



Terms of Reference for the Royal Commission into Mental Health in Victoria

**Submission prepared by
COTA Victoria**

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1. About COTA Victoria

COTA Victoria is the leading not-for-profit organisation representing the interests and rights of people aged over 50 in Victoria. For 70 years in Victoria, we have led government, corporate and community thinking about the positive aspects of ageing. Today our focus is on promoting opportunities for and protecting the rights of people 50+.

We see an ageing population as a time of opportunities for personal growth, contribution and self-expression. We believe there are obvious National, State, community, family and individual benefits from this approach. We are also focused on the protection of the rights of people 50+.

COTA Victoria is a not-for-profit member based organisation run by, for and with Victorians 50+. We fund our activities and services through the support of government, members, philanthropic trusts, businesses and the public.

We have an experienced Board, highly qualified, permanent staff located in a central Melbourne office location and a broad State membership. We also have over 130 community volunteers throughout Victoria with skills in training, group facilitation, policy development and advocacy, including volunteers bi-lingual in a number of languages. We work with local government, senior citizen centres, community houses and a broad range of community and service organisations.

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2. Introduction and TOR recommendations

We thank the Department of Premier and Cabinet for providing us with an opportunity to have input into the development of the terms of reference for the Royal Commission into Mental Health. The promise of a Royal Commission, the first of its kind in Australia, presents a significant opportunity to shine a light on a number of systemic issues that continue to impact upon the health and wellbeing of older Victorians. While there have been some improvements in accessing mental health services following the release of Victoria's 10 Year Mental Health Plan, Victoria's ageing population continues to experience significant and increasing mental health issues that require special attention. To this end, this submission makes a number of recommendations outlining how the terms of reference for the Royal Commission can help ensure these matters are adequately addressed.

This submission has been developed in partnership with Seniors Rights Victoria (SRV). SRV is a significant program of COTA Vic that holds an independent role as the key state-wide community legal service dedicated to preventing and responding to elder abuse. SRV's services are multidisciplinary and include a Helpline, specialist legal services and support and advocacy for individuals. SRV also plays a leadership role in policy development, law reform and education, and works with organisations to raise awareness of elder abuse.

The following is a summary of our recommendations for the Mental Health Royal Commission's Terms of Reference:

Summary of Recommendations:

1. Older Victorians and the evolving needs of Victoria's ageing population must be included under a separate focus area within the terms of reference.
2. The Mental Health Royal Commission investigate the relationship between mental illness and elder abuse.
3. The terms of reference must extend to all specialist mental health services, including Aged Persons Assessment and Treatment Services and Aged Persons Mental Health Services.
4. The terms of reference must extend to issues relating to the criteria and age restrictions for accessing community mental health services and the models of mental health treatment available to older people.
5. The terms of reference must cover dementia as a separate focus area, in light of the unique challenges that mental illness, and misdiagnosis of mental illness can present for this target group.
6. The terms of reference must cover issues arising for people at heightened risk of vulnerability including those living in residential care and supported accommodation.
7. The terms of reference must examine the needs and experiences of families and carers of people with mental health issues.
8. The terms of reference must examine the diversity and intersectionality of populations in accessing and experiencing mental health services and responses – including gender, culture, ethnicity, disability, LGBTIQ and the impact of social isolation and living in rural and remote communities as an older person.
9. The terms of reference must cover issues arising in relation to the interfacing arrangements between different service systems, and between state and federally-funded services.

10. Any issues relating to the administration of aged care services that are uncovered throughout the Royal Commission's investigations should be communicated to the Aged Care Sector Committee and the Department of Health at the Commonwealth level.

11. The terms of reference must extend to the exploration of innovative strategies for early intervention and prevention of mental illness that have proven effective in other jurisdictions.

12. All information and materials produced to inform the broader community on the Royal Commission process (including the website) must be written in plain English and in a range of accessible formats.

13. There must be a range of non – digital options available to enable people to submit information to inform the Royal Commission's investigations:

14. The Victorian Government should consider providing additional funding to COTA Victoria and Seniors Rights Victoria to specifically support older Victorians, their families and carers to be actively involved in the Royal Commission process.

