

Planning your Submission to the Royal Commission into Mental Health



Consumer Cheat Sheet Terms of Reference

Submissions
open until
5 July 2019

This cheat sheet explains the Royal Commission Terms of Reference, from a consumer perspective.

If you choose to write a submission **in your own format**, you will need to tell the Royal Commission how it's related to their Terms of Reference.

This flyer explains the Terms of Reference, including:

- Simple explanations
- Common topics of interest to consumers that relate to each item in the Terms of Reference

What are Terms of Reference?

They're the things that the Royal Commission has to think about. It's like the 'scope' or 'limits' of what they can look at.

They are written up in a very formal document called the 'Letters Patent' that is signed by the Governor and Premier of Victoria.

What if I want to say different things unrelated to the Terms of Reference?

You should say whatever is important to you, even if it's not covered by the Terms of Reference. But you should know there is a risk that the Royal Commission may not do much about issues that are outside the Terms of Reference. So, if you can, it's important to try and relate your issue to one of the topics on their list.

About the Royal Commission

The Royal Commission into Mental Health has been set up to look at how to improve mental health services across Victoria.

It's running until the end of 2020.

Right now, they are asking the public to make 'submissions' to tell them about what's working, what's not working, and ideas to improve.

A submission can be as simple as a few short sentences, or it can be a long and complicated document—it's up to you.

This is an important opportunity for consumers to have their say about the issues that matter most to you.

TERMS OF REFERENCE

No. 1

How to most effectively prevent mental illness and suicide, and support people to recover from mental illness, early in life, early in illness and early in episode, through Victoria's mental health system, and in close partnership with other services.

Simple explanation

This section is all about 'prevention and early intervention'

'Prevention' means: *How to stop 'mental illness' & suicide before it starts*

What might have prevented your 'mental illness' or distress? If you know what would have stopped you getting unwell in the first place, talk about it here.

Do you think your mental health problems/suicidal urges were caused by things that happened in your life? For example: trauma, bullying, child abuse, sexual violence, family violence, neglect, poverty, torture, war, crime, racism, intergenerational trauma...? Talk about ways to stop those things here. Talk about what should be offered to people immediately after these things happen.

Do you think your mental health problems or suicidal urges were caused by something else? Talk about it here and what could have prevented it.

'Early in life, early in illness, early in episode' means: *How to quickly help:*

- Children, teenagers and young adults
- People at the start of 'mental illness'
- People starting to get unwell again ('relapse')

by using the mental health system or other services, instead of leaving people in distress for a long time without help.

Did your mental health problems start when you were young? Talk about what should have been offered to you as a child, teenager or young adult. Who should be offering this mental health service?

Have you experienced 'recovery'? Talk about what helped and what didn't.

Did it take a long time to get the right help? Talk about what that help was, and how you could have gotten it more quickly. Talk about what you need when you first start getting unwell or distressed.

Do you disagree that you even have a 'mental illness'? Some people say they'd rather be left alone, or they needed something totally different to a mental health service. Talk about it here, and what supports would help, and what you want to happen.

Common things that consumers tell VMIAC about this topic

'Mental illness' prevention:

- Trauma (abuse, bullying, crime, violence, etc) and adversity
- Social determinants of health
- Support for parents & families
- Early attachment
- Alternatives to emergency departments and medical treatment
- Access to GPs in regional areas
- Access to therapy & counselling
- Community-based services

Suicide prevention:

- Emergency Rooms (EDs), long waiting times, feeling judged or told to go home
- CAT team
- People saying 'it's just a cry for attention' or ignoring you
- PARC services / step-up, step-down
- Peer support
- A safe place to go to
- Being scared to ask for help
- Good friends

TERMS OF REFERENCE

No. 2

This has 5 sub-questions

How to deliver the best mental health outcomes and improve access to and the navigation of Victoria's mental health system for people of all ages, including through: (see the next four sub-questions)

Simple Explanation

When considering the sub-questions (2.1 to 2.4), think about the points below.

