National Mental Health Commission December 2022

# Australian Cancer Plan

Public Consultation Feedback



Australian Government

National Mental Health Commission

# 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 systems; 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 illness can expect the same rights, opportunities, physical and mental health outcomes as the wider community.

As developed by the Commission, *Vision 2030* – a national blueprint for mental health and wellbeing in Australia – promotes the opportunity for people to be mentally well in their full social context. This includes intersections with physical health, where care should be comprehensive and functionally integrated with primary and hospital care, and provided alongside allied health and social services.

The Commission welcomes the opportunity to provide feedback on the 10-year plan for the Australian Cancer Plan (ACP) that aims to provide a transformative agenda to accelerate world-class outcomes and improve the lives of all Australians affected by cancer.

Should you wish to discuss this submission in further detail, please contact Alex Hains, Executive Director, Policy at <u>alex.hains@mentalhealthcommission.gov.au</u>.

# Feedback

# Equity of cancer outcomes for those with lived and living experience of mental ill health

To effectively achieve the objective of equity in cancer outcomes and treatment experiences for all Australians, the ACP would benefit from a greater focus on the needs of those experiencing mental ill health and cancer. This is to also include increased screening opportunities for more vulnerable populations.

Current inequities of cancer outcomes are demonstrated by the rates of cancer morbidity and mortality among those with mental illness when compared to the general population. Those with mental illness have a higher cancer mortality rate, even though their cancer incidence is the same or lower than that of the general population. In Australia, over 6,000 people with mental illness die prematurely of cancer each year<sup>i</sup> and there are significant disparities in mortality risk for those with a diagnosis of severe mental illness e.g. schizophrenia. Those with diagnoses of schizophrenia and cancer have been found to have 60% higher mortality rate than people with cancer who do not have a diagnosis of a severe mental illness.<sup>ii</sup>

Despite the increased mortality from cancer in people with mental illness, this population receives less cancer screening compared with that of the general population. Specific approaches should be developed to assist people with mental illness to undergo appropriate cancer screening, especially women with schizophrenia.<sup>III</sup> The Commission notes that while incidence rates are not significantly different than that of the general population, the disparity in mortality rates points to delayed detection of cancer and is likely related to lack of engagement with preventative health care e.g. screening programs.<sup>IV</sup>

In order to ensure the engagement of those with lived and living experience of mental ill health with preventative cancer measures, particular focus should be given to why people avoid engagement with the health system, for example, the impact of diagnostic overshadowing, stigma and discrimination and the lack

of trauma-aware and person-centred care. Additionally, the Commission recommends that further investment and research should focus on improved opportunities for screening for vulnerable populations and on ways to improve cancer awareness.  $^{v}$ 

The Commission notes those with mental illness are identified within the ACP as a priority population, with some actions identifying specific implementation considerations. However, the Commission recommends the ACP address the additional factors outlined below to improve cancer outcomes for those with lived and living experience of mental ill health.

## Training

People living with mental ill health have reported that cancer screening professionals often lack an understanding of their situation, symptoms of mental ill health, and the side-effects of medications. In addition, cancer screening professionals have reported not having training in mental health, and mental health providers reported not knowing enough about cancer screening and available cancer services.<sup>vi</sup> Training opportunities must also address issues of mental health-related stigma and discrimination that impact cancer care for those with lived and living experience of mental ill health.

To address these systemic gaps, the Commission recommends the ACP:

- Be strengthened through inclusion of integrated training to ensure that all mental health and cancer care providers have working knowledge of mental health needs and cancer care pathways.
- Include training on mental health for ancillary healthcare staff to create a holistic and welcoming environment from first point of contact and encourage ongoing engagement in treatment for patients with lived and living experience of mental ill health.
- Address the variety of experiences of mental ill health, distress and suicidality and the need for providers and medical staff to avoid generalisations and stereotypes.
- Actions that provide for stigma-specific training and education to be incorporated into existing courses and onboarding processes for all staff involved in cancer care, including administrative staff and ancillary staff who could potentially interact with patients.

#### **Outreach**

While the ACP references the need for greater access to equitable primary and secondary prevention activities, more proactive and affirmative approaches, such as the use of outreach services, should be prioritised for those with experiences of mental ill health or who have past mental ill health experiences. Outreach activities should have a particular focus on increasing contact with health promotion activities and preventative care – for example, screening programs, for those with lived and living experience of mental ill health.

The Commission recommends the ACP:

- Utilise the knowledge and skills of the Lived Experience (peer) workforce to assist in facilitating engagement. This could be done by embedding members of the Lived Experience (peer) workforce within outreach programs targeting those with lived and living experience of mental ill health, for example, within actions 2.2.1 and 2.2.2.
- Support the creation of multidisciplinary, cross-sectoral outreach programs that actively recruit people with lived and living experience of mental ill health into health promotion and preventative care activities.
- Ensure that tailored health information is available through both digital and non-digital means. This takes into account the spectrum of digital familiarity and access among people with lived and living experience of mental ill health.

