

Submission to Productivity Commission Review – Mental Health and Suicide Prevention Agreement

26/03/2025

The National Mental Health Consumer Alliance (the NMHCA) has prepared this submission in response to the invitation to provide input into the Productivity Commission's Final Review into the National Mental Health and Suicide Prevention Agreement. This submission is based on consultations undertaken by each State and Territory mental health consumer peak body.

All references to 'Consumer' and 'lived experience' in this submission refer to mental health consumers with lived experience of mental health challenges and/or suicidality. We use the term "mental health consumers" as a catchall term due to its connection with our movement's history, but we acknowledge that different people identify with different terms. We do not include family, carers, kin or the bereaved in our definition of lived experience as it appears in this report.

The NMHCA

The NMHCA is the national peak body representing mental health consumers. We work together to represent the voice of all mental health consumers on national issues. We are the people experiencing mental health issues/distress; at the table advocating with government and policy makers; and working with a robust network of grassroots communities. More information is available on the NMHCA's website: <u>nmhca.org.au</u>.

Acknowledgement of Country

We acknowledge Aboriginal and Torres Strait Islander Peoples as the traditional custodians of the land on which we work and pay our respects to Elders past and present. Sovereignty was never ceded.

Contents

Review process4
Inclusion of mental health consumers – co design4
Focus
Inclusion of other Australian Government consultations with mental health consumers
Review needs to make a difference to peoples' lives6
Review of the National Mental Health and Suicide Prevention Agreement7
Key Points7
What we think is missing from the National Agreements13
Addressing the Terms of Reference14
a) the impact of mental health and suicide prevention programs and services delivered under the National Agreement to Australia's wellbeing and productivity14
b) the effectiveness of reforms to achieve the objectives and outcomes of the National Agreement including across different communities and populations16
c) the opportunities under the National Agreement to adopt best practice approaches across Australia, particularly where productivity improvements could be achieved17
d) the extent to which the National Agreement enables the preparedness and effectiveness of the mental health and suicide prevention services to respond to current and emerging priorities
e) whether any unintended consequences have occurred such as cost shifting, inefficiencies or adverse consumer outcomes
f) effectiveness of the administration of the National Agreement, including the integration and implementation of Schedule A and the bilateral schedules that support its broader goals
g) effectiveness of reporting and governance arrangements for the National Agreement
h) applicability of the roles and responsibilities established in the National Agreement
i) PC should consider the complexity of integrating services across jurisdictions and ensuring that the voices of First Nations people and people with lived experience of mental health challenges and suicidality those. with lived and/or living experience of mental ill-health and suicide , are heard and acted upon
Recommendations
Recognition of Lived Experience
Appendix 1 – NMHCA Preferred Language

Submission

Review process

Inclusion of mental health consumers – co design

To ensure that this important review of the National Mental Health and Suicide Prevention Agreement is successful and relevant for mental health consumers, for whom the focus of the review should be, the Terms of Reference should have been co-designed and the review process led by mental health consumers. Substituting co-design with consultation removes the ability for consumers to set the scene for the review. Likewise, providing a four week consultation period is not enough time for community consultation about important national funding that impacts everyone.

Focus

The National Agreement recognises that psychosocial supports are an important part of a well-equipped mental health service system. Psychosocial supports are non-clinical and recovery-oriented services, delivered in the community and tailored to individual needs, which support mental health consumers to live independently and safely in the community¹.

While we welcome the use of the term 'wellbeing' throughout Hon Dr Jim Chalmers MP background to the Terms of Reference for this review, the terms of reference do not mirror these words and are too focused on productivity and economics. Mental health consumers recommend:

- wellbeing needs to be measured beyond economic and productivity outcomes, including social and emotional wellbeing. New Zealand has had a national wellbeing budget since 2019² and we recommend something similar to be incorporated in Australia.
- the review needs to ask whether specific mental health services and supports as well as general health services and supports are helping, and not harming, mental health

¹ Statement from Australian Health Ministers: Analysis of unmet need for psychosocial supports outside of the National Disability Insurance <u>Scheme</u> <u>Wellbridge Budget 2022: A Secure Future I. The Treasury New Zealand (https://www.treasury.co.t.nc/oublictions/wellbridge</u>

² Wellbeing Budget 2022: A Secure Future | The Treasury New Zealand (https://www.treasury.govt.nz/publications/wellbeingbudget/wellbeing-budget-2022-secure-future)

consumers. This goes beyond looking at the cost of running the service and bed days saved.

looking at suicide as an economic issue, that is the cost impact of suicide, completely
misses the real human experience and nuance that is needed in the suicide prevention
space.

Inclusion of other Australian Government consultations with mental health consumers

The Australian Government has invited mental health consumers to make submissions/participate in consultation over the last nine months that directly and/or indirectly relate to this review. To ensure that the voices of mental health consumers are heard, we recommend the following submissions provided by the National Mental Health Consumer Alliance (NMHCA)³ and other organisations are considered:

- October 2024: Advice on the National Suicide Prevention Strategy.
- November 2024: Reforms to Strengthen the National Mental Health Commission and National Suicide Prevention Office.
- December 2024: With limited information regarding targeted Foundational Supports –
 Psychosocial Supports for people outside of the National Disability Insurance Scheme
 (NDIS) and little information available from the States/Territories regarding their ability
 to provide the services is concerning.
- January 2025: Primary Health Network Business Model Review and Mental Health Flexible Funding Stream Review - needs to be considered alongside as they are responsible for funding/running services in States/Territories.
- Ongoing changes to NDIS the legislated and proposed changes to the National Disability Insurance Scheme are relevant to the National Agreement as the unmet need for psychosocial services continues to increase.

