31 July 2025

Mental Health and Suicide Prevention Agreement Review Productivity Commission GPO Box 1428
Canberra ACT 2601

Sent via email: mentalhealthreview@pc.gov.au

Dear Sir/Madam,



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Final Review of the National Mental Health and Suicide Prevention Agreement

Stroke Foundation welcomes the opportunity to provide a submission to the Productivity Commission's Final Review of the National Mental Health and Suicide Prevention Agreement (the Agreement).

As the national voice for stroke in Australia, Stroke Foundation supports a National Agreement that takes a whole-of-government approach to transforming and improving Australia's mental health and suicide prevention systems. This is needed to ensure all Australians can equitably access a universal mental health care system that integrates seamlessly with other parts of the health and social system to provide best-practice and evidence-based essential services in the right place, at the right time, and in the right environment to meet the needs of individuals and communities.

Stroke Foundation broadly supports the Agreement Principles, including the focus on a people-centred system; embedding of lived experience into design, planning and delivery of services; reducing overlap, gaps and fragmentation; supporting workforce capability with a focus on rural and remote areas; supporting a stepped care model, early intervention and prevention and service provision across the entire spectrum of care; cooperation across providers, systems and governments; improved transparency and accountability; recognition of social determinants that contribute directly or indirectly to distress and suicide.

We acknowledge the significant effort undertaken by the Commission to assess the effectiveness of the current Agreement and gather crucial insights from a wide range of stakeholders, particularly those with lived and living experience. We believe this interim report highlights critical areas where the current approach is falling short and signals an urgent need for fundamental change to improve mental health and suicide prevention outcomes for all Australians.

Stroke Foundation broadly agrees with the interim report findings and recommendations:

- Promoting mental health and wellbeing should be underpinned by a National Strategy that articulates a clear and shared vision for the wellbeing of Australians and priority areas for action based on contemporary evidence.
- A National Strategy must include approaches to strengthen social and economic determinants that impact mental health and contribute to suicidal distress and crisis of survivors of stroke, people with chronic health conditions and disability, as well as their families, carers, kinship groups, and supporters.
- Development, implementation, and evaluation of a National Strategy, action plan(s), outcomes frameworks, and/or government agreements should be co-produced and/or



co-designed with people with lived experience, as well as carers, families, and kinship groups to ensure a reformed systems approach that will increase trust, improve outcomes, and reflects the needs of the people the system serves.

- Extension of the current National Agreement until 2027 to ensure adequate time for meaningful engagement with consumer, and to allow adequate time for the evaluation of the Commonwealth Psychosocial Support Program, release of the National Stigma and Discrimination Reduction Strategy, and development of a new National Mental Health and Wellbeing Strategy.
- There is an urgent need to act on outstanding Agreement commitment, particularly to address unmet needs for psychosocial supports and to release the Stigma and Discrimination Reduction Strategy
- Equitable access to appropriate resources and funding models must be developed and implemented to support greater flexibility and devolving power that enable bottom-up, community-led, place-based approaches to be developed by communities with greater control over the ways services and initiatives are designed, delivered, and monitored.
- Better integration of mental health, disability, aged care, and health systems with other systems (e.g., housing, education, employment) to improve the quality and continuity of care for survivors of stroke, their families and supporters, and all people impacted by mental health challenges and suicide.

Additionally, Stroke Foundation supports calls for:

- A comprehensive overhaul of the National agreement in partnership with consumer and carer peak bodies to include recommendations from other inquiries relevant to the Agreement, and ensure alignment with the principles, objectives and identified enablers outlined in the National Suicide Prevention Strategy 2025-2035¹ and the National Aboriginal and Torres Strait Islander Suicide Prevention Strategy 2025-2035²;
- Urgent need to embed lived and living expertise into the governance framework, including embedding co-production and co-design into National Agreement overhaul and negotiations processes;
- More community psychosocial supports both within and outside the NDIS including permanently funding the Commonwealth Psychosocial Support Program;
- Need for improved mental health literacy for the community, including making
 information available in accessible formats so individuals and communities can be
 empowered to make informed decisions about the supports and services that are right for
 them;
- More training models and workforce pipeline planning to avoid staff turnover, attrition and burnout and to ensure service staff and volunteers have the right resources, skills, knowledge, and experience to provide effective, person-cantered, trauma-informed support; and
- Need for greater clarity and transparency in the collection of data and reporting of outcomes, including clearly defined responsibilities and roles for stakeholders and alignment with the National Suicide Prevention Strategy 2025-2035 and National