3. Why older people should be included as a separate focus group within the Royal Commission's terms of reference

It is imperative that the terms of reference for the Royal Commission adequately reflect the demographics of the Victorian population. The Department must therefore consider:

- More than 20% of Victoria's population is aged over 65 years of age
- The number of Victorians aged 85 and over has doubled over the past few years.
- Australian men aged over 85 have the highest suicide rate in Australia; more than double that of teenagers.
- By 2031 – almost one in four Victorians will be aged over 60 years. In rural and regional Victoria, almost one in three Victorians will be over the age of 60.¹
- The number of older people accessing mental health services increased by 12.3% from 2016/17 to 2017/18. This rate will continue to rise as Victoria's population ages.²

While the majority of older people report good mental health, the onset of mental health issues in later life is well known and documented, as is the continuation of chronic conditions which extend into later life.

Research undertaken by Sane Australia in 2013 showed that 72% of older Victorians found that their mental health changed as they became older. Issues impacting upon mental health outcomes and access to services for this target group are quite unique and must be

investigated separately in recognition of this fact. As an example, older people can experience distress and grief due to circumstances such as loss of independence, loss of status, loss of financial security, loss of partner and friends, social isolation and loneliness. These factors can contribute to people developing depression in later life and exacerbate symptoms for older people with an earlier diagnosis of mental illness.³

Capturing the insights of those older people with long-term mental health issues will ultimately be of great value to the Commissions' investigation process. Older people have lived long lives and have had extensive experiences with illness and with intervention and treatment services. Their lived experience offers unique insights and historical perspectives. Further, a considerable number of older community members have mental health issues/ illnesses which are long term and chronic, and each person will have experienced many years of intervention, medication and case management.

Recommendation 1:

Older Victorians and the evolving needs of Victoria's ageing population must be included under a separate focus area within the terms of reference.

4. Mental health of Victoria's ageing population

4.1. The relationship between mental illness and elder abuse

In its investigation of issues unique to the life experience of older Victorians, the Commission must pay keen attention to the relationship between mental illness and elder abuse, particularly when exploring strategies for early intervention and prevention.

The Australian Institute of Family Studies estimates that elder abuse affects around 10% of the population. A 2015 analysis of service user data collected by Seniors Rights Victoria revealed that:

- 33% of older people experiencing neglect had mental health issues
- 26.7% of alleged physical abuse involved a perpetrator who had mental health issues
- 18.5% of alleged psychological abuse involved a perpetrator who had mental health issues.

There are a number of issues that are unique to people experiencing elder abuse that will require careful attention as part of the Royal Commission's investigations. This includes:

- older people living with adult children who have mental illness
- the increased vulnerability of older people to elder abuse through social isolation and its mental health impact
- where the mental health conditions of older people can be ameliorated by removing elder abuse (the perpetrator)
- The assumption of lack of capacity by services and police when an older person may present with 'treatable' mental health issues.

Through its casework, SRV has found that:

- Social isolation of an older person can increase the risk of mental health issues in the older person, and the risk of elder abuse occurring
- Older people living with mental health conditions that can be managed can be treated as not having capacity or with dementia when in fact the removal of elder abuse can significantly improve the older person's mental health and capacity.
- In elder abuse crisis situations where police have been called to intervene, perpetrators have persuaded police that the older person does not have decision making capacity and/or has dementia and is falsely calling abuse.
- Many people experiencing elder abuse continue to live with the abuse and the abuser (despite obtaining legal advice about their options) because of their concern for the adult child who is the perpetrator. A parent is faced with few options due to the limited or non-existence of mental health and housing support services their child. Rather than "throwing their child onto the street" they live with the abuse. As the parent ages, this can mean that they are living in a very vulnerable and volatile situation, despite increasing frailty (possibly) and limited financial means.
- Mental health services have often put pressure on older parents to take in their adult children after a time of crisis and/or hospitalisation and/or assessment of the adult child, without taking into account the impact of living with a mental ill adult on an ageing older person. (Mental health services may put this pressure on parents because there are limited or no other supports available to the adult child, but nonetheless this attitude perpetuates the view of the parent's responsibility for the child even into the child's middle age regardless of the impact on the parent)
- Where older people are living with mental health issues or early stages of dementia there is often the assumption they have no decision making capacity. The experience of elder abuse can exacerbate mental health and dementia conditions in older people. The removal of elder abuse can improve an older person's mental health.