#### Trauma-aware care

The Commission recommends that actions around the provision of *trauma-aware care* be expanded to more explicitly include those with lived and living experience of mental ill health. Currently, the ACP outlines tailored actions for trauma-informed care specific to Aboriginal and Torres Strait Islander people (actions 1.1.1, 2.2.3, 3.1.4, 3.2.4) with a generalised application across priority populations (action 5.1.3). However, trauma-aware care is critically necessary to increase engagement with treatment for those with lived and living experience of mental ill health and should be central to all interactions.

Trauma-aware care is being able to empathise with an individual's experience, to be able to correctly identify when a person might be distressed, and understanding the effects and symptoms of trauma responses.<sup>vii</sup> This includes recognising that there are a range of potential responses an individual can have to the same situation and being able to respond in trauma-informed ways<sup>viii</sup>. Trauma informed care is about integrating the action and practice of trauma awareness and following trauma-based principles and recovery orientated language.<sup>ix</sup>

A significant number of people with experiences of mental ill health have experienced life-altering trauma that has directly contributed to their mental ill health, and many may have been further harmed by their experiences of seeking support from the health system. Prior negative interactions with the health care system, characterised by stigma, discrimination, and coercive practices, can lead to avoidance of medical care. Trauma-aware care is vital to ensuring ongoing engagement and safety in treatment for those with lived and living experience of mental ill health.

### **Impact of Stigma and Discrimination**

The Commission was tasked by the National Federation Reform Council with developing the <u>National Stigma</u> and <u>Discrimination Reduction Strategy (the Strategy</u>). The Commission recommends the National Stigma and Discrimination Reduction Strategy be referenced within the ACP as relevant to those with lived and living experience of mental ill health.

There is substantial evidence to indicate that those with lived and living experience of mental ill health often avoid engagement with the healthcare system due to anticipation of stigma and discrimination.

The Commission notes that the impacts of stigma and discrimination on the experiences of those with mental illness are referenced within the ACP, however, reduction strategies should be further integrated into specific actions outlined in the ACP – for example, action 2.1.2.

Stigma and discrimination are linked to a number of significant health outcomes, particularly due to the experience of diagnostic overshadowing. Diagnostic overshadowing contributes to the significant gaps in cancer outcomes for those with lived and living experience of mental ill health and the general population. The ACP must provide specific actions to ensure that those with lived and living experience of mental ill health are not having their physical health needs overlooked and misattributed due to their mental health diagnosis.

The impacts of stigma and discrimination need to be addressed as a central piece of the ACP in order to provide equitable and effective cancer care for those with lived and living experience of mental ill health. Key actions to address mental health-related stigma within cancer care are grounded in training and education. These are included in the training recommendations above.

### Supporting the mental health needs of all people affected by cancer

It is stated within the ACP that "for many people, a cancer diagnosis will be one of the most traumatic experiences in their lives". As such, the mental health needs of those affected by cancer should be central to the ACP, even for those who have no prior history of mental ill health. A variety of holistic and supportive treatment options should be accessible across the full spectrum of cancer care.

Research shows that patients with cancer experience depression at higher rates than the general population and are at higher risk for suicide.<sup>xxi</sup> In order to address the mental health needs of all people affected by cancer, the Commission recommends:

- The implementation of integrated screening for suicide-risk among those receiving cancer care.
- The ACP include specific actions to ensure providers have the resources to effectively explore a range
  of treatment options with clients and facilitate easy access to a broad range of psychosocial
  supports, ranging from psychiatry and psychology services to creative arts therapy and group
  psychotherapy, so individuals can access services that fit their needs.

### Psychosocial support for death and dying

The Commission recognises that death and dying are a part of life, and not everyone survives cancer. While we acknowledge that talking about death and dying can be uncomfortable, it is critical to provide the unique mental health/psychosocial support needed by people with cancer who are faced with the reality of dying. As the ACP highlights, the mortality rates of people diagnosed with cancer is high – it is estimated there will be around 50,000 deaths in 2022 from cancer in Australia.

The Commission supports the ACP's inclusion of the need to develop and refine integrated care models to maximise access to high-quality, timely and evidence-based palliative and end-of-life care. The Commission highlights that health and social care services cannot fulfill all the needs of the dying, recognising that dying has unique mental health needs and this has resulted in a recent shift in individuals resorting to home care and alternative non-medical approaches.<sup>xii</sup>

The Commission highlights there are psychotherapeutic approaches that can benefit people with cancer that enable the psychological impacts of death and existential anxiety to be explored. There are a range of psychological tasks that need to be undertaken and psychotherapy can help to reduce psychological pain, relieve psychosocial distress and provide opportunities for personal growth in the last stage of life.<sup>xiii</sup>

Section 3.1.4 makes a list of actions recommended to be included as part of a two-year action plan to develop and integrate care models for palliative and end-of-life care. The Commission recommends the twoyear action plan could achieve greater benefits by also including:

- The ACP includes the need for professional development on communicating appropriately to children during difficult conversations on death and dying. Professional development on communicating appropriately for adults and their families should also be included, more broadly than just in the remit of a palliative care medical approach. This recognises that the impact of illness, death and grief includes the need for physical, emotional, and spiritual needs to be addressed holistically for all populations.
- Considerations for greater research investment and integration of new models of care and support
  professionals who provide non-clinical psychosocial support, should be considered, with the
  potential for these models to incorporate specialist supports required to address the unmet needs
  of the dying.