³ National Mental Health Consumer Alliance | Our Advocacy (https://nmhca.org.au/our-advocacy/)

Additionally, the Royal Commission into Victoria's Mental Health System⁴ and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability⁵ both finished and reported their findings during the current National Agreement. The full recommendations of both Royal Commissions need to be considered, and the agreed recommendations included in any future agreements for the funding and delivery of mental health supports and services.

Review needs to make a difference to peoples' lives

This review of the National Agreement needs to influence future National Agreements and funding decisions that make a difference to the lives of mental health consumers. The voices of mental health consumers need to be listened to and respected as the experts in the mental health landscape that we live in. We know what works for us, what doesn't work for us, and what changes are needed to provide safe and socially, emotionally and economically supports.

We understand that the Productivity Commission (PC) has been asked to holistically consider, assess and make recommendations on the effectiveness and operation of these programs and services in line with the National Agreement, including, but not limited to the Terms of Reference.

Mental health consumers ask the Commissioners to also consider/question/identify the following as part of the review:

- Identify why previous recommendations made regarding the National Mental Health and Suicide Prevention Plan were not implemented.
- Question what it would take to move to the human rights model of disability for people with mental health challenges, as opposed to the current medical model, which could then enable ongoing funding for alternative support services such as Safe Haven, Alternative to Suicide (Alt2Su), Recovery Colleges.
- Promote, with costings, the embedding of lived experience governance in Government departments, organisations and the processes responsible for the development,

⁴ <u>Royal Commission into Victoria's Mental Health System - final report | vic.gov.au</u> (https://www.vic.gov.au/royal-commission-victoriasmental-health-system-final-report)

⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (https://disability.royalcommission.gov.au/)

negotiation and implementation of all funding decisions, including future National Agreements.

 Consider what is, and what is not, measured when looking at the effectiveness of services, and whether there is an inherent bias due to power and historical dynamics that reduces the value of some services compared to others.

Review of the National Mental Health and Suicide Prevention Agreement

Key Points

Lived experience governance

Unfortunately, the National Agreement has not succeeded in embedding ongoing, curated co-design and co-development, limiting the amplification of the voice of, or providing appropriate services for, people with lived experience. South Australia's Lived Experience and Leadership Network (LELAN), states that: "lived experience needs to be embedded in systems, structures, policies, processes, practices, programs and services to increase trust and improve outcomes by avoiding harm and prioritising healing"⁶. This statement considers the reality of operational challenges, such as the difficulty in shifting power structures and fostering a participatory mindset among health professionals.

It is essential that any new National Agreements embed lived experience governance into the sector. It appears that there is a willingness to be open to lived experience involvement but the "how" of including lived experience governance is not clear. Lived experience governance must be meaningful and not a tokenistic effort, making space for the diversity of perspectives that exist in the lived experience space.

We need to embed the Lived Experience theory of change into the perspectives of how we deliver mental health. Lived expertise needs to be included in addition to "evidence-based practice" when assessing the usefulness and safety of programs or service delivery.

Language

The language used when referring to, or speaking of, mental health consumers is very

⁶ Hodges, E., Leditschke, A., Solonsch, L. (2023). The Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All. Prepared by LELAN (SA Lived Experience and Leadership Network) for the National Mental Health Consumer and Carer Forum and the National PHN Mental Health Lived Experience Engagement Network, Mental Health Australia, Canberra

important. The language used should be informed by the expertise, being the collective knowledge of the consumer movement. Language in the movement is about using our experiences in a way that's useful to other people. The language we use is responsive and evolving. Mental health consumers ask the Commissioners to recommend the government update the tired, deficit based, clinical language that appears throughout various documents, including the current National Agreement. We note that the use of *mental ill-health* and *mental disorder* are used in the Terms of Reference for this review. The preferred language is lived experience of mental health challenges.

The NMHCAs definition of consumer lived experience is "experience of mental health challenges that have caused life as we knew it to change SO significantly, we must reimagine and redefine ourselves, our place in the world and our plans". For this reason, we also reject terms that are deficit based like *chronic mental health* and *severe and complex mental health*. Instead, terms like high support needs or medium support needs better describes what we need right now, and what we need right now should be determined by us.

Definitions in the National Agreement need to be up to date and 'verified' by the communities they are speaking of and/or for. Two examples raised by mental health consumers are:

- *self-harm* definition does not illustrate any understanding of the thoughts, feelings, and motivations of people who engage in self-harm.
- person centred care is very vague and does not outline the holistic care that a person needs to have self-directed recovery. Our language guide recommends the use of the term 'person led care' as the individual should be leading their care journey, not just be in the middle of it.

The 2020 PC report into mental health (2020)⁷ included terms that are not used by mental health consumers including *mental ill-health, mental illness* and *severe mental illness*. This suggests these were the terms the PC heard most loudly and consistently when consulting for its last report.

⁷ Inquiry report - Mental Health - PC (https://www.pc.gov.au/inquiries/completed/mental-health/report)

The NMHCA has a preferred language guide which has been included at the end of this submission (Appendix 1). We ask the Commissioners to use our preferred language and to recommend that future documents that are written for, or refer to, mental health consumers are written using the language that we use.

