



WITNESS STATEMENT OF VRINDA EDAN

- I, Vrinda Edan, Acting CEO of the Victorian Mental Illness Awareness Council Inc., of 1/22 Aintree St, Brunswick East, in the State of Victoria, say as follows:
- I make this statement on the basis of my own knowledge, save where otherwise stated.

 Where I make statements based on information provided by others, I believe such information to be true.

Background, qualifications and expertise

- I am currently the Acting CEO of the Victorian Mental Illness Awareness Council Inc (VMIAC). I was previously the Chair of VMIAC for four years. I have stepped down from that role to take on the role of Acting CEO. As Acting CEO of VMIAC, I am responsible for the operational management of the organisation.
- I have worked in consumer roles in mental health services for the last 20 years, including as the Director of Consumer and Carer Relations at Monash Health for 10 years. More recently I have been involved in research at Monash University on recovery-oriented practice. I am also completing a PhD on the experience of consumers who have an advance statement and a compulsory inpatient admission.
- I am also a qualified Nurse. I hold a Diploma in Applied Science (Nursing) (La Trobe University), a Post Graduate Diploma in Advanced Nursing, Oncology and Palliative Care (La Trobe University) and a Masters in Nursing (Monash University).

VMIAC

- VMIAC is the peak Victorian non-government organisation for people with lived experience of mental health or emotional issues. The criteria to be a member of VMIAC is anyone who identifies as having emotional or mental or distress.
- 6 VMIAC is principally an advocacy organisation. Most of the consumers who use VMIAC's advocacy services are people who have been compulsory patients of mental health services.
- 7 VMIAC is dually funded by State and Federal governments.
- 8 VMIAC is funded by the State to engage in systemic advocacy work. This advocacy involves providing consumer expertise to a variety of State government department committees and projects. We are also engaged to run projects, for example we are

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currently running a peer support program for people who have experienced sexual assault in inpatient units.

- With the Federal Funding, VMIAC engages in advocacy work around the National Disability Insurance Scheme (NDIS). This work involves person-directed advocacy. We support consumers in appealing decisions made in relation to access or packages under the NDIS. We also educate the community on how to get access to the NDIS and support consumers through the process through peer support groups.
- We also engage in community education. We advocate and raise awareness in community and professional settings. This includes attending and presenting at conferences and other forums on consumer perspectives and engaging in health promotion activities such as Mental Health Week and human rights promotion such as our recent Seclusion Report.

The role of consumer and carer workers in mental health services

Victoria

- There are two principal roles in the lived experience workforce: consumer and carer consultants, and consumer and carer peer support workers. These are all formally recognised roles, where the person is employed (and paid) to perform the role.
- The role of consumer consultant has existed since 1996. It is a systemic advocacy role that is embedded in clinical mental health services. By embedded, I mean that the positions are required to be filled in clinical services by the State government and cannot be outsourced. The role involves using information received from consumers who use a service, to advocate and implement change within that service.
- The demands on the consumer consultant role have grown exponentially over time. Initially, a consumer consultant role involved speaking to consumers and management of an organisation, and the consumer was employed to do this for two or three days a week. Now, in addition to speaking to consumers and management, a consumer consultant role involves work in committees, accreditation, education, running advisory groups and a whole range of other activities, but for the most part the consumer is still only employed for two or three days a week.
- 14 Carer consultants were first employed in 2002. At that time, carer consultants often had a strong focus on peer support, that is, carers providing support to other carers. However, over the last 17 years, carer consultants have been moving more into the systemic advocacy space, and advocating for systemic change from the carers' perspective.

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- Peer support work is increasingly recognised as a discipline in its own right. Peer support is a relationship of respect, support and reciprocity between people who identify a significant, shared identity and/or experience. Peer support roles involve working in one on one or group settings with people, using lived experience to connect and develop a relationship with someone with the intention of enhancing wellbeing and promoting human rights. Peer support also provides a space in which peoples' experiences of symptoms are honoured and accepted without the judgemental framework of the medical model being applied. The evidence is very strong that peer support reduces re-hospitalisation rates, reduces inpatient stays and lowers the overall cost of services.¹
- Historically, consumer peer support workers were quite a small workforce in clinical services, but quite a large workforce in the community managed mental health sector up until the advent of the NDIS. A census survey conducted in October 2018 reported 342 positions that amount to 187 equivalent full time (EFT) positions, and 187 positions employed at three days per week or less (0.1 0.6 EFT). There were 32 vacancies at the time of the census reporting.² This number is low considering how many Victorians have a lived experience of mental health.
- About 3 years ago, a decision was made that peer support workers should be placed in clinical services to support people in the post-discharge space it's called the 'Expanding Post Discharge Support Initiative'. This is a Victorian government program which funded consumer peer support workers to support people with complex mental health needs following discharge from an inpatient admission. As I understand it, the program was designed to utilise peer support workers and reduce the 28-day readmission rates a KPI for mental health services.
- In my experience, the implementation of this program has had a lot of issues, principally because it was done without input from consumers and consumer workers. I subsequently contributed to a guideline prepared by the Department of Health and Human Services to assist organisations to recruit and support peer support workers to perform this role. In my view, the program is worth retaining but will require some serious investment in organisations to change the management of the program to consumer managed rather than clinician managed. Management change is needed to preserve the integrity of the discipline while it is still a very small minority amongst the overall workforce. At the moment this is the only funded peer support service in Victoria, others exist but run on shoe string budgets and rely on philanthropic or grant funding to continue (Voices Vic).

¹ See

https://www.mentalhealthamerica.net/sites/default/files/Evidence%20for%20Peer%20Support %20January%202017.pd

² See 'Lived experience workforce positions in the Victorian public mental health services – October 2017', at https://www2.health.vic.gov.au/mental-health/workforce-and-training/lived-experience-workforce.