'Best outcomes' means: *You actually get the help you need.*

Think about the impact mental health services have on your mental health and your life more generally. Describe:

- Things that were helpful for you
- Things that didn't make much of a difference
- Things that made it worse for you

'Improve access' means: *It's quick and easy to get help.*

Think about how you got into mental health services.

- Describe what made it easy—or hard—for you to get help
- Describe ways it could be quicker and easier to get help

Were you taken to services against your will, or have compulsory treatment? This is also a form of access.

- Describe how this felt and the impact on your mental health and life
- Describe if there would have been better ways to support or provide you with help

'Navigation' means: *It's quick and easy to find your way around different mental health services or professionals*

How did you know what services or professionals were available? How did you find your way to them?

- Describe how you found your way to different professionals or services.
- Describe what made it easy or hard.
- Describe if things took the right amount of time or if they took too long
- Describe ways you could get information more easily

Common things that consumers tell VMIAC about this topic

- Personal recovery versus clinical recovery
- Long-term impacts of treatment, medication, ECT

TERMS OF REFERENCE

No. 2.1

best practice treatment and care models that are safe and person-centred;

Simple Explanation

'Best practice' means: *What works the best*

'Treatment' means: *What is given to you by services (eg, medication) that is supposed to help your 'mental illness'.*

'Care models' means: *The way you are treated by professionals and services. This includes staff attitudes, skills and actions, the buildings, rules. It includes things like forms of control, respect, dignity and trust.*

'Safe' means: *Anything in a mental health service that makes you feel safe—or not safe—in your thoughts, emotions, body, culture, spirituality or environment.*

'Person-centred' means: *Treating people the way they want to be treated, instead of what's easy for the service.*

Some questions to think about:

What do you think about the mental health treatments and services you have experienced?

Were they helpful, or harmful, or a bit of both? Why? How should they change?

If you raise issues, try to explain how these issues impacted on your mental health, or any long-lasting impacts.

If you have accessed more helpful supports, treatments or services outside the mental health system, you could talk about that here.

Common things that consumers tell VMIAC about this topic

- Medical models, biomedical models
- Trauma informed care
- Recovery oriented practice
- Peer support
- Consumer-run services
- Safety impact of things like:
 - Compulsory / forced treatment
 - Coercive treatment (threats / pressure)
 - Being in hospital
 - Seclusion, restraint
- Sexual violence in hospital
- No separate units for mental health and substance use
- Community support services
- Talking therapies and counselling
- Addressing social determinants of health

TERMS OF REFERENCE

No. 2.2

strategies to attract, train, develop and retain a highly skilled mental health workforce, including peer support workers;

Simple Explanation

If you're a peer worker, talk here about what's needed for the peer workforce.

What do mental health workers do well? How have good workers improved your mental health, and what do they do that's different?

What are the issues with mental health workers? You might talk about their skills, knowledge, attitudes and behaviours.

Do mental health services have all the kinds of workers you need? If not, what kinds of workers are missing and how could they help?

Common things that consumers tell VMIAC about this topic

- Loss of community support workers
 - Not enough peer workers
 - No enough counsellors or therapists
 - Not enough staff trained in basic therapeutic skills
 - Over-medicalised training
- Workplace issues for peer workers:**
- Underpaid, undervalued
 - Bullying, harassment & discrimination
 - Co-opting of peer work practice
 - Pathways into peer work
 - Burnout, exposure to violence

TERMS OF REFERENCE

No. 2.3

strengthened pathways and interfaces between Victoria's mental health system and other services

Simple Explanation

'Pathways' means: How you get from a mental health service to another service. For example, from hospital to a housing service, an employment service or the NDIS.

Is it quick and easy to get from one service to another? Or hard? Or impossible? Share your experience and the impact on your life.

What should be kept the same? What should be changed? Share any ideas that would make it better.

'Interface' means: What happens when the two services connect with each other.

Do services share all the right information with each other? For example, does your GP get the right info when you're discharged from hospital? Or do things get missed?

What's the impact on you? How could it be improved?