Accountability

The Analysis of unmet need for psychosocial supports outside of the National Disability Insurance Scheme⁸ identified that in 2022–23, an estimated 230,500 people with high support needs (called *severe mental illness* in the report) and 263,100 people with moderate support needs (called *moderate mental illness* in the report) aged 12 to 64 years were not receiving required psychosocial support through the NDIS or other governmentfunded programs. With the proposed changes to what is available through the NDIS, even more mental health consumers will either not be eligible for the NDIS or have their support drastically limited, placing even greater pressure on the States and Territories to provide these support services. The NMHCA is concerned that the numbers of people with psychosocial disability that are unable to access required services will rapidly increase, with demand far outstripping supply.

Additionally, increasing the number of services and supports available to mental health consumers does not automatically result in better care. Cultural safety, trauma-informed and consumer-led care, and responsiveness matter and need to be included in any accountability measurement.

Measurement of Outcomes

Mental health consumers advised that they struggled to assess the outcomes of the National Agreement because it lacked clear accountability measures, measurable objectives, and metrics like timeframes, deadlines, and funding amounts. This lack of clarity undermines the transparency of the agreement and makes it seem superficial. It's crucial to include the perspectives of mental health consumers in the reporting process, as we are the ones directly affected by the National Agreement.

⁸ Analysis of unmet need for psychosocial supports outside of the National Disability Insurance Scheme, Health Policy Analysis, 15 August 2024

Data collection

Data collection, analysis and reporting needs to be improved to allow adequate analysis of future National Agreements. As identified in the National Report Card 2023⁹ from the National Mental Health Commission, there is an incomplete national picture of mental health service outcomes, impact and effectiveness of government funded activities.

Funding must be provided to collect and evaluate effective data for traditional and new services and be collected in a way that is meaningful and relatable to mental health consumers. Identifying failures in service delivery can then be understood and addressed on an ongoing basis.

Social Determinants

Comprehensive, coordinated, and consumer-focused mental health services address the social determinants of health, such as housing, unemployment, and financial insecurity, which are known to contribute to mental distress and suicidality. However, mental health consumers have advised that these services are underfunded not able to keep up with demand.

There is little mention of how social determinants of mental health were to be addressed in the National Agreement, despite their well-documented positive social impact.

The National Agreements primarily focus on clinical service delivery, such as Head to Health Hubs, perinatal mental health screening, and eating disorder day programs. While these services are important, they do not address the broader systemic factors that contribute to poor mental health outcomes. The review must acknowledge the following as key factors in distress and suicidality:

- Financial supports to combat poverty and financial stress.
- Employment to combat unemployment and insecure work.
- Housing affordability and homelessness.
- Trauma.
- Domestic and family violence.

⁹ https://www.mentalhealthcommission.gov.au/sites/default/files/2024-07/national-report-card-2023_0_0.pdf, Accessed 21/10/224

- Barriers to accessing healthcare, including cost and service availability.
- Discrimination in systems (this is particularly important given that currently, many people are reluctant to disclose mental health challenges due to discrimination and the fear of being caught up in punitive involuntary mental health treatment, the mental health system and – for people who are parents or to-be parents – the child protection system).

Medical model vs Human Rights model

While the system says it supports the social model, it is evident that it is still stuck in the medical model where psychiatrists, and to a lesser degree other clinicians and allied health professionals, are deemed to be the "experts". While the sector is slowly moving towards including people with lived experience in the workforce, this progress has been too slow, with the status quo continuing to hold too much power.

We are advocating for a shift towards a human rights-based model of disability in the National Agreement, as opposed to continuing to place authority and power in the hands of clinicians and law enforcement. Investing in effective, non-coercive alternative supports would encourage more individuals to seek help. Such services could create a safe and supportive environment where those experiencing challenges—such as grief, sadness, anger, frustration, or suicidality—can turn without the fear of coercion. For instance, mental health consumers propose that crisis care in the community be delivered by peer workers, who often provide a more empathetic approach informed by their lived and learned experiences, rather than by the police. Mental health consumers urge the Commissioners to explore what it would take to transition to a human rights-based model for individuals facing mental health challenges.

The NMHCA supports moving from a risk management focus to a harm minimisation focus emphasising dignity of risk. Providing a person the right to live the life they choose, even if that choice involves some risk or does not fit into social norms, is a human right under the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD)¹⁰ to which Australia was one of the first signatories albeit with interpretative declarations on Articles 12 and 17 that enable restrictive practices. Acute response services need to be able to

 $^{^{10} {\}rm https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd$

provide harm minimisation supports such as agreeing to take a person in distress to an alternative support service such as a Safe Haven instead of leaving them at home or taking them to a hospital emergency department where they may experience long wait times and the possibility of coercive and restrictive practices.

A whole of community approach needs to be adopted and this might be led by the Social and Emotional Well Being (SEWB) model by Aboriginal and Torres Strait Islander people. However, it is imperative that the SEWB approach remains a non-clinical approach selfdirected by Aboriginal and Torres Strait Islander people for implementation in their communities, with implementation in the broader community under their direction and wisdom.

Mental health consumers advised that successful local community initiatives are often not funded on an ongoing basis due to a lack of evaluation demonstrating their success. These initiatives are usually run on limited funds and additional funding needs to be provided for the evaluation process to take place so the local initiatives can prove their success and get funding to continue.

That real alternatives to the medical model need to be made available to people experiencing mental health challenges and suicidality. We need innovation outside the clinical models and a move away from the current piecemeal approach to the funding and running of these supports including Safe Havens and Alternative to Suicide (Alt2Su) services. Consumers from around Australia are interested in how Australian governments could ensure peer-run services are available throughout Australia.