- 19 Newer roles that are emerging include consumer policy advisers in government and consumer team leaders. However, these roles are rare. There are also roles emerging for consumer academics. This is a positive change because consumer perspective workers view mental health systems, issues and opportunities through a very different lens to other workers. For example, psychiatrists are focused on the body and the brain, occupational therapists are focused on participation in everyday life. Consumer workers are focused on the lived experience of mental and emotional distress and the experience of profound power imbalances. This means we bring very different, valueadded ideas for good practice and reform. Consumer perspective work needs to be recognized as a discipline, separate and distinct from other work. It is a job that increasingly is seen as a career option for people, but it currently has a very flat career structure. Positions in government, leadership and academia all support the growth of the discipline. Specifically, academic positions are needed to grow and develop the understanding of the work as well as the theoretical background that supports the continued development of consumer perspective work.
- While I support consumer peer support workers and think they are an important role for consumers, that is not the only role that consumers are capable of performing. In my experience, there is a tendency for consumers to be directed towards consumer peer support worker roles, without an understanding or grounding of the principles of consumer work more broadly.

Other jurisdictions

- In relation to other jurisdictions, Victoria is doing poorly. Victoria was the first government that had an experienced declared consumer in a dedicated policy position, that is, a senior policy advisor in the Department of Health. We are now the only jurisdiction that doesn't have an experienced declared consumer in a policy position. In New South Wales, it is my understanding that most services have some form of consumer consultant role.
- I also know that Western Australia's peak consumer organisation, Consumers of Mental Health Western Australia (COMWHA), delivers training and support to approximately 300 peer support workers each year. Most training in Victoria is not coordinated or accredited in any way. There are examples of training being developed and conducted by people who are not consumers. A survey of consumer and family/carer workers indicated that training about roles and perspectives that is grounded in the consumer movement is urgently needed. Additional training would include: strategic thinking and management, influencing change and systemic advocacy skills.
- Overseas studies have established that stand-alone peer delivered services have a huge impact on consumers' need to access services. In cities where there are a lot of

peer delivered services, for example, San Francisco, the need for consumers to access clinical services has decreased and consumers often feel better supported when they are in clinical services.³

- An example of a peer delivered service is a drop-in centre or a support service run entirely by consumers. The difference between peer delivered and peer led is that the management of a peer led service is also by consumers, whereas a peer delivered service might sit in the framework of another organisation that's not consumer led.
- A good example of a peer delivered service is 'Piri Pono' in Auckland, New Zealand. It is a five bed peer delivered alternative to an inpatient unit, where the nurses also have lived experience. I visited it a couple of years ago and it is phenomenal. The level of respect that people were offered was extraordinary for what amounts to a sub-acute but non-critical service.
- An example of how Piri Pono functions differently is that the risk management assessment is done by the manager of the service and the consumer. The risk assessment is not shared with any other staff member unless the consumer agrees. This means that everyone is treated on an equal playing field and it reduces the discrimination that can occur when someone picks up a clinical file without even meeting a consumer and sees the words 'high risk'. I am also aware of a similar service in the United Kingdom called 'Leeds Survivor Led Crisis Service', and another service in the US called 'Afiya', run by the Western Massachusetts Recovery Learning Community.

Issues with accessing and navigating mental health services

The consumers that come to VMIAC are often consumers that have not been heard by anybody else for a whole variety of reasons. Usually, consumers don't seek advocacy from us to gain access to mental health services, but rather to get out of or stay away from services. VMIAC has made a submission to the Royal Commission which addresses (among other things) the discriminatory effects of the *Mental Health Act* (including that people diagnosed with mental illness do not have a choice about whether or not they receive medical treatment in certain circumstances, that the Act has made no changes to the rates of compulsory treatment or the uptake of supported decision making tools such as advance statements, and that Victoria should be moving towards being compliant with the International Convention on the Rights of Persons with Disabilities). A copy of the submission is attached to this statement and marked 'VE-1'. It focuses on four critical areas, namely human rights, serious harms, social

³ See

https://www.mentalhealthamerica.net/sites/default/files/Evidence%20for%20Peer%20Support %20January%202017.pd

determinants and community-led responses and the importance of putting consumers' views ahead of others.

- VMIAC hears consumers speak about the State and Federal divide being quite disjointed and issues relating to geographical catchment areas. Catchment areas do not exist for other health services, and this is a point of discrimination against people with mental health challenges.
- The impact of fragmented services is increasing distress. Having a system that is disjointed across the State and Federal governments means there is a high level of confusion about what services people are eligible for, which creates further distress for people experiencing mental health challenges and emotional distress.
- There is a lack of coordination between many services, for example child and family services and mental health services, as well as carer support organisations and consumer services. The NDIS has also pushed people further away from being able to access the supports that they need.

What could be done to improve access and navigation of mental health services?

- We need to give people who are in the system and those who are not in the system more options, including specialist services that respond to trauma, alternative therapeutic approaches such as counselling (distinct from a psychologist who still works from an illness model), peer support services and health and wellbeing services that include physical health outcomes.
- If the system were better able to respond to people's distress then there would be less of a need for navigation of the system. VMIAC's submissions make clear VMIAC's view that if services were more focussed on human rights, we would have more humanity and if we had more humanity we would have less harm. Anecdotally, VMIAC often hears stories of discrimination affecting consumers' access to services, for example an individual with a diagnosis of borderline personality disorder is less likely to receive access to services than an individual with a diagnosis of schizophrenia. We argue strongly that ineffective and often compulsory services cause increased mental and emotional distress.

Engagement of consumers in the management of mental health services

I believe that services would be improved if governance requirements of any publicly funded mental health service required equal governance by consumers. That is, someone employed at the same level as the clinical director or operational manager who is a consumer. I also consider the involvement of consumer expertise in research

and evaluation of services to be highly important. There is evidence of the impact that consumer expertise can have in the evaluation of services.⁴

- While at Monash Health, I was in a position that was equal to all other senior managers in the mental health program. In that position, I was able to make significant changes. For example, in relation to the design of new inpatient units in Dandenong, I worked with our consumers and successfully advocated for the reduction of seclusion rooms, inclusion of en-suites, person controlled locks on doors and single loaded corridors. This was important because it meant that every room had a window to the outside and when you came out of your room you saw the court yard.
- This model of management starts to address some of the principles of co-production, that is: starting to right some of the power differentials that traditionally consumers and even workers experience in services. There is a huge power differential implicit in the *Mental Health Act*, as a psychiatrist can make decisions about you based on what they assess to be your capacity and that feeds down right through the system. So as soon as you become a declared consumer in any sort of role, you start to be treated through that lens.
- This work is really important I do it because I know that this change needs to happen. Most people working in this space take on this work because we've had really awful experiences and we want to make it better. It is highly important that the views of consumers are acknowledged and brought into every level of decision-making 'nothing about us without us.'
- Having consumer-delivered and consumer-led services would show a commitment to true reform that will push services to be more innovative about what they deliver. Services can be restricted in their thinking when you ask them to come up with something that's really innovative they tweak around the edges of what's currently there. But if more peer delivered, consumer delivered services were available to people it would force clinical services to change.
- Other suggestions for reform and focus for the Royal Commission are outlined in the VIMIAC submission.