National Aboriginal and Torres Strait Islander Suicide Prevention Strategy | Australian Government Department of Health, Disability and Ageing

¹ National Suicide Prevention Office. The National Suicide Prevention Strategy 2025-2035. Canberra: 2025. ISBN: 978-1-7636173-1-5 https://www.mentalhealthcommission.gov.au/sites/default/files/2025-02/the-national-suicide-prevention-strategy.pdf
² National Aboriginal and Torres Strait Islander Suicide Prevention Strategy | Australian Government Department of



Aboriginal and Torres Strait Islander Suicide Prevention Strategy 2025-2035 objectives and monitoring frameworks.

This letter (and Attachment 1: Evidence and Supporting Information) focuses on highlighting the key issues and areas that require particular focus and further action through a reformed Agreement with an emphasis on broader national impact and application of the Agreement, recognising that there are also individual bilateral agreements in place with States and Territories. Essentially, while the Agreement may have started progress towards its goal, there is more to be done.

Thank you for the opportunity to provide this submission. Stroke Foundation and our 440,000-strong community of survivors of stroke, their families and carers stand ready to work with all Federal and Jurisdictional Governments, Productivity Commission and other relevant stakeholders to work towards improving mental health outcomes for all Australians, and particularly survivors of stroke and their families and carers. This is vital work, and we have no time to waste.

We look forward to the final report and remain committed to supporting efforts to improve mental health and suicide prevention outcomes across Australia.

Yours sincerely

Dr Lisa Murphy Chief Executive Officer Stroke Foundation



Attachment 1: Evidence and Supporting Information

The Challenge

Stroke is one of Australia's leading causes of disability, with lasting impacts on the physical, mental, and emotional wellbeing of survivors and their families.

Each year, nearly 46,000 Australians experience a stroke (one every 11 minutes), and 8,400 lose their lives. Over 440,400 survivors of stroke live in Australia, many with complex, ongoing needs.³

It is estimated that 1 in 4 (25%) people who experience a first-ever stroke and 1 in 10 (10%) people who experience a recurrent stroke are under 65 years of age. ⁴

Regional Australians face a 17% higher risk of stroke compared to those in metropolitan areas.⁵ Aboriginal and Torres Strait Islander Australians experience strokes and stroke-related mortality at rates 2-3 times higher than non-Indigenous people, and at younger age.⁶

Mental health challenges after stroke

The brain is fed by blood carrying oxygen and nutrients through blood vessels called arteries. A stroke is when blood can't get to all parts of the brain because of a blocked or burst artery. If this happens, the brain can be injured. As a result, the brain cells die due to a lack of oxygen and nutrients.

The impact of the stroke depends on the area of the brain where the injury occurs. When cells die or damage occurs in a particular area of the brain it can impact how a person uses words, swallows, sees, touches, and moves their body. However, the impacts often extend beyond the physical, affecting how a person thinks, feels, and behaves, which can consequently impact wellbeing.

Depression and anxiety are common following stroke and for many survivors of stroke and can hamper recovery and have a significant social impact.

Survivors of stroke often report experiencing major depressive episodes, suicidal ideation, post-traumatic stress disorder, difficulty managing changes in emotions, social isolation, and other mental health distresses, often with minimal appropriate support or even knowing where to turn⁷.

³ Kim J., Neville E., et al. (on behalf of the Stroke Foundation) Economic Impact of Stroke 2024. Stroke Foundation 2024. Melbourne Australia. Pages 1-115. DOI: 10.26180/27049219

⁵ Deloitte Access Economics. 2020. <u>No postcode untouched</u>, Stroke in Australia 2020.

⁶ Australian Institute of Health and Welfare. 2024. Heart, stroke and vascular disease –Australian facts, AIHW, Australian Government

⁷ Zhang, S., Xu, M., Liu, Z. J., Feng, J., & Ma, Y. (2020). <u>Neuropsychiatric issues after stroke: Clinical significance and therapeutic implications</u>. *World journal of psychiatry* 10(6), 125–138.