Mental health consumers ask for funding to evaluate local community initiatives such as ALt2Su and Safe Haven to demonstrate their success so that they can continue beyond their short-term funding rather than having to close and be replaced with the state/national based treatment model. These services are ripe for being authentically designed, run and managed using the lived experience governance framework¹¹.

¹¹ Hodges, E., Leditschke, A., Solonsch, L. (2023). The Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All. Prepared by LELAN (SA Lived Experience and Leadership Network) for the National Mental Health Consumer and Carer Forum and the National PHN

Rural and Remote

It is important for policy makers to understand that the needs and experiences of regional and remote mental health consumers are different from each other. Putting together plans and policies to look at both regional and rural population has not been successful. For example, Western Australia is a very large jurisdiction, and the access and barriers are very different across the state. Local conditions and solutions that work in one place may be inefficient, ineffective, or damaging in another.

Mental health consumers recognise that the main issues for those outside the metropolitan area need to be solved at a local level but should generally be based on social needs including:

- Transport issues.
- Staffing issues.
- Staff accommodation issues.
- Availability of Step Up/Step Down facilities.
- Requirement to go to city for specialist help.

What we think is missing from the National Agreements

The National Agreement does not include the opinion of lived expertise nor a focus on human elements. Mental health consumers often experience not feeling heard or not being able to identify with health workers within programs and services, and so the National Agreement further exacerbates this problem.

Consumers propose that care should be person-led with a focus on recovery and consider that peer workers – who are equipped with both lived and learned expertise – are best placed to improve this issue within services.

Consumers in the justice system

Non-forensic mental health consumers that are in the justice system are still siloed away from mainstream mental health and other services. There needs to be serious consideration of the safety of people who are in custody and the frameworks needed for reintegration of family and community. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability¹² made several recommendations about the forensic system and its impact on people with complex support needs in correctional and forensic facilities. The Royal Commission found that seclusion, even when its harmful effects are recognised, is commonly used and can become entrenched. Forensic patients can be at risk of indefinite detention, meaning no date is fixed for their release. This can lead to a period of detention longer than if they had been convicted and sentenced in an ordinary criminal trial. Prolonged detention places forensic patients at risk of violence, abuse and neglect and experiencing cumulative trauma.

Other missing elements

In addition, the last PC report called for the following that are not part of the National Agreement and have not been funded nationally:

- National stigma reduction strategy was completed but was never published or implemented.
- Training for police as first responders e.g. NSW Police cut an in person 4-day mental health training program for police in 2020, which to our knowledge has not been reinstated¹³.

Addressing the Terms of Reference

a) the impact of mental health and suicide prevention programs and services delivered under the National Agreement to Australia's wellbeing and productivity

As identified earlier, mental health consumers want to ensure outcomes are measured beyond economic and workforce outcomes and include social and emotional wellbeing. The current National Agreement primarily focuses on selective or indicated clinical service delivery, such as Medicare Mental Health Hubs (previously known as Head to Health Hubs), perinatal mental health screening, and eating disorder day programs. While mental health consumers recognise that these services are important, they identified the lack of universal strategies that strengthen protective factors and mitigate social determinants of distress.

¹² <u>Final Report | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability</u> (https://disability.royalcommission.gov.au/publications/final-report)

¹³<u>https://www.police.nsw.gov.au/ data/assets/pdf file/0004/884974/Review of the NSW Police Force response to mental health in cidents in the community.pdf</u>

Focused selective services do not address the broader systemic factors such as the social determinants of health that contribute to poor mental health outcomes, including:

- Poverty, financial insecurity and financial stress.
- Unemployment and insecure work.
- Domestic and family violence.
- Housing.
- Barriers to accessing healthcare, including cost and service availability.
- Discrimination in systems (this is particularly important given that currently, many people are reluctant to disclose mental health due to the stigma and the fear of being caught up in punitive involuntary mental health treatment, the mental health system and for people who are parents or to-be parents, the child protection system).

There is little mention of how these social determinants of mental health will be addressed, despite their well-documented impact. Mental health consumers identified that these services are underfunded and stretched beyond capacity, restricting their ability to keep up with demand. More focus is needed on trauma-informed, peer led services within the community away from clinical settings to support individual wellbeing.

The impact of individual focused services also depends on how they are run. The success of Medicare Mental Health Centres depends greatly on who manages them and where they are located. For example, mental health consumers in the ACT reported that the Medicare Mental Health Centre was a good service and a useful resource, but this wasn't reported by other States/Territories.

Although the National Agreement has seen the funding for suicide prevention activity increase in recent years suicide rates have not decreased¹⁴. Australia still lacks a whole-of-system approach and a shared understanding of the drivers of suicidality¹⁵. There are still critical service gaps such as a lack of long-term support and community-based options.

¹⁴ <u>Suicide and intentional self-harm - Australian Institute of Health and Welfare</u> (https://www.aihw.gov.au/suicide-self-harmmonitoring/summary/suicide-and-intentional-self-harm)

¹⁵ Bassilios, B., Currier, D., Krysinska, K., Dunt, D., Machlin, A., Newton, D., Williamson, M., & Pirkis, J. (2024) 'Government-Funded Suicide Prevention in Australia – An Environmental Scan', *BMC Public Health*, 24:2315. https://doi.org/10.1186/s12889-024-19483-w

b) the effectiveness of reforms to achieve the objectives and outcomes of the National Agreement including across different communities and populations

The National Agreement does not go far enough in addressing discrimination. There are no accountability measures that mental health consumers are aware of for services that carry out discriminatory or stigmatising practices. We question what accountability measures are in place to make sure the populations listed in paragraph 111 of the National Agreement are receiving adequate services. Australia needs to go beyond addressing stigma and discrimination and adopt a social justice framework for mental health consumers.