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⁴ (2001) The Essential U&I – A one-volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services (ed.), VicHealth, Carlton South, Victoria.

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Date	10/7/19.	





ATTACHMENT VE-1

This is the attachment marked 'VE-1' referred to in the witness statement of Vrinda Edan dated 10 July 2019.



FROM HARMS TO HUMANITY

Submission to the Royal Commission into Mental Health

Submitted by VMIAC

July 2019

our vision is a world

where all mental health consumers stand **proud**, live a life with **choices** honoured rights upheld, and these principles are embedded in all aspects of society.

Suggested citation: VMIAC. (2019). *Submission to the Royal Commission into Mental Health*. Melbourne, Victorian Mental Illness Awareness Council. Retrieved from: https://www.vmiac.org.au/rcmh

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Approval: This position paper was endorsed by the Victorian Mental Illness Awareness Council's Committee of Management in July 2019.

About VMIAC

The Victorian Mental Illness Awareness Council (VMIAC) is the peak Victorian non-government organisation for people with lived experience of mental health or emotional issues. We provide advocacy, education, consultation and information to promote the rights of people using, or wanting to use, mental health services.

VMIACS's work is premised on the following beliefs:

- People's experiences are respected and valued
- People are experts in their own lives
- People have a right to self determination
- People's diversity is embraced

- People have capacity to make genuine choices, free from coercion
- People should be safe, respected, valued and informed

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Acknowledgements

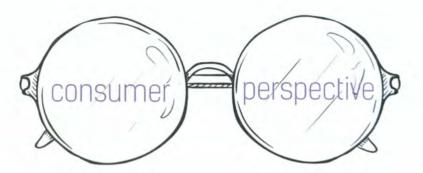
This paper was developed by consumer/survivor workers at VMIAC, based on our decades of advocacy work and consultation with and for consumers/survivors of Victorian mental health services. We draw on research and consumer/survivor movement narratives as relevant.

We acknowledge that no submission paper can fully capture the depth and breadth of consumer/survivor experiences—particularly those experiences which cause us harm. We gratefully acknowledge those people who have shared their stories with us.

Acknowledgement of country

VMIAC is located on the lands of the Wurundjeri people of the Kulin Nation. We work in partnership with First Nations people and communities across Victoria. We acknowledge the traditional custodians of the land on which we work, and pay our respects to elders past, present and emerging. This land was never ceded.

EXECUTIVE SUMMARY



This submission is written from a consumer and human rights perspective, by VMIAC, the peak body for the people who use mental health services.

Our sole concern is that Victoria responds to the mental and emotional wellbeing needs of its citizens in ways which:

- Are helpful
- Do no harm
- Respect and uphold human rights

We submit that Victoria is failing on all three of these measures. Victoria's current approach to mental health fails to help many people, is often significantly harmful, and seriously breaches many human rights. There is a strong case for major reform of Victoria's mental health system, and we are hopeful of a final Royal Commission report which supports this level of reform.

This submission aims to provide a high-level lens for the Royal Commission.

It's a way to consider the many and complex issues, and a way to filter and assess the many options for reform. We have not responded to the explicit detail of the terms of reference, but rather we have focused on the requirement for the Royal Commission to provide recommendations which take account of human rights and the views of people with lived experience.

Our submission focuses on four critical areas:

- 1. Human rights
- 2. Serious harms
- 3. Social determinants and community-led responses
- 4. Consumer voice

No mental health without humanity. No humanity without human rights.

Human rights restrictions and breaches are not benign—they hurt people. Yet in Victoria's current mental health system, human rights are restricted and breached in broad and deep ways, with a regularity and carelessness that should concern every Victorian.

We often hear system leaders justify these rights issues as being necessary to uphold the right to health—but that is incorrect. It is not a right to be healthy, but rather a right to access health determinants and services. The right to health also includes the right to freedom from non-consensual treatment.

We urge the Royal Commission to critically assess Victoria's discriminatory approaches to mental health, to pay serious attention to consumers and United Nations recommendations, and to recommend significant legislative and sector reform. Victorians deserve to have their humanity and human rights put before our current fearful, riskaverse, discriminatory and often harmful approaches to mental health.





Do no harm.

Current approaches to mental and emotional distress in the acute system are hurting thousands of people. Degrading and humiliating treatment, seclusion, restraint, sexual violence, chemical restraint and more all serve to traumatise many of the consumers admitted to the acute mental health system.

There are insufficient protections or oversight of the mental health system, and it should be no surprise that consumers often tell VMIAC that their mental health was worsened as a consequence of using our health system. This should be unacceptable to every Victorian.

The right to freedom from cruel, inhuman and degrading treatment is breached for Victorians every day, in hospitals across Victoria. In international law this is an absolute right, and there is no excuse for violation. Legislative reform will help, but it's not enough. Every aspect of the system needs reform to prevent harm, including rethinking the system's main activities and intended outcomes, workforce composition and skill requirements, accountability and oversight, and service types.



Distress is a normal response to abnormal experiences.

It is indisputable that mental 'illness' is linked to social determinants—trauma, isolation, adversity, socioeconomic disadvantage, violence, racism, homophobia, bullying, family violence, sexual violence, and other forms of harm. An effective mental health system must respond to these factors, it must be a whole-ofgovernment response (not just the health system), and it must move beyond current approaches that attempt to 'fix' human distress with simplistic responses like providing (or forcing) medication.

The right to health includes the right to access the social determinants that prevent health problems, and for mental health this means we need to build a society that is safe, equitable, respectful and inclusive. We recognise this is an enormous mission, but it must be the foundational business for any long-term mental health strategy if we want genuine progress.

