimination towards those affected by mental ill-health and suicidality in identified settings.

- Action 6.4 Enabling individuals to grant consent to access all their information, including in My Health Record.
  The Commission can provide expert advice related to the experiences of people with lived experience of mental illness.
  Suicide prevention interventions, risk assessments and safety plans should be recorded as discrete events to other health (including mental health) interventions, risk assessments and plans in an individual's Record, and be subject to consumer consent. Currently there is no standard way to document and identify suicide prevention services being provided within the health system. This should be done noting the potential for stigma and discrimination, if suicide attempts or ideation recorded in a Record are visible to other providers who may be providing unrelated services.

- Action 6.6 Identifying individuals within a consumer's formal and informal care management network.
  The Commission can provide expert advice related to the mental health service system.

- Action 6.10 Development of consistent definitions.
  As outlined below, there are unique considerations around the terminology and approach to language in mental health and suicide prevention. The Commission recommends specific consideration be given to standards and definitions in relation to mental health and suicide prevention to support the development of system-wide interoperability standards and to help guard against unintended consequences around stigma and discrimination on the basis of mental ill-health and suicidality. A priority action under the Final Advice of the National Suicide Prevention Advisor is for NSPO to lead the development of national definitions of, and standards for, self-harm and suicide attempts. This may include developing standardised coding for the range of suicidal behaviour, together with workforce capability training to align practice to standards. The Commission recommends that the Agency work with the NSPO in leading this work.

- Action 6.11 Harmonising legislation.
  The Commission's work around stigma and discrimination includes consideration of the protections and impacts of legislation and legislative instruments across state and federal jurisdictions.

Interoperability Initiatives

5. Which, if any, of the implementation initiatives in section 7.4 (pg. 53) would you like prioritised for delivery and why?

NMHC Response

The Commission recommends the following implementation initiatives be prioritised for delivery:

- Notifying community providers of acute care events:
  Enabling healthcare providers to follow individuals (with their consent) and be notified of acute care events will help reduce gaps in care for people experiencing mental ill-health and suicidality, and support more seamless care between hospital and community services, particularly for those recovering from a suicide attempt. These are priority reforms identified by the final report from the Productivity Commission Inquiry into Mental Health, establishing universal aftercare for anyone who presents to a hospital, GP or community mental health service following a suicide attempt.

- Exchanging care plan goals and outcomes:
  Developing standards and infrastructure that support the exchange of care plans and outcomes between systems involved in an individual's care will support care continuity and coordination, a priority reform identified by the final report from the Productivity Commission Inquiry into Mental Health.

- Practice-to-practice record transfer:
  Enabling individuals to move from one provider to another and be confident their information will travel with them is a key enabler of person-centred care by empowering healthcare consumers with greater ability to choose preferred care providers and treatment options.

- Visibility of an individual's top 5 things to know:
  Developing standards and infrastructure so that individuals can provide details of the top 5 things to know about them from their perspective is a key enabler of person-centred care. This will allow healthcare practitioners take a more holistic view of individuals in their care and provide consumers greater control and agency over information sharing.

- Managing patient information sharing and consent:
  Retrieving and managing an individual's information sharing and access consent rules via a mobile app will support person-centred care by empowering healthcare consumers with greater control over sharing, or not sharing, information about themselves. The Commission suggests the Plan should specifically reference a goal of ensuring that consent processes maximise the opportunity for autonomy and agency of the individual and are free from coercion.

- Effective capture and communication of diagnoses:
  For the reasons outlined in response to question 4 regarding priority action 6.10, the Commission and the NSPO recommend prioritising the development of standardised terminology for diagnosis, and for this to include the range of suicidal behaviours.

General feedback

6. Is your organisation leading any activities that should be identified in the final Plan?

NMHC Response

The NSPO has been tasked with developing national definitions of, and standards for, self-harm and suicide attempt. As recommended above, this work should inform the final Plan.

The Commission notes the following work underway, being led by the Department of Health, which should be identified in the final Plan:

- Relating to Action 4.8 *Jurisdictions will work with Healthdirect Australia to use the National Health Services Directory (NHSD) as the service directory for digital health programs and where it is not possible (such as for a specialised directory), work with Healthdirect Australia and the Agency to support the required flow of information*.
  The Commonwealth Government's work to create a single digital platform under Head to Health that will provide online professional counselling, peer support, clinical support, and referrals. This includes $2.8 million to support implementation of the National Safety and Quality Digital Mental Health Standards (NSQDMH) to improve the quality of digital mental health service provision and protect service users and their support people. NSQDMH were released on 30 November 2020 and are available here: https://www.safetyandquality.gov.au/standards/national-safety-and-quality-digital-mental-health-standards.
- The Australian Commission on Safety and Quality in Health Care (ACSQHC) has developed an accreditation model for digital mental health services that will operate under the Australian Health Service Safety and Quality Accreditation (AHSSQA) Scheme. Assessments under the scheme will commence in mid-2022.

7. Do you have any additional feedback on the Plan?

Person-centred and trauma-informed care should be key guiding principles

The Draft Plan would benefit from articulating person-centred care as an explicit principle, and by highlighting throughout the document how proposed actions will strengthen person-centred care by providing individuals with greater access and control over information held about them, agency in sharing their information, maximising agency and autonomy in making decisions, and support them to more easily choose and move between different care providers and treatment types. There is also value in identifying how the Plan can support 'trauma-informed' approaches to care, including in public-facing and individual communication, and the way in which health providers access, interpret and discuss data.