Effective reforms have seen the implementation of non-clinical, community led services like Safe Spaces, Safe Havens and Alternatives to Suicide (Alt2Su). However, these are not accessible in all communities, States and Territories and are underfunded to meet demand in the community. In NSW for example, Safe Havens are being used as a community drop-in service for people without homes due to the lack of other support services. Additionally, due to these services being managed by different organisations including Primary Health Networks (PHNs) across Australia, some are being overrun by clinical governance i.e. depending on the funding provider, some clinical aspects are being introduced into some Safe Havens/Safe Spaces such as the requirement for the completion of a distress scale (e.g. Kessler Psychological Distress Scale) and/or a requirement to provide identification or contact details. Requiring people to fill in paperwork to "prove" either who they are or the severity of their symptoms is inappropriate as it (a) perpetuates the medical model of mental health services, and (b) suggests the funder does not trust the consumer or peer service provider, further entrenching discriminatory ideas that someone may be pretending to be experiencing suicidality for attention.

The National Agreement includes commitments to mental health consumer involvement and the inclusion of specific marginalised groups including people who identify as LGBTIQA+, Aboriginal and Torres Strait Islander, and culturally and linguistically diverse communities. However, there is no clear accountability mechanism to ensure these commitments have led to meaningful action. The National Agreement needs more consideration of the perspectives of each of these groups, with a focus on holistic approaches, not just funding.

The PHNs and Local Hospital Networks (LHNs) were identified in the National Agreement to

coordinate regional care, but poor integration between federal and state-funded services remains a barrier.

Mental health consumers recommend ongoing reforms and regular evaluations throughout the National Agreement period to ensure changing demands/needs of each community are met. Additionally, reforms provide the impetus for organisations to co-design new services with consumers if done appropriately through a trauma informed, human rights-based, and lived experience lens.

The current National Agreement occasionally mentions Alcohol and Other Drugs (AOD). Given the intersectionality with mental health challenges, mental health consumers recommend that the National Agreement should specifically reflect this.

c) the opportunities under the National Agreement to adopt best practice approaches across Australia, particularly where productivity improvements could be achieved

As identified earlier, mental health consumers call on the Commissioners to prioritise the development of a co-design process to include consumer experience and consumer led outcomes alongside economic productivity in evaluating best practices.

Mental health consumers define "best practice" to include community-based as well as peer-led and lived experience-driven models, not just clinical efficiency. To ensure best practice, mental health consumers recommend the National Agreement embeds lived experience governance in every part of service design and implementation, with a lived experience workforce required to be embedded in every service funded including at the management level.

Telehealth and digital tools improve accessibility but need better funding, awareness, and evaluation.

Programs like The Way Back Support Service (TWBSS) and HOPE have shown short-term benefits of adopting a lived experience operated model (e.g., reduced suicidal ideation, increased emotional wellbeing), but, again, there is limited evidence on long-term

17

outcomes¹⁶.

Preventative approaches (e.g., financial counselling, housing support, employment programs) remain underdeveloped, limiting broader mental health improvements.

d) the extent to which the National Agreement enables the preparedness and effectiveness of the mental health and suicide prevention services to respond to current and emerging priorities

The ongoing cost of living crisis, the psychiatrist dispute in New South Wales, and the growing demand for underfunded alternative supports highlight that the National Agreement has failed to address current and emerging priorities. Despite mental health challenges and Alcohol and Other Drugs (AOD) use representing 14.1% of the burden of disease in 2024¹⁷ (which is the second-highest burden of disease in Australia after Cancer) chronic underfunding remains a major issue. Mental health funding has remained stagnant at around 7% of the total health budget since 1992, with the 2024 Budget's additional \$360 million investment falling short of meeting the increasing demand.

The cost of living has increased, yet access to free/low cost mental health services and supports is still limited with long waiting times experienced nationally. Workplace shortages, especially in regional areas, have put strain onto services and supports. Crisis response continues to be prioritised over long term recovery and prevention of mental health challenges such as adequate funding for the social determinants of health such as housing and income support.

More money needs to be devoted to community care with less focus on crisis care (acute care/hospital admissions) which will reduce the risk of re-traumatisation. There have been some promising innovations, for example the Distress Brief Intervention trials, but broader systemic reforms remain limited under the National Agreement.

As the national peak body for mental health consumers, the NMHCA believes that the commissioning process that PHNs utilise has been disappointing. For this reason, the next Australian Government should rebalance commissioning of mental health services towards

¹⁶ Centre for Mental Health (2023) *Evidence Brief Focus Area 5 (Final – 30 May 2023)*, Retrieved 25 February 2025. <u>https://everymind.imgix.net/assets/Uploads/Focus-Area-5 Final-Brief 30-5-2023.pdf</u>

¹⁷Australian Burden of Disease Study 2024, Key findings - Australian Institute of Health and Welfare (https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-of-disease-study-2024/contents/key-findings)

community-based and lived experience-led services through the next National Mental Health and Suicide Prevention Agreement and National Mental Health Plan.

e) whether any unintended consequences have occurred such as cost shifting, inefficiencies or adverse consumer outcomes

Mental health consumers advise the PC to ensure consumer experiences are central in assessing inefficiencies and adverse outcomes.