Recognising social determinants and the right to health means that 'early intervention' cannot be about diagnosis and prescribing. Instead it must be about compassion, therapeutic responses to the things in our world that hurt people's hearts and minds. Things like supporting communities to support each other. Access to counselling, therapy and peer support. Services that respond to complex trauma. Services based in community rather than hospitals. Services based around communities that experience greater disadvantage, and coproduced by those same communities. More services that respond directly to causes of harm, like sexual and family violence, bullying, isolation, homophobia and racism.

Our minds, our bodies. Our voices come first.

We are mindful that many submissions made to the Royal Commission may contradict this submission. We ask the Commissioners to remain mindful of:

Bias, stigma and discrimination

This may be evident in submissions that assume consumers are violent, or that we lack capacity and need others to speak on our behalf, or in our 'best interests'.

Experience of services

We know a much larger group of people have never used the acute system and may argue for more access to hospital beds. However, we also know these people have not experienced that system and may not realise what they are asking for. As people who have used the system, we agree wholeheartedly that people do need access to help, but not the system as it currently stands.

Carers can't speak for consumers

Carers and family members have every right to speak out, and they are the experts in their own support needs. But they are not the experts in what we need as consumers. Far too often, the fears of family members are allowed to override the rights and needs of the person in distress.

Vested interests and sector bias.

We are mindful of the potential for sector submissions to:

- Be limited by existing practice and a history of not upholding human rights
- Be biased by vested interests for a workforce to want more jobs or services to want more funding

Our submission may seem challenging, but all we're asking is to be safe, treated with dignity, to be free from violence and abuse, to have our fundamental rights respected, and have access to reasonable, helpful services.

NO HUMANITY WITHOUT HUMAN RIGHTS.

Human rights are the most critical underpinning factor to achieve the aims of the Royal Commission into Mental Health.

Accordingly, this submission will focus solely on providing a consumer-informed, human rights lens. Our focus on human rights is supported by section III(g) of the Royal Commission Letters Patent (2019), which asks the Commissioners to give regard to:

'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.'

Our prior submission, to the Terms of Reference for this Royal Commission provided more detailed advice that maps broadly against the terms of reference.



Download our previous, more detailed submission here:

www.vmiac.org.au/royalcommission-into-mental-health

Human rights issues in the mental health system

People who use public mental health services are hurt by some of the most extreme human rights restrictions and breaches¹ of anyone in Victoria. These issues are significant by almost any measure:

Breadth of rights issues

Human rights restrictions and breaches impact across many life domains. The combined impact can devastate people's lives. Mental health consumers:

- Are victims of violence and abuse at higher rates to the general public.¹
- Experience many rights issues while using, or trying to access, mental health services.^{2,3}
- Face discrimination and inequality across almost all aspects of citizenship, including housing, employment, income, relationships, and community access.

¹ In this report, human rights 'restrictions' refers to lawfully sanctioned limits on human rights, although we note that in the mental health context, Victorian laws can be viewed as sometimes conflicting with international conventions ratified by Australia. Human rights 'breaches' refers to unlawful actions which impede on human rights. Human rights 'issues' is used to refer collectively to both restrictions and breaches.

Depth of rights issues

Human rights issues for people experiencing mental and emotional distress are serious and harmful:

- 7,215 people were bodily restrained in mental health units during 2016/17.4
- There were 90 complaints about sexual violence in inpatient units in the 2018 Mental Health Complaints Commissioner report, 'The Right to be Safe'.⁵
- Consumers have a reduced life expectancy of between 10 – 20 years.^{6,7,8}

Regularity of rights issues

Rights restrictions and breaches are so frequent in mental health services that they have become 'business as usual' rather than the exception:

- The majority of people admitted to mental health inpatient units are under compulsory detention and treatment.⁹
- In contravention of the law, it is common knowledge that voluntary patients are regularly denied leave from inpatient units, especially during the first 24-48 hours of admission.
- Victoria uses Community Treatment Orders (CTOs) at a rate that is amongst the highest in the world ¹⁰, despite the lack of evidence for their effectiveness.^{11,12}

Carelessness with which rights are impacted

There is a disturbing failure of many mental health clinicians to understand or respect human rights. Rights are restricted and breached in mental health services without

consideration for the impact on dignity, emotions, mental or physical health. There appears to be wide-spread assumption that taking away people's rights is somehow benign. It is not.

- It is common practice for psychiatrists to not tell consumers about serious treatment adverse effects, like the risk of reduced life expectancy or cognitive impairment, or to downplay the likelihood or seriousness of those effects.
- Despite the well-known risk of sexual violence on inpatient units, it is consistently reported that staff often leave bedroom doors unlocked after night checks, services fail to keep bedroom locks in working order, and some units don't even have locks installed on bedroom doors.⁵
- It is common practice for psychiatrists to initiate detention and compulsory treatment based on 'risk of harm to others'—despite repeated research findings that psychiatrists are unable to reliably predict this risk.^{13,14}

The inability of mental health professionals to accurately predict risk of harm entirely undermines risk management as a justification for involuntary treatment.¹³

The information in Attachment 1 of this submission provides a summary of the differing human rights issues experienced by mental health consumers,

Attachment 2 provides a ranked list of human rights priorities for consumers, based on a recent survey by VMIAC.

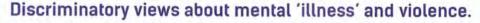
Impact of human rights issues

There are exceptionally serious impacts for people who lose so many human rights. Human rights exist to preserve life, dignity, humanity and safety. Without these things, it is impossible to have good mental health. We can never have a successful societal response to mental health by taking away the very things that give us our humanity.

The foundation of rights issues

We believe that almost all of the most serious human rights issues in mental health stem from three fundamental issues:

- 1. Discriminatory views about mental 'illness', particularly the false assumption that we are 'dangerous'.
- 2. Compulsory detention and treatment, enshrined in the Mental Health Act 2014 (Vic).
- 3. Failure to recognise or respond to social determinants and trauma.



The myth that people with mental 'illness' are dangerous is used to justify the Mental Health Act 2014 (Vic) and human rights restrictions—yet the facts don't back this up:

- The vast majority of people diagnosed with mental illness are victims of violence, not perpetrators.^{1,15}
- Some people diagnosed with mental illness commit violence, but not at a much higher rate than other people.¹⁶
- When people diagnosed with mental 'illness' commit violence, it's not necessarily because of their mental health (i.e., violence is more strongly related to other factors).¹⁷

Compulsion and the Mental Health Act 2014 (Vic)

The Mental Health Act 2014 (Vic) is a discriminatory barrier to equal rights. International law recognises that few rights are absolute, and so reasonable limitations can be implemented under specific circumstances. However, the Act fails to meet many of the requirements for reasonable limitations.