The Plan should be guided by the insights and experiences of people with lived experience of mental ill-health and suicidality

The Plan should prioritise, and be led by, the insights and experiences of people with lived experience of mental ill-health and suicidality. Leveraging lived experience knowledge and leadership will help ground the Plan in a genuine understanding of people's needs and ensure the efforts to create genuinely interoperable healthcare do not miss the mark for consumers. Diverse lived experience voices particularly need to be heard to support engagement with these cohorts including: young people, older people, Aboriginal and Torres Strait Islander people, men, women, LGBTIQ+ communities, people from culturally and linguistically diverse backgrounds, veterans and their families, and rural communities. This could be enabled by convening a lived experience working group to co-design the planning, development, and monitoring of the proposed key actions in the Plan.

The Plan should include recognition of the digital divide

People living with complex and enduring mental ill-health and suicidality are disproportionately impacted by systemic social issues which means lack of access to technology and lower levels of digital literacy. This is likely to impact on the ability of this cohort to exercise individual choice as they may have lower access to, or capacity to use, the digital tools needed to exercise their choices. These issues and possible mitigation strategies should be included in the Plan.

Greater articulation of how the Plan will be implemented across different sectors is needed

While the Draft Plan states that it considers interoperability across all sectors: acute care, primary care, allied health, community care, aged care and disability services, and health and human services, how this might differ is not clear through the document. The Plan would benefit from highlighting throughout the document how the actions would be implemented, and benefit, different sectors. As an example, the Draft Plan includes actions to conduct a baseline and ongoing survey to assess interoperability, but limits the scope of this survey to hospitals, pharmacy, and GP organisations. The Commission recommends expanding the scope of the surveys to include all sectors, in line with the stated scope of the Draft Plan.

Further work is required to address the challenges in identifying consistent mental health and suicide prevention definitions to underpin interoperability standards

The Plan highlights the importance of uniform standards for “attaining unambiguous shared meaning” and supporting “clear, reproducible and consistent interpretation of data”, and identifies Action 6.10 for developing consistent definitions to support health information sharing. However, the experience of mental ill-health and suicidality is highly individual, and for many people, a diagnosis or type/stage of treatment will not accurately represent their situation. In addition, many people with experiences of mental ill-health and suicidality conceptualise their experiences differently and use different terminology to describe them, which may or may not include diagnostic/clinical language. As noted elsewhere in this submission, it is unclear whether/how broader contextual information from allied health and other providers outside of the clinical system would be incorporated to provide a more nuanced picture of the care and support needs of a person with mental ill-health.

There is a risk that providers may misunderstand or misinterpret a person’s experience of mental ill-health and suicidality when the data available (and digital standards underpinning this information) are focused on clinical/diagnostic indicators and are not accompanied by (or considered alongside) broader contextual (i.e. person-centred) information.

The Commission would welcome working with the Agency to progress this work.

The Draft Plan should acknowledge risk and identify risk mitigations

The Commission strongly supports the aim of the Draft Plan to improve interoperability in order to support safe, secure, efficient, and quality care through an ecosystem of connected providers that conveniently and seamlessly share high-quality data with easily understood meaning. However, it is important to note that greater interoperability, and the actions proposed through the Draft Plan, are not without risk.

Greater sharing of patient information poses genuine risks of privacy breaches. There is also increased risk of stigma and discrimination towards people with experience of mental ill-health and suicidality. For example, medical practitioners may make assumptions about a person’s mental health diagnosis when they receive information about a person’s current medication regime, even when their mental health or suicidality diagnosis isn’t documented. People with mental ill-health and suicidality also often report diagnostic overshadowing – where a complaint of a physical health condition is wrongly attributed as arising from a person’s mental health condition.

These risks should be identified in the Draft Plan, and the Draft Plan should highlight how many of the already proposed actions will help to mitigate these risks.

The Commission would like to work with the Agency to provide advice and ongoing support related to mental health and suicide considerations across language, standards, privacy, governance, complaints, training and oversight and evaluation, with a focus on addressing the risk of stigma and discrimination to people experiencing mental illness and suicidality.

Consider opportunity for cross-portfolio interoperability via National Digital Identity

The Commission supports further investigation of linking Individual Healthcare Identifiers with the Digital Transformation Agency's National Digital Identity, as touched on in section 4.1 of the Draft Plan. Interoperability between healthcare and other social services would support early intervention to identify suicidal risk. This aligns with the final report from the Productivity Commission Inquiry into Mental Health, which recommended governments pursue a cross-portfolio approach to suicide prevention, including non-health government portfolios that have influence over suicide prevention activities. The National Suicide Prevention Adviser's final advice to the Prime Minister identified key transition points in life, and unemployment and financial distress, as stressors that contribute to suicidal behaviour. These and other stressors could be detected and managed through cross-portfolio interoperability. Ideally, individual identifiers (or a means to routinely link individuals across data sets) should be used beyond the health system to support a whole of governments approach to mental health and suicide prevention, so we can better research and understand an individual's whole journey through government services and supports.

Enable the capture of data on priority populations impacted by suicide

Greater interoperability has the potential to enable better service responses for those at high risk of suicide by creating greater visibility of priority populations. Data sets should seek to capture demographics that can be used to routinely identify priority populations that are disproportionately impacted by suicide. Without this linkage, we will remain reliant on survey data to identify priority populations, that may not be supported by a direct association with service data.

References

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