The funding structure underpinning the National Agreement does create challenges. Fragmentation between federal and state systems leads to duplication, service gaps, and inefficiencies. Federal funding has been primary care focused, supporting Medicaresubsidised mental health services, while states manage hospital based acute care including hospitals, emergency care, and community mental health. We believe this has resulted in a funding dilemma for states/territories, who need to juggle funding of hospital-based care and community-based services. Given mental health funding sits with Health departments – which preference the medical model of mental health "treatment" – funding is favourably distributed to "bricks and beds" (i.e. hospitals) at the detriment of community-based services. This has led to the dismantling of community mental health services (e.g., assertive outreach teams) and increased emergency department presentations and costs. This policy focus pushes people into coercive and/or involuntary hospital care instead of voluntary support and assistance, causing harm to mental health consumers.

Further, continuity of care is an important part of mental health recovery but does not seem to be prioritised in the National Agreement, with the systems not built to enable this. Aftercare is imagined as service referral after hospital stays. This does not address the needs of people being discharged who are just placed on waitlists. After care needs to be holistic and delivered regardless of the status of the person's referrals to other organisations.

Service gaps for non-clinical and peer-run services are evident. This has led to service fragmentation and unmet needs, particularly for people with high support needs.

Mental health consumers are faced with high out-of-pocket costs when seeking clinical support from Medicare Benefits Schedule funded services including General Practitioners (GP), psychologists and/or psychiatrists. Few bulk-billed options are available for GPs,

especially in the Australian Capital Territory, Tasmania and in Australia's rural and remote settings. With caps on the number of telehealth psychiatry and psychology services a mental health consumer can access through the Better Access Initiative, mental health consumers face high out of pocket costs to access these services. Access to private psychiatry services is prohibitively expensive, with the required top level of private health insurance cover required to be covered privately which doesn't cover the mental health total hospital admission costs.

The impact of the State/Territory closures of community psychosocial supports, such as the Personal Helpers and Mentors service (PHaMs)¹⁸ with funding being syphoned to the National Disability Insurance Scheme (NDIS) is still being felt throughout Australia. Unmet need resulting from gaps in psychosocial support leaves people with lived experience of psychosocial disability who are evaluated as not meeting the requirements to join the NDIS without adequate care. This increases crisis recurrence and long-term suicidality risks and speaks to an urgent systemic need to consider the unmet needs of people with disability and a plan for how those needs can be met, including assigning clear responsibilities for funding and providing essential supports.

Mental health consumers ask the Commissioners to evaluate whether cost shifting has created gaps in service access, particularly for non-clinical and peer-run services.

Additionally, we need to shift the focus from solely responding to crises to fostering wellbeing and resilience at all stages of life. Suicide prevention remains crisis-focused, with emergency and hospital-based care prioritised, while preventative and long-term recovery services remain underfunded and lack sustainability due to short-term funding cycles.

Traditionally, suicide prevention has used coercion to stop people from dying. Through coercion, consumers are silenced, resulting in many consumers experiencing distress alone out of fear of ending up in the hands of police or clinicians. Our preferred approach is to have an open dialogue about suicide with other people with lived experience (which might include peer workers), so that suicidality can be openly spoken about along with options about why we might want to stay alive, without the fear of being punished or discriminated

¹⁸ Bring back PHaMs - Learn more about the PHaMs program and the Bring Back PHaMs advocacy campaign (https://bringbackphams.com/about)

against.

As BEING Mental Health Consumers¹⁹, New South Wales Peak Body for Mental Health Consumers, articulated in their Position Paper on suicidality, people who experience suicidality are treated in an acute setting, with their care based on a risk equation. These risk-averse environments tend to violate the human rights of individual consumers and yet were supported by the National Suicide Prevention Strategy²⁰.

The outcome of standardised suicide risk management assessments has adverse impacts on mental health consumers in rural and remote Australia. The cost of an ambulance to take a mental health consumer to the closest suitable hospital after being called because they have expressed suicidal thoughts or ideation to a service is often financially devastating. Again, while this differs widely between the different States/Territories, the resultant financial stress may hamper recovery and stop someone from using crisis services in the future. The cost can be even greater if a consumer is visiting a state where they are not resident.

Standardized suicide risk management assessments have negative impacts on mental health consumers in rural and remote Australia. One significant issue is the cost of ambulance transport to the nearest appropriate hospital, often called by a support service or help line when a mental health consumer expresses suicidal thoughts or ideation. This expense can be financially overwhelming with the financial burden hindering recovery and discouraging people from seeking crisis services in the future. While we understand that this differs between states and territories, all consumers across Australia have equitable access to emergency supports including assessment, treatment and transport, that do not financially burden them.

²⁰ The National Suicide Prevention Strategy | National Suicide Prevention Office | National Mental Health Commission

¹⁹ https://being.org.au/storage/2024/07/Position-Statement-no.6-Suicidality-Suicide-Suicidism.pdf, Accessed 21/10/2024

⁽https://www.mentalhealthcommission.gov.au/national-suicide-prevention-strategy)

f) effectiveness of the administration of the National Agreement, including the integration and implementation of Schedule A and the bilateral schedules that support its broader goals

Mental health consumers would like to see an improvement in the transparency of funding allocations between federal and state systems.

PHNs are struggling to deliver core parts of the National Agreement. While PHNs are attempting to integrate services and supports, care coordination remains limited, due to difficulties with navigating the system and digital tools like the National Mental Health Platform remain underdeveloped. Additionally, regional integration varies, with joint regional mental health plans in place, but their success depends on state and PHN cooperation, which is stronger in some states (e.g., NSW, Victoria) but lacking in others.