The Mental Health Act 2014 (Vic):

- · Reinforces stigmatising, outdated attitudes.
- Relies on subjective, normative judgements rather than objective criteria.
- Has criteria based on assumptions that lack reasonable evidence.

Criteria under the Act	Lack of evidence		
The person has a mental illness	Mental illness diagnoses are subjective and lack reliability. 18		
The person needs treatment	Mental health treatments have poor efficacy (see below).		
The person is at risk of harm to self or others	A tiny proportion of consumers are actually violent, and even so, psychiatrists are unable to accurately predict a risk of harm to self or others ^{19,14}		
There is no less restrictive option	There are many less restrictive options available for treatment which are rarely provided in mental health services, such as therapy, peer support or simply allowing people space and time.		

Poor evidence for antipsychotic medication

Only a minority of people (23%) have a 'good' response to antipsychotic treatment, while 51% have a 'minimal' response, according to a systematic review and meta-analysis of the past 60 years of antipsychotic research.²⁰ Worse, antipsychotics are classed as high-risk medications with a large number of serious adverse effects.^{21,22} Compulsory treatment is discriminatory regardless of these findings, but it is exceptionally unreasonable given the poor efficacy and high risk.



Poor evidence for electroconvulsive therapy

Evidence for electroconvulsive therapy does not support its use as a compulsory treatment, particularly given the potentially disabling side effects of memory loss. There is a clear lack of adequate evidence for using ECT as a treatment for schizophrenia,²³ yet about one-third of ECT treatments in public services are for schizophrenia or other psychoses.²⁴ While there are more studies on the use of ECT for depression, the quality of research is not high²⁵ and the efficacy rates are only 52.9% (people who experience 'remission' after ECT)²⁶. Any compulsory use of ECT is completely unreasonable.

Lack of adequate rights protections

There has been a long-standing failure of government and statutory bodies to provide adequate protections for human rights.

There is no real effective, independent sector oversight, and there is a serious lack of transparent accountability for services. Even those protections provided by the current Act are poorly implemented: few clinicians understand what supported decision making means,²⁷ only around 3% of consumers have an advance statement,²⁸ and we hear frequently from consumers about a lack of procedural fairness in Mental Health Tribunal hearings, such as not being informed of appeal rights, not being given adequate notice of hearings, or being unable to access a lawyer.

VMIAC is committed to advocating for repealing of the Mental Health Act 2014 (Vic) and abolishing substitute decision making.

We understand that changes of this magnitude tend to occur over time and through smaller increments of change. We urge the Royal Commission to recommend increments of reform which move us closer to a system that fully respects and upholds human rights.

These reforms might include:

Bring the Mental Health Act 2014 (Vic) into line with rights in the Medical Treatment Planning and Decisions Act 2016 (Vic): introduce advance directives so that our preferences for treatment and care can be upheld, just like for other citizens.

Or, as an interim step, place limits on the extent of rights restrictions, such as:

- Abolish compulsory ECT
- Tighten the criteria, e.g., from 'harm to self' to 'imminent risk of death'
- Limit compulsory treatment to recommended therapeutic doses
- Require the cessation of compulsory treatment if a person experiences any serious adverse effects
- Fund IMHA advocates on an opt-out basis, and access to legal representation for all people who want it

Create much greater system transparency, accountability and oversight.



The serious harms and abuses being heard in the Aged Care Royal Commission are happening in mental health services as well.

Many of these harms breach the right to freedom from cruel, inhuman and degrading treatment because:

- They can cause serious, lasting injury (physical, psychological, cultural, sexual)
- They are sometimes used as punishment, in response to 'rule breaking' on units
- They are rarely, if ever, necessary

Some of these harms are well-known to the sector and government, while others are rarely acknowledged. Policies about safety in mental health services tends to focus on physical safety in the immediate short term, and avoids consideration of other kinds of harm (e.g., emotional injury) or harm in the medium to long-term (e.g., traumatic flash backs).

For example, it would not be uncommon for a person thought to be at risk of suicide to be subjected to physical restraint and seclusion. Official reports may be made if the person sustains a physical injury while they are held down by a group of staff, but little if any attention will be paid to the resulting emotional injury.

We know from decades of advocating with and for the consumer community that many people live with a lifetime of traumatic memories, flashbacks and nightmares from incidents such as these. Some consumers decide that it is not safe to ever ask for help again, leaving them isolated and at risk during future periods of distress. But these kinds of harms are not seen or reported, despite their severity.

It is wholly unacceptable that so many people experience serious, lasting injuries as a consequence of healthcare services. Common forms of harm include:

- 1. Detention
- 2. Compulsory treatment in hospital
- 3. Compulsory treatment in the community
- 4. Sexual harassment & assault
- Staff not believing disclosures of sexual harassment or assault
- 6. Strip searches
- Seclusion (solitary confinement, sensory deprivation)
- 8. Mechanical restraint
- 9. Physical restraint
- 10. Chemical restraint
- 11. Psychological restraint (threats)

- Adverse effects from medication that causes dysfunction, illness or disability
- Early death from medication adverse effects
- Memory loss and cognitive impairment from ECT
- 15. Punishments
- Derogatory, humiliating and belittling behaviour
- 17. Assault by security guards
- Prevented from engaging in cultural or spiritual practices

Failures by oversight bodies

Overly restrictive legislation, poor service culture and insufficient staff skills contribute to these harms—but that's not the whole story.

Government and oversight bodies are consistently failing to hold mental health services to account, allowing harms and abuses to continue behind closed doors.

7 of the 10
worst Australian
hospitals for
mechanical restraint
are from Victoria.²⁸

Reporting is far from sufficient: only six of the items on the above list are reported publicly at a state-wide level, and only two of these items are reported on a per hospital basis. Even when hospitals perform below the state-wide key performance indicators, like with seclusion, there does not appear to be any consequence. There is a lot of data that is never released publicly (e.g., strip searches) and other areas where no data is collected at all (e.g., chemical restraint).