#### **Risk-based screening**

The ACP recognises the value of implementing risk-based cancer screening. In exploring how to broaden current risk-based screening programs, it would be beneficial to include examination of the risks related to specific experiences of mental ill health.

Actions 1.1.4 and 1.2.3 do not provide any additional information on the specific needs around cancer risks for those with lived and living experience of mental ill health. The Commission recommends these actions be modified to identify those with lived and living experience of mental ill health as a high-risk group and distinguish between the different experiences of mental ill health (rather than consider all people with mental ill health to be the same). In addition, the Commission recommends these actions specify the need for ongoing assessment and investigation of cancer risk for those experiencing a variety of experiences of mental ill health.

<sup>&</sup>lt;sup>1</sup> Roberts R, Johnson C, Hopwood M, Firth J, Jackson K, Sara G, Allan J, Calder R, Manger S. The Potential Impact of a Public Health Approach to Improving the Physical Health of People Living with Mental Illness. *International Journal of Environmental Research and Public Health*. 2022; 19(18):11746. https://doi.org/10.3390/ijerph191811746 <sup>II</sup> Launders, N., Scolamiero, L., Osborn, D. P., & Hayes, J. F. (2022). Cancer rates and mortality in people with severe mental illness: Further evidence of lack of parity. *Schizophrenia Research*, 246, 260-267.

<sup>&</sup>lt;sup>iii</sup> Roberts R, Johnson C, Hopwood M, Firth J, Jackson K, Sara G, Allan J, Calder R, Manger S. The Potential Impact of a Public Health Approach to Improving the Physical Health of People Living with Mental Illness. International Journal of Environmental Research and Public Health. 2022; 19(18):11746. https://doi.org/10.3390/ijerph191811746 <sup>iv</sup> Solmi, M., Firth, J., Miola, A., Fornaro, M., Frison, E., Fusar-Poli, P., ... & Correll, C. U. (2020). Disparities in cancer screening in people with mental illness across the world versus the general

population: prevalence and comparative meta-analysis including 4 717 839 people. *The Lancet Psychiatry*, 7(1), 52-63. <sup>v</sup> Morère JF, Eisinger F, Touboul C, Lhomel C, Couraud S, Viguier J. Decline in Cancer Screening in Vulnerable Populations? Results of the EDIFICE Surveys. Curr Oncol Rep. 2018 Mar 5;20(Suppl 1):17. doi: 10.1007/s11912-017-0649-7. PMID: 29508084.

<sup>&</sup>lt;sup>vi</sup> Roberts, R. The physical health of people living with mental illness: A narrative literature review. NSW: Charles Sturt University; 2019. ISBN: 978-1-86-467344-9. https://www.equallywell.org.au/wp-content/uploads/2019/06/Literature-review-EquallyWell.pdf <sup>vii</sup> What is trauma-informed care? - Principles for effective support (nsw.gov.au) <sup>viii</sup> The Difference Between Being Trauma Aware And Trauma Informed (myiict.com)

ix Recovery-Oriented-Language-Guide-Mental-Health-Coordinating-Council-2022.pdf (mhcc.org.au) × Heinrich M, Hofmann L, Baurecht H, Kreuzer PM, Knüttel H, Leitzmann MF, Seliger C. Suicide risk and mortality among patients with cancer. Nat Med. 2022 Apr;28(4):852-859. doi: 10.1038/s41591-022-01745-y. Epub 2022 Mar 28. PMID: 35347279. <sup>xi</sup> Krebber AM, Buffart LM, Kleijn G, Riepma IC, de Bree R, Leemans CR, Becker A, Brug J, van Straten A, Cuijpers P, Verdonck-de Leeuw IM. Prevalence of depression in cancer patients: a meta-analysis of diagnostic interviews and self-report instruments. Psychooncology. 2014 Feb;23(2):121-30. doi: 10.1002/pon.3409. Epub 2013 Sep 16. PMID: 24105788; PMCID: PMC4282549.

x<sup>iii</sup> Death doulas in end of life care - Research Notes: Palliative Care (flinders.edu.au) x<sup>iii</sup> COHEN, S., & BLOCK, S. (2004). Issues in psychotherapy with terminally ill patients. Palliative and Supportive Care, 2(2), 181-189. doi:10.1017/S1478951504040246.