The review should confirm whether peer-led and lived experience services are properly funded and embedded in both national and state-level agreements, rather than being treated as short-term projects or excluded from mainstream mental health planning. It should also assess how well the Commonwealth and States are coordinating resources to support these services, ensuring they are sustainable and not just add-ons.

Suicide Prevention

Whole-of-government collaboration is weak, as suicide prevention efforts remain fragmented across portfolios, and while the National Agreement commits governments to cooperation, practical implementation and funding alignment are inconsistent.

g) effectiveness of reporting and governance arrangements for the National Agreement

Consumer peak bodies, both the national body and the State/Territory bodies, should be funded to actively contribute to the planning, implementation, and governance of the National Agreement in each jurisdiction, noting that the Northern Territory is the only State/Territory without a mental health consumer peak body. This would ensure lived experience perspectives shape decision-making at all levels.

Peak bodies play a vital role in providing informed lived expertise and advice to governments, shedding light on what matters to people experiencing mental health distress. Peak bodies can offer insights into service usage, interactions with bureaucracy and

emergency services, and how these experiences shape outcomes. Peak bodies also provide capacity building to mental health consumers who can then advocate for systemic change providing a voice to those who cannot.

For too long, mental health consumers have been disempowered, with decisions made about us by psychiatrists, medical professionals, and service providers without our input. Often, those who speak on mental health issues are the very professionals whose practices may have caused harm, such as psychiatrists who have confined us or medical professionals who may only offer quick fix medications, rather than understand holistic needs.

Funding for Peak bodies provides an informed and ready voice to provide thought leadership, high-level committee representation and deep policy advice to Governments. They should be funded adequately to perform this important role, noting that most mental health consumer peaks receive core funding covering wages for 3-4 staff plus funds for paid participation and general operating expenses. This is inadequate to cover the breadth of tasks required of them (which extends beyond health into areas such as NDIS and social services) and therefore does not indicate a commitment to lived experience leadership by governments despite their placations. Instead, adequate funding of mental health consumer peak bodies should be increased and viewed as an investment in genuine system reform. Partnering with lived experience peaks across all levels of government early in policy development will produce better outcomes for people. Peaks should be embraced by the sector, not just seen as an irritant or the lone voice for lived experience inclusion.

Measurement of Outcomes

Concerns regarding the Your Experience of Service (YES) surveys and whether they are trustworthy were raised by mental health consumers. There is no transparency of the completion and/or the collection of these surveys, making it unknown as to who completes the survey – is it all mental health consumers who use the service or is it just those who are likely to give the service a positive review. The YES survey data is overly positive compared to the evidence we hear from mental health consumers during direct engagement.

Data collection

Data collection, analysis and reporting needs to be improved to allow adequate analysis of

23

future National Agreements. As identified in the National Report Card 2023²¹ from the National Mental Health Commission, there is an incomplete national picture of mental health service outcomes, impact and effectiveness of government funded activities.

Transparency and accountability are weak, with mental health funding and service delivery lacking oversight, and governance structures have failed to ensure equitable service access across states. Lack of long-term evaluation frameworks makes it difficult to assess program effectiveness, as initiatives like The Way Back Support Services in Queensland show promise but lack comprehensive outcome tracking.

Suicide Prevention

Data collection remains inconsistent, with the National Suicide and Self-Harm Monitoring System improving availability, but suicide attempt data and priority population insights (e.g., First Nations, LGBTQ+) remain incomplete, limiting effective policy responses.

h) applicability of the roles and responsibilities established in the National Agreement

Mental health consumers need to be included in the National Agreement's governance and funding structures. Mental health consumers need to have decision making roles, not just advisory positions and be included at the beginning, not just be consulted with. As identified previously, the voice of lived experience will only be heard as loudly as the voice of the traditional, clinical bodies by embedding lived experience into the governance of the National Agreement. Nothing about us, without us.

To ensure the voices of lived experience are included and to remove the current power imbalance, mental health consumers call for a National Mental Health Chief Consumer Officer to sit alongside equivalent officers within the Commonwealth Government. This Office will create an equalisation to the clinical voices (Chief Psychiatrist, Chief Medical Officer, Chief Nurse) and health economics voice (Chief Health Economist).

²¹ https://www.mentalhealthcommission.gov.au/sites/default/files/2024-07/national-report-card-2023_0_0.pdf, Accessed 21/10/224

i) PC should consider the complexity of integrating services across jurisdictions and ensuring that the voices of First Nations people and *people with lived experience of mental health challenges and suicidality* those with lived and/or living experience of mental ill-health and suicide, are heard and acted upon.

Consumers ask that the Commissioners assess whether lived experience and First Nations leadership influenced funding, policy, and service models, beyond consultation.

Mental health consumers ask the Commissioners to ensure an equity-focused assessment of the reforms and outcomes of the National Agreement is carried out. To ensure this, priority populations (First Nations people, culturally and racially marginalised communities, LGBTQIA+, rural and remote communities, younger people) need to be adequately supported to participate in the assessment process. Additionally, lived experience perspectives must be included in evaluating the National Agreement.

Suicide Prevention

Suicide prevention strategies acknowledge First Nations and LGBTQIA+ people as priority groups, but implementation is inconsistent. Few services are designed and delivered by First Nations organisations. We refer you to the Aboriginal and Torres Strait Islander Lived Experience Centre (ILEC) for their expertise on this matter.