Recommendation 2:

The Mental Health Royal Commission investigate the relationship between mental illness and elder abuse with specific reference to the following:

- Examine the impact of an adult child with poor mental health, living with an ageing parent/s, including the increased risk of elder abuse. In particular, the adequacy of support services available to older adults who become or remain carers of their grown up children with mental health issues where elder abuse is occurring or likely to occur.
- Examine the provision of more accessible mental health services for alleged perpetrators and victims of elder abuse and its role in the prevention and early intervention of elder abuse.
- Examine the development of education and service pathways to support family members in accessing mental health treatment for someone close to them, taking into account the complexities associated with elder abuse, prior to a crisis occurring or so that elder abuse is prevented.
- Examine the understanding among front line services, including police of their understanding and diagnosis of treatable mental illness as opposed to dementia in an older person.
- Examine the availability of safe, supported and linked-in housing options for older people as a way of safeguarding the mental health and wellbeing of older generations.

4.2. Aged Persons Mental Health Services

Aged Persons Mental Health Services and Aged Persons Assessment and Treatment Services are key components of the support journey for many older Victorians. Despite this fact, whether this is the most appropriate service model to support Victoria's ageing population is a matter that requires further examination.

COTA has been made aware by its members that access to state funded community mental health services has become increasingly based on chronology (age) rather than need. Specialist treatment services exist for the purpose of assessing and treating older Victorians experiencing poor and complex mental health issues. Generally these services cannot be easily accessed by some older people, and the issue of service access is further compounded by Commonwealth / State funding arrangements that exist around age eligibility for many community mental health and mainstream services.

Recommendation 3:

The terms of reference must extend to all specialist mental health services, including Aged Persons Assessment and Treatment Services and Aged Persons Mental Health Services.

Recommendation 4:

The terms of reference must extend to issues relating to the criteria and age restrictions for accessing community mental health services and the models of mental health treatment available to older people.

4.3. Older people with dementia

According to Dementia Australia, one person is diagnosed with dementia every 6 minutes.⁴ Some of the symptoms of dementia can be confused by workers as symptoms of other forms of mental illness.⁵

Dementia also frequently presents with comorbidities such as depression and anxiety, with the effective treatment of each diagnosis relying on a multi-disciplinary approach.⁶ Dementia can also make an older person more susceptible to delirium which can impact significantly on a person's mental ability if it is not recognised.

These factors are likely to present growing challenges for the health and wellbeing of Victoria's ageing population. As such, they require separate investigation throughout the Royal Commission process to ensure that effective early intervention strategies and treatment options can be put in place.

Recommendation 5:

The terms of reference must cover dementia as a separate focus area, in light of the unique challenges that mental illness, and misdiagnosis of mental illness can present for this target group.

4.4. Older people in residential and institutional settings

2018 Data from the Australian Institute of Health and Welfare has revealed that specific sub-groups that are at heightened risk of experiencing poor mental health include:

- People in hospital
- People in supported accommodation or residential aged care⁷

While the themes already proposed by the Department refer to services provided in hospital settings, there is currently no attention given to residential aged care and the service options and barriers that exist for older Victorians living in residential and institutional facilities.

Recommendation 6:

The terms of reference must cover issues arising for people at heightened risk of vulnerability including those living in residential care and supported accommodation.

4.5. Older Carers

Victoria's Carer Strategy 2018-2022 states that the average age of primary carers in Victoria is 55 years, and that more than 162,000 carers are aged 65 years or over.⁸ Research demonstrates that carers face a heightened risk of experiencing poor mental health.⁹ In light of the factors contributing to increased isolation, loss and grief outlined in section 3 of this submission, it can be assumed that this risk is much higher for Victoria's older carers.