Data shows one-third of survivors of stroke will experience depression⁸, and between 18 and 25 percent will experience anxiety⁹ and between 10 and 30 percent of survivors will experience post-traumatic stress reactions.^{10,11,12}

Stroke Foundation own data reveals that 1 in 6 (17%) calls to StrokeLine—our free and confidential national helpline – come from survivors of stroke and families seeking help with suicide, depression, or anxiety concerns. This represents a three-fold increase in such calls since 2021.

Having depression or low mood after a stroke has long been associated with increased suicidal ideation and increase risk of suicide attempt and suicide.

Several studies have shown that stroke is a risk factor for both suicidal ideation and death by suicide¹³ and the suicide rate in survivors of stroke can be as high as 3 to 4 per 1,000 in the first five years after the stroke event¹⁴.

Stroke Foundation's 2024 National Audit of Rehabilitation Services found that 1 in 3 eligible patients did not receive psychological assessments as part of their stroke recovery. Of those with mood and mental health challenges, just over half (51%) had access to a psychologist—revealing major gaps in specialist mental health care¹⁵.

While mental health conditions can be associated with increased suicide risk, it is not the only contributor.

Best-practice Stroke Management and Rehabilitation is proactive Mental Health Promotion and Suicide Prevention

⁸ Hackett ML, Pickles K. Part I: Frequency of depression after stroke: An updated systematic review and metaanalysis of observational studies. International Journal of Stroke. 2014; 9:1017-25.

⁹ Burton, C. A. C., Murray, J., Holmes, J., Astin, F., Greenwood, D., & Knapp, P. (2013). Frequency of anxiety after stroke: a systematic review and meta-analysis of observational studies. International Journal of Stroke, 8(7), 545-559. ¹⁰ Bruggimann, L., Annoni, J. M., Staub, F., Von Steinbuchel, N., Van der Linden, M., & Bogousslavsky, J. (2006). Chronic posttraumatic stress symptoms after nonsevere stroke. Neurology, 66(4), 513-516.

¹¹ Chun, H. Y. Y., Ford, A., Kutlubaev, M. A., Almeida, O. P., & Mead, G. E. (2022). Depression, anxiety, and suicide after stroke: a narrative review of the best available evidence. *Stroke*, *53*(4), 1402-1410.

¹² Field, E. L., Norman, P., & Barton, J. (2008). Cross-sectional and prospective associations between cognitive appraisals and posttraumatic stress disorder symptoms following stroke. Behaviour research and therapy, 46(1), 62-70.

¹³ Pompili, M., Venturini, P., Lamis, D. A., Giordano, G., Serafini, G., Belvederi Murri, M., ... & Girardi, P. (2015). Suicide in stroke survivors: epidemiology and prevention. *Drugs & aging*, *32*, 21-29;

Nafilyan, V., Morgan, J., Mais, D., Sleeman, K. E., Butt, A., Ward, I., ... & Glickman, M. (2023). Risk of suicide after diagnosis of severe physical health conditions: a retrospective cohort study of 47 million people. *The Lancet Regional Health–Europe*, *25*;

Teasdale, T. W., & Engberg, A. W. (2001). Suicide after a stroke: a population study. *Journal of Epidemiology & Community Health*, *55*(12), 863-866;

Vyas, M. V., Wang, J. Ž., Gao, M. M., & Hackam, D. G. (2021). Association between stroke and subsequent risk of suicide: a systematic review and meta-analysis. https://doi.org/10.1161/STROKEAHA.120.032692;

Grobman, B., Kothapalli, N., Mansur, A., & Lu, C. Y. (2023). Risk of suicide among stroke survivors in the United States. *Journal of stroke and cerebrovascular diseases*, *32*(10), 107272.

¹⁴ Chun, H. Y. Y., Ford, A., Kutlubaev, M. A., Almeida, O. P., & Mead, G. E. (2022). Depression, anxiety, and suicide after stroke: a narrative review of the best available evidence. *Stroke*, *53*(4), 1402-1410.