Recommendations

The following recommendations have been summarised from this submission:

- The review should identify why previous recommendations made regarding the National Mental Health and Suicide Prevention Plan were not implemented.
- 2. The review should question whether services are helping not harming people. The harm caused by a service is difficult to quantitate. While a service may look like it is cost effective based on bed days or assumed Quality Adjusted Life Years based on clinical information, the harm caused by services is enduring.
- 3. The review should investigate and identify what is required to move to a human rights model of disability for people with mental health challenges.
- 4. The review should outline a process to ensure, with costings, the embedding of lived experience governance in organisations and processes responsible for the development, negotiation and implementation of all funding decisions, including future National Agreements.
- 5. Tired, deficit based, clinical language that appears throughout various documents, including the current National Agreement needs to be updated and 'verified' by the communities they are speaking for. The report from this review needs to ensure it uses language used by mental health consumers.
- 6. Clear accountability measures, measurable objectives and/or metrics such as timeframes, deadlines, and funding amounts must be included to provide the transparency needed to evaluate outcomes from future agreements.
- 7. The National Agreement will not be able to provide comprehensive, coordinated, and consumer-focused mental health services without also addressing the social determinants of health, such as housing, unemployment, and financial insecurity. The development of interdepartmental coordination of mental health services, and services to address social determinants of health, is necessary to ensure this occurs.
- Adequate support needs to be provided to allow priority populations (First Nations, culturally and racially marginalised, LGBTQIA+, rural communities, young people) to participate in the assessment process
- The review should confirm whether peer-led and lived experience services are properly funded and embedded in both national and state-level agreements, rather

than being treated as short-term projects or excluded from mainstream mental health planning. It should also assess how well the Commonwealth and States are coordinating resources to support these services, ensuring they are sustainable and not just add-ons.

- 10. Consumer peak bodies, both the national body and the State and Territory bodies, should be funded to actively contribute to the planning, implementation, and governance of the National Agreement in each jurisdiction. They should also be adequately funded to provide advice to all levels of Government.
- 11. Funding allocated to collect and evaluate effective data for both traditional and new services and supports. Data needs to be collected in a way that is meaningful and relatable to mental health consumers. Consumer-driven data and qualitative lived experience reporting needs to be used, not just service metrics.
- 12. National Mental Health Chief Consumer Officer position to be created to sit alongside equivalent officers within the Commonwealth Government.

Recognition of Lived Experience

As a consumer lived experience-led organisation, the National Mental Health Consumer Alliance values the skill and expertise of consumers with lived experience. We pay tribute to those we have lost for the work that they have done to advocate for our rights. We acknowledge that we stand on the shoulders of giants who have paved the way for the rights we have today, and we will continue their work today and every day until the mental health system recognises and upholds our human rights. Nothing about us without us.



Submission prepared March 2025. National Mental Health Consumer Alliance. See <u>nmhca.org.au</u> for more information about the NMHCA. For questions about this submission, please contact us at <u>policy@nmhca.org.au</u>.



Appendix 1 – NMHCA Preferred Language

NMHCA Preferred Language

The NMHCA will advocate for specific language to be used at the National level. In doing this, we recognise that the State and Territory consumer Peak Bodies will have different views on language. We also recognise that individual mental health consumers will have different views to us.

The language we are promoting is informed by the expertise and the collective knowledge of the consumer movement.

We are promoting the use of language that is both:

- rights-based and strengths-based not deficits based, and
- person centred not clinically centred.

In addition, the recognition of lived experience by organisations, Departments and Government, have become performative and is often said by the very institutions that have done the most harm. The 'recognition' and the 'respect' has not been amplified in real terms which causes further harm. We have asked organisations and government departments to reflect on this, and whether their words are being put into action.

We also note that some words will change along with the consumer movement, and new words will be added or modified over time.

The table below has been circulated to the Department of Health and Assistant Minister Emma McBride's office, who have agreed to ensure that these terms are used. We also advised these two bodies that State and Territory Peaks may still use, and advocate for, different language.



	Leave these terms behind	Replace with these terms	Reasoning
1	"lived/living experience", "patients"	"consumer lived experience", "mental health consumer"	Mental health consumer lived experience is defined as experience of mental health challenges that have caused life as we knew it to change so significantly we must reimagine and redefine ourselves, our place in the world, and out plans.
			Lived experience implies living experience as well. Generally people with mental health challenges go through phases of wellness and challenges so using the term lived/living is unnecessary.
			Be specific about whose lived experience we are speaking about – consumer, family member, a person who uses drugs.
			The term "Mental Health Consumer" includes people who identify as having a psychosocial



			disability, who identify as having lived experience of mental health challenges, who identify as mental health consumers. We use these interchangeably.
2	"mental illness", "mental ill health", "mental health", "mental impairment", "mental disorder", "mental impairment"	"mental health challenges"	The words in the first column refer to medical model of treatment and are deficit based.
3	'chronic mental health", "severe mental health", "mental disorder"	"high support needs" or "medium support needs"	Describes what we need right now, and what we need is determined by us.
4	"psychosocial disability"	??	This is still a contested term in the consumer movement. The NMHCA has decided to use the NDIS Review report definition of disability (and therefore psychosocial disability): <i>intersecting</i> <i>societal barriers are the obstacles to equal</i> <i>participation</i> .
5	"Recovery"	??	Seen as a desire by our late capitalist society for us to be recovered enough to contribute back to society through working, partnering and paying the rent. Consumers have started to question the



			relevance of this term and we expect it to become outdated in the coming years.
			Note this is different to the term "recovery- oriented" which has not been disputed by consumers.
6	"Stigma"	"discrimination"	Calling for change as there are no protections against stigma, and there are protections against discrimination. We are calling for Australia to adopt a Disability Rights Act so it is clear to everyone what behaviour constitutes discrimination, given there are currently several definitions.