There are a number of unique issues impacting on older carers that require further exploration. As an example, through its' work with older people in the community, Seniors Rights Victoria has found that mental health services often put pressure on older parents to take in and care for their adult children in circumstances where there are few other support options available. This often happens without any regard for the impact this might have on the older person themselves.

Recommendation 7:

The terms of reference must examine the needs and experiences of families and carers of people with mental health issues including:

- The impact of an adult child with poor mental health living with an ageing parent/s, including the increased risk of elder abuse.
- The adequacy and accessibility of support services available to older adults who become or remain carers of their adult children with mental health issues, particularly where elder abuse is occurring or likely to occur.

4.6. Diversity and intersectionality

An older persons experience of accessing the mental health system, just like a younger person's, can be impacted by a range of factors such as disability, cultural background, language spoken, sex, sexual orientation, gender identity or residing in a rural or remote area. The Royal Commission process should aim to actively engage with people from diverse backgrounds and expose barriers and systems issues that are unique to specific population groups.

Recommendation 8:

The terms of reference must examine the diversity and intersectionality of populations in accessing and experiencing mental health services and responses – including gender, culture, ethnicity, disability, LGBTIQ and the impact of social isolation and living in rural and remote communities as an older person.

4.7. Service coordination and interfacing arrangements

The issue of better coordination and collaboration between service sectors needs to be carefully explored as part of the Royal Commission, with a particular focus on the intersection between state and federally-funded services. The effective provision of mental health services throughout the lifecycle relies on timely and proper assessment, referral, transition and case management; focusing on a ‘no wrong door’ approach. This means ensuring an individual’s mental health is properly taken into account during their assessment for aged care services or transition into residential aged care.

Aged Care Assessment Services assist older Victorians and their carers to identify care that best meets their needs. While these services are delivered at a state level, they are bound by the processes that have been established at the federal level. Conversely, residential aged care services across Australia are funded and regulated by the Department of Health at a federal level but can be operated by state government providers.¹⁰

There is a protocol that is shared between Victorian aged care assessment services and Aged Persons Mental Health services that has been designed to assist staff working under each service system to refer and consult with one another when undertaking assessments and facilitating access to services. The effectiveness of this protocol and whether there are still barriers arising for older people in relation to the interfacing arrangements between different service systems will require further exploration.

Recommendation 9:

The terms of reference must cover issues arising in relation to the interfacing arrangements between different service systems, and between state and federally-funded services.

Recommendation 10:

Any issues relating to the administration of aged care services that are uncovered throughout the Royal Commission’s investigations should be communicated to the Aged Care Sector Committee and the Department of Health at the Commonwealth level.

4.8. Best practice approaches to early intervention and prevention

When looking at strategies relating to early intervention and prevention, it is crucial that the Royal Commission investigates new and innovative models of service delivery and examples of best practice both in other state jurisdictions and overseas.

One consideration for the development of early intervention and prevention strategies would be to focus on a life stage approach. Such an approach would recognize the way in which factors contributing to poor mental health change throughout the lifecycle, and would explore strategies aimed at proactively addressing the evolving needs of Victoria's ageing population.

Recommendation 11:

The terms of reference must extend to the exploration of innovative strategies for early intervention and prevention of mental illness that have proven effective in other jurisdictions.

5. Ensuring the Royal Commission's processes effectively meet the needs of older Victorians

The Royal Commission into Mental Health presents positive opportunities for improving the health and wellbeing of older Victorians. To support its success, inclusive and accessible strategies to gather information to inform the Commission's investigations must be put in place. Those that are vulnerable and/or have specific support needs must be afforded opportunities to tell their story.

COTA has recently considered the processes surrounding the Royal Commission into Aged Care Quality and Safety; particularly the complexity of the information that has been produced to inform the community how to have their say. Much of the language used is very technical and may be difficult for some members of the community to engage with - particularly people with cognitive impairment and people whose first language is not English. In order to ensure that information about the Royal Commission process can be understood by as many people as possible, the Victorian government must commit to:

- Providing information in plain English. This means avoiding the use of technical jargon and acronyms and setting out information in short digestible chunks.
- Ensure information is available in a range of different and accessible formats. The Royal Commission website must comply with the Web Accessibility Guidelines 2.1.