¹⁵ Stroke Foundation. National Stroke Audit – Rehabilitation Services Report 2024. Melbourne, Australia. Stroke Foundation
InformMe - Stroke Foundation



Mental health and wellbeing after stroke are critically important to survivors of stroke and their families and carers. With many survivors experiencing increased risk of psychological distress and suicidality after stroke.

Stroke Foundation is currently working with the Commonwealth, State and Territory Governments to deliver essential services for survivors of stroke. For example, the **F.A.S.T Community Education Program** delivers community talks across the country to increase awareness of the signs of stroke. Stroke Foundation information resources, such as <u>My Stroke Journey</u> and <u>EnableMe</u>, and our national helpline <u>StrokeLine</u>, deliver critical information, advice and support to survivors and their families to assist them with their next steps ponce they leave hospital.

Through **stroke data (Australian Stroke Clinical Registry – AuSCR)**, participating hospitals can assess their progress towards embedding evidence-based quality improvement guidelines for delivering high quality acute and rehabilitation care for stroke patients in dedicated stroke care units. And the world-leading *Living Guidelines for Stroke Management* ensure health professionals are provided with real-time health evidence translation to support best-practice stroke care.

However, there is always more that can be done and there are critical gaps in mental health support and suicide prevention for survivors of stroke that requires our urgent attention.

Adequate resourcing and service provision is needed to enable survivors of stroke and their significant others to have access to the right services, in the right place, at the right time.

Stroke Foundation believes there is now a strong opportunity to work with governments at all levels to ensure all survivors of stroke with psychological distress and suicidality have access to supports they need to optimise wellbeing after stroke.

Effective mental health promotion and suicide prevention must be holistic

A key principle of the Agreement is to recognise the role of social determinants of health on people's mental health and wellbeing and draw together other services delivered by government outside the health system to facilitate a whole-of-government approach to mental health and suicide prevention.

Key socio-economic determinants that are important for survivors of stroke and their families include good health and recovery after stroke, economic security through adequate income support and return to work pathways for survivors of stroke, social inclusion through accessible communities, environments and peer support, and improved access to hospital and community rehabilitation services and psychosocial supports to enhance adjusting to life after stroke.

This includes opportunities to improve mental health literacy and awareness in relation to stroke and suicide; promote wellbeing among survivors of stroke; and taking proactive action to prevent distress and suicide through enhances stroke rehabilitation and improved mental health pathways after stroke.

The recently released National Suicide Prevention Strategy recognises that "suicidal distress is a human response to overwhelming suffering. It is complex— typically, there are many factors at play rather than a single isolated cause. These factors include social determinants (such as income, education, employment, housing, early childhood development, social inclusion and access to health care) and individual factors, including contextual factors (such as stressful life events, trauma, abuse and discrimination), clinical factors (for example, mental illness, drug and



alcohol use, chronic physical illness), personality factors, genetic factors and demographic factors (such as age, gender, sexual orientation, ethnicity, cultural heritage)."16

Stroke Foundation is concerned that a National Agreement that conflates the two issues risks focusing only on the mental health related contributors to suicide risk and overlook the very real contribution of other socio-economic determinants such as health, economic insecurity, and social isolation on psychological and suicidal distress.

We welcome the recent release of the National Suicide Prevention Strategy and the recent National Aboriginal and Torres Strait Islander Suicide Prevention Strategy 2025-2035 with their clear actions that seek to address the complexity of suicide. Aligning a reformed Agreement with these Strategies and their implementation, will be important to ensure long-term, coordinated suicide prevention activity in Australia.

Clarifying objectives and strategic direction through a renewed National Mental Health and Wellbeing Strategy that compliments and aligns with the National Suicide Prevention Strategy 2025-2035 and National Aboriginal and Torres Strait Islander Suicide Prevention Strategy 2025-2035, and other National strategies across government portfolios (e.g., National Preventive Health Strategy 2021-2030, National Women's Health Strategy 2020-2030, National Closing the Gap Agreement, National Health Reform Agreements, Measuring What Matters Framework) could broaden and strengthen the focus on socio-economic determinants and systems integration.

Promote Mental Wellbeing and Preventing Suicide – Importance of Embedding Lived Experience and Co-Design in Health and Mental Health Services

At the point of care survivors of stroke and their families need stepped models of care and support that give them options for accessing the level of care that meets their needs, ranging from low intensity supports to crisis services that are person-centred and provide wrap-around support.