Harms and abuses vary significantly across services and units. For example, our 2019 Seclusion Report (Attachment 4) found that seclusion was used 18 times more often at Barwon Health than it was at Latrobe Health. Some hospitals didn't use mechanical restraint at all during 2017/18, yet Box Hill Hospital and the Royal Children's Hospital had the highest rates of mechanical restraint out of 133 hospitals across Australia.²⁹

The Mental Health Act 2014 (Vic) defines a number of statutory bodies and roles, but this oversight system is not functional and is in need or urgent reform.

Seclusion-Just one type of cruel, inhuman and degrading treatment

There are national and Victorian goals to reduce seclusion, and until 2015 Victoria achieved five years of steady decline. But since 2015, seclusion use has been increasing in Victoria. Seclusion involves locking a person, on their own, into a space from which they cannot leave. The conditions of seclusion rooms vary significantly—however there are no regular, transparent and independent inspections of these facilities.

Consumers describe frightening, traumatic impacts from seclusion which meet the criteria for cruel, inhuman and degrading treatment:

- Sensory deprivation, made worse because of pre-existing distress, feeling trapped with their distress, e.g., hearing frightening voices with no distraction possible
- Isolated for extended periods
- The degrading experience of having to squat on the floor over a small cardboard bedpan for toileting—with an observation window preventing privacy and any dignity
- Some consumers have told us about being stripped naked before being secluded, and the feeling of extreme vulnerability that comes with being naked in a locked room while others can look in through a window



These conditions would be distressing for anyone, but are particularly cruel when used on people who are already extremely distressed, and who most likely have a history of trauma or abuse. The psychological trauma from being secluded can last for many years.

It is entirely unacceptable that healthcare services, of all places, are actively causing severe, increased distress and suffering. It is also unacceptable that while countries like New Zealand have made a commitment to eliminate seclusion, in Victoria seclusion is actually rising.

We urge the Royal Commission to recommend significant reforms that aim to prevent harms and abuses in mental health services, including:

- Major reform of sector oversight and accountability with a focus on preventing harms and abuse, creating transparent and accountable services, and remedies for people who experience these harms
- · Setting a date for the elimination of seclusion and restraint
- Urgent state-wide actions to create sexual safety, including women's only units, and patient controlled locks on bedroom and bathroom doors
- Defining and legislating against chemical and psychological restraint
- Legislating against strip searches in mental health services
- Standards and measures to ensure that consumers are fully informed about adverse effects prior to treatment, and that regular assessments are made to identify adverse effects and respond accordingly (e.g., change treatment and address adverse effects)

MENTAL AND EMOTIONAL DISTRESS IS A NORMAL RESPONSE TO ABNORMAL EXPERIENCES



The single most significant predictor that an individual will end up in the mental health system is a history of childhood trauma, and the more severe and prolonged the trauma, the more severe are the psychological and physical health consequences.³⁰

The underlying issue for this Royal Commission is not a health problem. It's a social problem of trauma, adversity and other social determinants of health.

If the Royal Commission is serious about preventing mental health problems in a systemic way, it must respond to trauma, adversity and social determinants across the Victorian community. An overwhelming majority of people using acute mental health services have a history of serious trauma. Repeated research and government reports tell us that around 85% of the people using public mental health services have at least one of the following experiences of trauma:

- Sexual or physical abuse in childhood, and or
- Sexual or physical assault as an adult.^{31,32,33}

Trauma has been linked to almost every type of mental illness diagnosis, including schizophrenia, depression, anxiety and borderline personality disorder, and can often be the root cause of mental and emotional distress. Research into social determinants of health, such as poverty, further illustrate links between life adversity and the development of mental health problems.³⁴

We urge the Royal Commission to acknowledge the underlying issues behind mental and emotional distress: inequality, socioeconomic disadvantage, discrimination, trauma, violence and abuse.

Mental health services are largely ignoring trauma and social determinants

It is unacceptable that mental health systems and practitioners continue to provide medication as the almost exclusive, simplistic treatment for mental health problems. Medication can be helpful for some, but the overall efficacy of psychiatric treatments is poor, and there is no medication that can heal adversity and trauma.



What we need Compassionate, empathetic connection with others.



What we get Detention, force & drugs.

Prevention is not a job for the health system.

An effective, state-wide response to mental health must respond to social determinants, and this requires a response that stretches far beyond the health system.

In this context, prevention of mental and emotional distress requires building a society that is safe, equitable, respectful and inclusive. This is a very long-term, whole of government commitment to reduce inequality, socioeconomic disadvantage, discrimination,

trauma, violence and abuse—and to uphold and protect human rights for all Victorians.

Social determinants and trauma drivers should also inform early intervention responses in a different way to current mental health models. Rather than focus on early mental illness diagnosis and prescribing, genuine early intervention should be about early response to distress caused by social and interpersonal forms of adversity and trauma.

Recovery-oriented, trauma-informed, community-led responses

Many people are in crisis but unable to access the current public mental health system, and we have no doubt that those people will ask for more hospital beds. As the people who've actually used that system, we know that building more beds is *not* an answer—the current system is fundamentally flawed, reductionistic and harmful. It's also exceptionally expensive for government, and there are much better options.

Ensuring people can access more funded counselling and therapy is part of the answer. Medicare funding for therapy is woefully inadequate, and makes no allowance for people's widely varying needs. The Victorian government has a responsibility to address this need, although this is still not all of the answer.

We recommend a shift away from the health system and towards communities. Given that most mental health problems are responses to trauma and adversity, and our health system has very little expertise in these areas, this makes much more sense.

Three of the principles for trauma informed practice are peer support, choice and empowerment.³⁵ We advocate for a state-wide, multi-tiered approach to peer support which includes professional peer workers in services at one end, and informal peer support in local communities, at the other end.

The beauty of informal, community-led peer support is that the people with the most expertise about issues and needs are the communities directly affected by those issues.

By incorporating principles of co-production^{36,37} with modest community development and practical resources, thousands more people can access support when they need it, in a model that is sustainable, rights-based and helpful. This might include initiatives like:



Supporting communities to support each other:

- Invest in resources like community support meeting spaces and more neighbourhood houses.
- Fund the provision of community development and informal peer support skills across the state, coordinating with local councils and existing community networks.
- Establish networks between communities to share ideas, skills and resources.
- Using coproduction methods, community members can both contribute to community support spaces, and seek support from those spaces.
- Over time, communities coproduce their own spaces, tailored to local culture and needs, where people gather for support groups, social connection, community action on disadvantage and informal peer support.