Common things that consumers tell VMIAC about this topic

- Being discharged into homelessness, or into boarding houses
- Support to get into NDIS
- Links between hospital and your GP, private therapists, or other services
- Hospitals and guardianship issues
- Hospitals speaking to our employers

TERMS OF REFERENCE

No. 2.4

better service and infrastructure planning, governance, accountability, funding, commissioning and information sharing arrangements; and

Simple Explanation

Service planning means: *How the service plans to meet the needs of people, including the type of services, and how many people it can see.*

Did you have to wait a long time in an emergency department before a bed was available?

Did you want an admission, or did you want something else?

Are services like the CAT team well-planned and available as needed?

Are there enough staff on the units?

Infrastructure planning means: *How the hospital makes sure the buildings, rooms and equipment meet people's needs.*

What did you think about the facilities in the hospital?

Did they meet your needs? Were they safe, dignified, practical? Or were there issues? Did they work?

How could it be improved?

Governance means: *How the service is managed at the very top.*

Do you think services are well managed? Why or why not?

Accountability means: *That the service is made to be responsible for doing a good job, and is responsible when something goes wrong.*

Do you think the hospital is made to be responsible for their actions? Did they do what they are supposed to do? Did they act fairly and lawfully?

Funding and commissioning means: *Which services get money and how they get it*

Do you think funding goes to the right places, and in the right ways? Why or why not?

Information sharing arrangements means: *How information is shared within the services, and with other services and people.*

Was information shared about you in an appropriate way? Describe any good experiences or issues.

Common things that consumers tell VMIAC about this topic

- Focus on beds versus community-based services
- Long waits in ED
- No alternatives to ED
- CAT team issues (waiting, not available, won't help)
- Not enough staff
- Not enough single rooms or bathrooms
- No women only units
- Women-only corridors not kept women-only
- Patient controlled locks on bedroom and bathroom doors
- Lack of toilets or sunlight in seclusion rooms
- Visitor areas, including for visits by children
- Prayer / faith rooms
- Public, transparent reporting about hospital issues, human rights breaches, safety issues, harms to consumers
- Holding hospitals accountable for following the Mental Health Act
- Who sees or addresses unlawful practices in hospitals?
- Majority of funding on hospitals, versus other types of service (eg, community support, therapy, peer-run services)

TERMS OF REFERENCE

No. 2.5

improved data collection and research strategies to advance continuity of care and monitor the impact of any reforms.

Simple Explanation

Continuity of care means: *That whether you are in hospital, or at your GP or a community service, everyone is coordinated and is working towards the same thing.*

Do you have to keep telling your story at every new service? Is this a good thing or a problem?

Do you want services to be coordinated? If so, how could this be improved?

Data collection to monitor impact of reforms means: *Recording what happens in services, so we can tell if changes have made a positive difference for real people.*

What information do you think would need to be collected in order to tell if real change happens in mental health services?

Where would that information come from? Why?

Common things that consumers tell VMIAC about this topic

- Not having to tell your story over and over again
- Real reform, authentic change
- Who decides what matters? Consumer self-rated surveys (what we think) or data reported by clinicians and services (what they think)?
- More consumer-led research
- Need independent audits

TERMS OF REFERENCE

No. 3

How to best support the needs of family members and carers of people living with mental illness.

Simple Explanation

This question is mainly relevant for carers and family. If you're a carer as well as a consumer, this is where you can talk about your needs as a carer. As a consumer, you might like to talk about any concerns or needs you have in relation to your family, carers or natural support people.

Common things that consumers tell VMIAC about this topic

- The need for consent and privacy with families
- Issues of safety for consumers from some family members (eg, elder abuse, family violence, child abuse)
- Being able to nominate 'excluded persons' as well as 'nominated persons'

TERMS OF REFERENCE

No. 4

How to improve mental health outcomes, taking into account best practice and person-centred treatment and care models, for those in the Victorian community, especially those at greater risk of experiencing poor mental health, including but not limited to people:

- from Aboriginal and Torres Strait Islander backgrounds;
- living with a mental illness and other co-occurring illnesses, disabilities, multiple diagnoses or dual disabilities;
- from rural and regional communities; and
- in contact, or at greater risk of contact, with the forensic mental health system and the justice system.