Although the importance of mental health in stroke recovery has been well established, many Australian survivors of strokes and their families do not have access to services they need for the assessment of mental health challenges and suicidal distress¹⁷.

When survivors are provided with information following a stroke, the information formats may not be accessible for survivors of stroke who can experience changes in vision, hearing and comprehension. Stroke, cardiovascular and cerebrovascular events are varied but discharge information is often generic. Survivors of stroke want tailored and specific discharge information to optimise support and recovery planning and personalised strategies to manage the diverse challenges and changes that can occur after stroke.

Carers consistently reflected on a lack of support for themselves and that they are often ignored and unable to access vital information needed to support those they care for. The current National Agreement makes no mention of responsibilities for carer or family supports. The Productivity Commission interim report recommends the next agreement "should clarify the level of

¹⁶ National Suicide Prevention Office (2025). The National Suicide Prevention Strategy 2025-2035. <u>National Suicide</u> Prevention Strategy 2025-2035

¹⁷ Stroke Foundation. National Stroke Audit – Rehabilitation Services Report 2024. Melbourne, Australia. <u>Stroke data</u> InformMe - Stroke Foundation



government responsible for planning and funding carer and family support services". Stroke Foundation supports this recommendation.

It is well recognised that the specific needs of survivors and carers from diverse communities or backgrounds are likely to be better met with initiatives and services that are sensitive to their experiences, culture, and the specific issues they face.

Therefore, it is critical the Agreement enables and prioritises person-centred care, including continuing to foster and support the growth of a lived experience (peer) workforce, not just in mental health peer work but embedding lived experience workers (peer navigators) in disability, aged care, youth services, and health.

Lived experience workers draw on their own experiences and recovery journey to support others in a similar situation and build relationships that strengthen connection, resilience, choice, and hope.

Evidence-based integrated care models informed by lived experience contribute to mental health promotion and suicide prevention by ensuring the right supports are available at the right time and in the right setting.

Evidence¹⁸ points to the value of engaging individuals with lived experience and embedding lived expertise in service design, implementation and evaluation for improved outcomes.

Lived experience knowledge is broader than an experience of illness, encompassing shared understanding of loss or changes to social status/inclusion; experiences of stigma and discrimination; and change to relationships, employment and concepts of self because of stroke (or other condition or experience, including psychological distress) and consequent service use.

Current arrangements for engaging lived experience across diverse stakeholder groups are insufficient and inconsistent in-service delivery and policy settings. The current Agreement lacks appropriate provisions for **meaningfully inclusion of people with lived experience in the governance arrangements,** or the design, planning, delivery, and evaluation of services under the Agreement.

Stroke Foundation supports calls for the current Agreement to be extended until 2027 and extended negotiation to facilitate partnerships with the national, state and territory consumer and carer peak bodies and meaningful engagement with people with lived experience.

An extension would also enable thorough planning to address critical policy and service gaps, including discussions about more appropriate funding models and flexibility in implementation.

Adequate and long-term funding is critical for systemic improvements and effective service integration

Equitable access to appropriate resources and funding models must be developed and implemented to support greater flexibility and devolving power that enable bottom-up, community-

¹⁸ Morley, C., Jose, K., Hall, S. E., Shaw, K., McGowan, D., Wyss, M., & Winzenberg, T. (2024). Evidence-informed, experience-based co-design: a novel framework integrating research evidence and lived experience in priority-setting and co-design of health services. BMJ open, 14(8), e084620. doi: 10.1136/bmjopen-2024-084620



led, place-based approaches to be developed by communities with greater control over the ways services and initiatives are designed, delivered, and monitored.

Over the past decade, governments have increased investment in mental health and suicide prevention. However, the level of investment, scalability and longevity that is needed to transform mental health in Australia continues to fall short. There is still a need for long-term and sustainable mental health funding to address the urgent need in the community.

Stroke Foundation supports calls for increased longer-term and more flexible funding models to ensure sustainability of services, including workforce planning and retention, to provide stability and certainty for service users. Additionally, Stroke Foundation supports funding models that support a mix of national and place-based solutions to improve consistency as well as improving local responsiveness to community needs.