More support where there are fewer social determinants of health:

- Similar to the above, but invest more heavily in areas and communities who experience greater disadvantage, such as rural and regional areas, Aboriginal and Torres Strait Islander communities, LGBTIQ communities, and areas with greater economic disadvantage.
- Using coproduction models of engagement, support community leaders and members to determine their needs and preferred support options, and to design and deliver those supports.

Specialist, community-based, therapeutic trauma services:

Victoria must also respond to the serious gaps in support and care for people with experiences of highly distressing trauma. Some trauma services already exist, like CASA for sexual violence, and Foundation House for survivors of torture. But there are no specialist services for most types of trauma, and no services at all for people who've experienced multiple and complex forms of trauma. We recommend:

- Investment in a new service stream, based in communities rather than hospitals, with community service approaches rather than health system approaches. Services should be staffed with therapists, counsellors and peer support workers, and different service models could be piloted, such as peer-run respite houses, therapeutic communities and more generic service models.
- These services should respond to people who experience severe distress from multiple or complex trauma, or traumas that don't have specialist services, and would otherwise have nowhere to go but the mental health system.

OUR MINDS, OUR BODIES OUR VOICES COME FIRST

We are mindful that lots of people have something to say about mental health—and these are not always the people who have lived through mental and emotional crises.

Bias, stigma and discrimination.

We ask the Royal Commission to remember that stigma and discrimination about mental health is widespread, and these unfortunate attitudes are likely to be present in some of what is submitted to you. It will be evident in submissions and testimony which assumes any of the following:

× Consumers are violent and need to be controlled.

But we are no more violent than you. Media and public views about mental illness and violence are not supported by facts.

Consumers lack capacity and need others to speak on our behalf.

But we have a right to legal capacity and we can speak for ourselves. To think otherwise is at best paternalistic and at worst a breach of the right to equality under the law.

* It's OK for them to decide what's in the 'best interests' of consumers.

The poor outcomes of mental health systems illustrate this is not the case. 'Best interest' mindsets are outdated forms of paternalism, better replaced with rights-based 'will and preferences' decision-making.³⁸

Experience of services.

Most Victorians with mental and emotional distress have never used the acute mental health system, they rely instead on primary and

secondary services funded mainly by the Commonwealth, or they are self-funded. This large group are clearly not having their right to access health services met, and this gap must be addressed. However, we remind the Royal Commission that people from this group who say that we need 'more hospital beds' have not in fact experienced them. Many of those who have experienced hospital 'beds', like our members, will tell you this is not the answer.

Carers speak for themselves, but not for consumers.

In many spaces, including the Royal Commission, there are often more carers/family members speaking out than consumers. We urge the Royal Commission to weigh these contributions with a consideration of relevance. Carers and family members have every right to speak out, and they are the experts in their own support needs. But they are not the experts in what we need as consumers. Far too often, the fears of family members are allowed to override the rights and needs of the person in distress. This is not acceptable.

Vested interests & sector bias.

There will be important and relevant advice in many submissions from the sector. However, there will also be vested interests, like unions wanting more jobs, or services wanting more funding. There will be biases and limitations because of the current system culture, with its long history of coercion, limited treatment options, and where human rights are a secondary consideration at best. People don't know what they don't know, we suggest that some sector submissions will be limited by this.



Summary of human rights restrictions and breaches for mental health consumers ATTACHMENT 1

Rights that are commonly restricted or breached, primarily in public psychiatric services, and in related statutory processes

- 1. Right to equality before the law 1,2,3,5
- 2. Liberty and security of person 1,2,3
- 3. Protection from torture and cruel, inhuman or degrading treatment 1,2,3,8
- 4. Freedom of information, opinion & expression 1,2,3
- 5. Freedom from interference with privacy, family, home and correspondence or reputation^{1,2,3}
- 6. Freedom of thought, conscience, religion & belief 1,3
- 7. Humane treatment when deprived of liberty 1,3
- 8. Participate in cultural life 1,2,4
- 9. Integrity of the person 2
- 10. Statement of rights given & explained 9
- 11. Right to physical and mental health 2,4,7
- 12. A fair hearing 1,2,3

Rights that are commonly restricted or breached in broader society

- 13. Right to adequate standard of living and social protection 2,4
- 14. Right to social security and social insurance 4
- 15. Right to habilitation and rehabilitation ²
- 16. Rights of women 2
- 17. Right to accessibility 2
- 18. Freedom from exploitation, violence and abuse 2

Rights that are sometimes restricted or breached for mental health consumers

- 19. Freedom of movement 1,2,3
- 20. Rights of members of ethnic, linguistic and religious minorities 3
- 21. Right to education 2,4
- 22. Right to work 2,4
- 23. Right to just and favourable conditions of work 4
- 24. Respect for families 1,2,3,4
- 25. Rights of parents & children 3
- 26. Property rights 1,2
- 27. Right to live in the community ²
- 28. Right to mobility 2
- 29. Right to an advance statement 9
- 30. Right to a nominated person 9
- 31. Right to seek a second opinion 9

¹ Charter of Human Rights and Responsibilities 2006 (Vic)

² Convention on the Rights of Persons with Disability (UN, 2006)

³ International Covenant on Civil and Political Rights (UN, 1976)

⁴ International Covenant on Economic, Social and Cultural Rights (UN, 1976)

⁵ Equal Opportunity Act 2010 (Vic)

⁶ Disability Discrimination Act 1992 (Cth)

⁷ Australian Charter of Healthcare Rights (ACSQHC, 2008)

⁸ Convention Against Torture (UN, 1987)

⁹ Mental Health Act 2014 (Vic)

Top 15 human rights priorities by & for consumers ATTACHMENT 2

This list is a ranking by mental health consumers of their top priority human rights issues for mental health. The data is amalgamated from (a) a survey on human rights conducted with consumers in the community, and (b) a survey of VMIAC advocacy staff, managers and governance committee (2018, n=47).