Simple Explanation

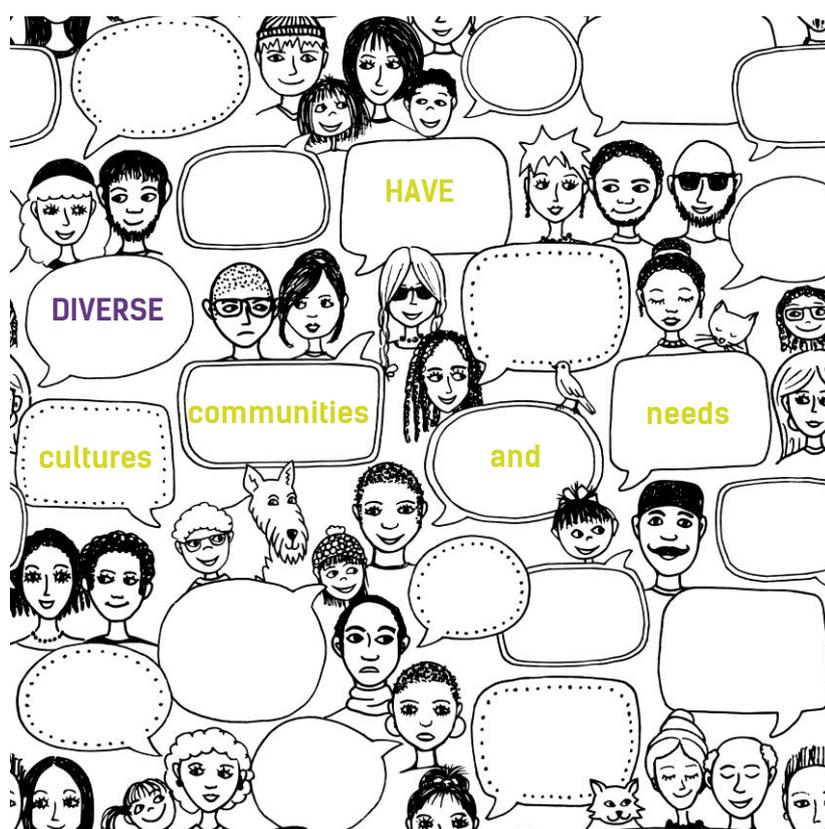
This is the same as question 2, but it is specifically asking if there are different needs for different communities. The terms of reference say that this question is not limited to groups listed. We think there might be some other groups as well with specific or different needs. If you have these experiences, you might like to talk about these needs in relation to this topic. These other groups may include:

- Young people
- Older people
- People with a history of trauma
- People from the LGBTIQ community
- People from non-English speaking countries and culturally diverse backgrounds
- People with religious or cultural beliefs that are less common or poorly understood
- People from refugee and asylum seeker backgrounds
- People living on pensions / in poverty

Common things that consumers tell VMIAC about this topic

We are mindful of not speaking on behalf of communities who can and will speak for themselves, but we have flagged a few well-known concerns that consumers from these communities have told us are priorities.

<p>People from Aboriginal and Torres Strait Islander backgrounds;</p>	<ul style="list-style-type: none"> • Impacts of intergenerational trauma • Impacts of disconnection from land and culture • Lack of cultural sensitivity • Lack of connection to elders, culture and family as part of services • Aboriginal-controlled services • Stigma and discrimination
<p>People living with a mental illness and other co-occurring illnesses, disabilities, multiple diagnoses or dual disabilities;</p>	<ul style="list-style-type: none"> • Lack of knowledge or skill in mental health services to adequately understand or meet needs—often even basic accessibility, communication and mobility needs • Stigma and discrimination
<p>People from rural and regional communities; and</p>	<ul style="list-style-type: none"> • Lack of services in regions, long travel distances, long wait times for GPs • Lack of privacy and dignity in small communities • Stigma and discrimination in communities • No choice in who to see outside hospital
<p>People in contact, or at greater risk of contact, with the forensic mental health system and the justice system.</p>	<ul style="list-style-type: none"> • Lack of compassionate care • Serious human rights abuses • Poor access to legal representation and advocacy



TERMS OF REFERENCE

No. 5

How to best support those in the Victorian community who are living with both mental illness and problematic alcohol and drug use, including through evidence-based harm minimisation approaches.