Where information is available in downloadable pdf format, an accessible Microsoft Word file should also be provided as an alternative.

- Information must clearly communicate:
 - The parameters of the inquiry
 - what will be done with information that is collected as part of the inquiry
 - What changes are realistic to expect
 - What time frames the Royal Commission will be working to

It will also be important for the Commission to find a balance between input from clients of mental health services and professionals.

To achieve this, consultation must include:

- Consumer advocates
- Consumers and their families
- Specialist aged mental health services and their clients
- Homeless outreach psychiatric services
- Forensic mental health services
- Aged care providers to older homeless people (e.g. Wintringham/ Corpus Christi)
- Police
- Community mental health services
- Community outreach services
- Family and caregivers

COTA Vic can facilitate the input of older Victorians through listening posts across the state, peer educators, volunteers and our policy working groups. Seniors Rights Victoria can support older people to relay their experiences of the impact of living with adult children with mental health conditions that are perpetrating elder abuse.

Residents of residential aged care services and supported accommodation must be provided with additional assistance to tell their stories. Older people are the least digitally connected population and supporting their input and access to information via non digital channels is a prerequisite to their participation in the Royal Commission.

Recommendation 12:

All information and materials produced to inform the broader community on the Royal Commission process (including the website) must be written in plain English and in a range of accessible formats.

Recommendation 13:

There must be a range of non – digital options available to enable people to submit information to inform the Royal Commission’s investigations, including:

- **Online form**
- **Email**
- **Hardcopy mail**
- **Telephone**
- **Face-to-face consultation forum**

Recommendation 14:

The Victorian Government should consider providing additional funding to COTA Victoria and Seniors Rights Victoria to specifically support older Victorians, their families and carers to be actively involved in the Royal Commission process.

6. Contact details

Thank you for providing COTA Victoria with an opportunity to inform the scope of the terms of reference for the Mental Health Royal Commission and take into consideration the needs and experiences of older Victorians.

Should you require further information about any of the matters that have been raised throughout this submission, please feel free to contact our Policy Officer, Lauren Henley on (03) 96552100. Lauren can also be contacted by email at LHenley@cotavic.org.au.

Footnotes:

¹ More precisely, 31% of people in regional and rural Victoria and 22% of people in Greater Melbourne and will be aged over 60 years. People aged 65+ contributed 60% of population growth in areas outside capital cities between 2010 and 2015.

² Victorian Department of Health and Human Services (2018) *VICTORIA'S MENTAL HEALTH SERVICES ANNUAL REPORT 2017–18*.

³ Sane Australia (2013) *Living Older, Staying Well: The Mental health care of older Australians*, accessed 20 January 2019 <https://trove.nla.gov.au/work/187177207?q&versionId=203737492>.

⁴ Dementia Australia (2018) *The Mental Health CRC - Science and Dementi*, accessed 19 January 2019>.

⁵ Sane Australia (2013) *Living Older, Staying Well: The Mental health care of older Australians*, accessed 20 January 2019 <https://trove.nla.gov.au/work/187177207?q&versionId=203737492>.

⁶ Dementia Australia (2015) Don't forget dementia on World Mental Health Day, accessed 27 January 2019 < <https://www.dementia.org.au/media-releases/2015/dont-forget-dementia-on-world-mental-health-day>>.

⁷ Australian Institute of Health and Welfare (2018) *Older Australia at a glance*, accessed 10 January 2019 <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/service-use/mental-health>.

⁸ State of Victoria (2018) *Recognising and supporting Victoria's carers: Victorian carer strategy 2018–22*.

⁹ Australian Institute of Health and Welfare (2018) *Older Australia at a glance*, accessed 10 January 2019 <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/service-use/mental-health>.

¹⁰ State Government of Victoria (2018) *Aged care*, accessed 16 January 2019 <<https://www.vic.gov.au/health-community/seniors/aged-care.html>>.