Rank	Priority issues	Relevant rights
1	Compulsory treatment Includes compulsory treatment, lack of informed consent, lack of autonomy, bodily integrity & self-determination, supported decision making not provided, lack of dignity	 Right to health Right to bodily integrity Right to equality before the law
2	Safety, abuse, assault, cruel, inhuman & degrading treatment Includes not feeling or being safe, being retraumatised, wanting mental & physical safety, the experience of cruel, inhuman & degrading treatment in mental health services	 Right to freedom from torture, cruel, inhuman and degrading treatment Right to humane treatment wher deprived of liberty
3	Seclusion & restraint Includes chemical restraint	 Right to freedom from torture, cruel, inhuman and degrading treatment Right to humane treatment wher deprived of liberty
4	Lack of procedural fairness in compulsory treatment Includes no access to a lawyer, lack of a fair trial/hearing at the Mental Health Tribunal	Right to equality before the lawRight to a fair hearing
5	Human rights protections in the Mental Health Act 2014 (Vic) not upheld	Rights under the Mental Health Act 2014 (Vic)
6	Liberty Includes being detained under the Act, and unlawful detention for voluntary patients (e.g., being denied 'leave')	 Right to liberty Rights under the Mental Health Act 2014 (Vic)
7	Discrimination	Right to equality under the law
8	Gaps in care for trauma & abuse survivors	Right to health
9	Less/no access to community support services (NGOs)	Right to health
10	Housing and homelessness	Right to adequate standard of living
11	Issues & impacts of electroconvulsive therapy (ECT)	Right to health
12	Reduced life expectancy	Right to healthRight to life
13	Sexual violence in hospital	Right to freedom from torture, cruel, inhuman and degrading treatment
14	Myths about mental illness and violence	Most other rights issues
15	Psychiatric medication & side effects	Right to health Right to life

The right to health: Implications for mental health ATTACHMENT 3

We have included this attachment because the right to health is:

- Frequently misinterpreted
- Sometimes used to (incorrectly) justify compulsory treatment

In a mental health context, the right to health is primarily protected by two United Nations conventions:

- The International Covenant on Economic Social and Cultural Rights (s12(1))
- The Convention on the Rights of Persons with Disability

Other conventions make explicit protections of the right to health for women and children, and additional protections on the basis of race. There are no explicit laws in Victoria or Australia which protect the right to health, although there are a number of laws and standards related to health, including the Australia Charter of Healthcare Rights, which is of particular relevance.

The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be

free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health. (UN, CESCR, 2000, emphasis added)

This has implications right across mental health prevention, access, service systems and outcomes.

The right to health is not a right to be healthy.

- The Mental Health Act 2014 (Vic) is sometimes understood to be fulfilling the right to health because of the criteria that the person 'has a mental illness' and 'appears to need treatment'.
- This understanding is flawed because it fails to appreciate that the right to health is not a right to be healthy.
- In almost every other area of health, people may appear to have an illness and need treatment, yet laws are not enacted to force the treatment. Compulsion only occurs in mental health because of underlying, discriminatory issues like:
 - Beliefs that consumers 'lack capacity' to make their own decisions
 - o Fear of diversity and difference
 - Fear of risk + a presumption that they know what's in our 'best interests'
 - o Fear of the Coroner's Court (for clinicians)
- The right to health does not justify the use of compulsory treatment.

The right to health includes an entitlement of access to timely and appropriate healthcare

In mental health, what is timely and appropriate are both matters of debate. Despite billions that have been invested in mental health research, there is still no definitive evidence as to the best supports and treatments. However, it is clear that there is no single or simplistic solution. We argue that:

- Timely mental health care should occur as close as possible to the underlying causes of distress,
 i.e., trauma, adversity and other social determinants
- Appropriate mental health care should mean that a range of support and treatment options are
 available to people, recognising that there are many helpful options beyond what current mental
 health services typically provide, and that different people respond to different things.

The UN clarifies that accessibility of health care must include: non-discriminatory access, physical accessibility, economic accessibility and information accessibility. None of these access factors are well addressed in mental health:

- Peer support is not accessible to the vast majority of people
- The overall system is fundamentally discriminatory by nature of the Mental Health Act 2014 (Vic).
 Fear of detention and compulsion, or harmful treatment effects, actually prevents many people from accessing mental health services.
- Services are not physically accessible to many Victorians in regional remote areas, and eHealth is not necessarily an equitable or effective response in mental health
- Counselling and therapy are not economically accessible, particularly given that mental and emotional distress can increase economic disadvantage.
- Information about mental health and services, and talking therapies, are rarely available in languages other than English, or with suitable adjustments for people with communication barriers.
 Services are often culturally inappropriate.

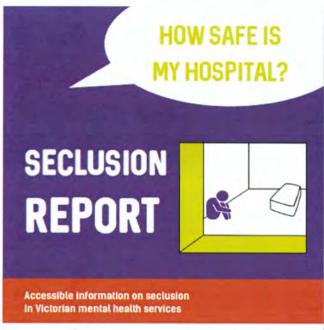
The right to health includes an entitlement of access to the underlying socioeconomic determinants of good health

This means that people have an entitlement, as far as practicably possible, to be free from violence, abuse, trauma and other social determinants which can contribute to mental and emotional distress.

The right to health includes the freedom to control one's health and body and freedom from interference (e.g., torture, non-consensual medical treatment and experimentation)

This is the aspect of the right to health which is most frequently and seriously breached in mental health services. Every instance of compulsory treatment is a breach, as is every instance of undue influence/lack of informed consent, restrictive practice, detention, and lack of protection from sexual violence. This part of the right to health is clear that forcing people into healthcare is a breach of rights, not an upholding of rights.

The Seclusion Report ATTACHMENT 4



VMIAC launched the Seclusion Report in April 2019. The report aims to:

- Make information about seclusion more accessible to consumers
- Create greater pressure for accountability in the mental health sector

The report will be reissued every six months with new data.

The report provides relevant, and more detailed information about seclusion, restrictive practices and sector accountability which can inform the Royal Commission.

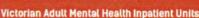


This report was produced by VMIAC, the peak body for mental health consumers across Victoria.

April 2019

www.vmiac.org.au

SECLUSION RATES





QUARTERLY RATINGS: OCTOBER-DECEMBER 2018 rate Rank Within 3.0 62 42 50 7.0 ol Rese He 11.4 9.3 114 124 20,1 15.3 18.2 15.2 18 20.8 22 23.8 erette District Base Hose

Download the report here:

www.vmiac.org.au/blog/seclusionreport-how-safe-is-my-hospital

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