Simple Explanation

Evidence-based means: There is research to prove that something works

Harm minimisation means: Not always trying to force people to stop using substances, instead supporting people to be safer in their substance use

If you have used substances and the mental health system:

What helped? What didn't help? Was anything harmful for you? What were the impacts on your mental health and life in general? How could services be improved or changed?

Common things that consumers tell VMIAC about this topic

- Lack of specialist units for acute intoxication
- Lack of specialist substance use/ AOD skills in mental health service staff
- Lack of access to detox, rehabilitation and support services for substance use

TERMS OF REFERENCE

No. 6

Any other matters necessary to satisfactorily resolve the matters set out in paragraphs 1-5.

Simple Explanation

If you think there are issues that don't quite fit under items 1-4 above, but would help to make a positive difference, you can name them here.

SECTION (iii): Recommendations considerations

The Royal Commission is officially required to consider a range of things when they come up with recommendations. These items are especially relevant to consumers:

From the official Royal Commission 'letters patent' document'	Description
(a) the evidence of people with lived experience;	This means that what you have to say as a consumer is important and must be respected.
(f) the need to address stigma associated with mental illness including problems of knowledge, attitude and behaviours towards people living with mental illness;	<p>Stigma means: <i>Poor attitudes about people diagnosed with 'mental illness'.</i></p> <p>What would help you feel more accepted and welcome in your own community?</p> <p>Discrimination means: <i>Being treated differently because you are diagnosed with mental illness.</i></p> <p>What would make sure you are treated in a fair way to other people? Some people call this 'equality'. Other people prefer to say 'equity'.</p> <ul style="list-style-type: none"> • Ways that stigma or discrimination gets in the way of you having a job, a home, an education, paying bills, getting paid fairly. What can help. • Be accepted by friends and family • Not feel like people are afraid of you, or make assumptions about you • When you go to hospital, be treated the same as people who are not in the mental health unit • Be safe from violence, bullying and harassment • Be treated fairly by police
(g) the need to safeguard human rights, promote safe and least restrictive treatment and ensure the participation of people with lived experience in decision-making that affects them;	Issues related to human rights that don't fit in the terms of reference can be mentioned here.
(h) existing legislative and regulatory frameworks, including the <i>Mental Health Act 2014 (Vic)</i> , and any associated reforms you consider necessary or desirable;	<p>Issues related to the Mental Health Act that don't fit in the terms of reference could be mentioned here. This could include:</p> <p><i>What do you think about the Mental Health Act? Does it have enough protections in it? Think about advance statements, nominated persons, appeal hearings, second opinions, the right to communicate...</i></p> <p><i>Are those protections working? Think about: The Mental Health Tribunal, The Mental Health Complaints Commissioner, The Chief Psychiatrist</i></p> <p><i>Are there extra protections that need to be added? Common ideas we hear consumers talk about include:</i></p> <ul style="list-style-type: none"> • Advance directives instead of advance statements • A right to access legal representation (lawyers) • A right to access an advocate • Religious and cultural protections • Changing / stopping compulsory ECT • Changing the criteria for compulsory treatment • Ensuring a fair hearing

<p>(i) any cross-jurisdictional matters that you consider would streamline the provision of mental health treatment or services or otherwise assist in implementing your recommendations.</p>	<p>Cross-jurisdictional issues can include things the federal government is responsible for, like the NDIS, or Medicare funded programs like psychology sessions or GP access or services provided by Primary Health Networks.</p> <p>If you think issues in these areas are related to issues in the state funded mental health system, you can talk about those issues here.</p>
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More info on our web site

You can find more information about making a submission to the Royal Commission on VMIAC's web site:

www.vmiac.org.au/RCMH

Peer support is available

Our Royal Commission peer support team is also on hand to help out, if needed.

We have a peer worker on duty Mondays and Wednesdays in our Brunswick East office, between 10am – 4pm.

- Contact us for advice or support by phone or email
- Or make an appointment to see us in person

Note: Please don't pop in unannounced as we can't guarantee someone will be available to see you.

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