ROYAL COMMISSION INTO MENTAL HEALTH

Terms of Reference Consultation

Submission by VMIAC

(Victorian Mental Illness Awareness Council)

Submitted to the Victorian Department of Premier and Cabinet

January 2019

WE ENVISION 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.

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1   ABOUT US

VMIAC (Victorian Mental Illness Awareness Council) is the peak Victorian organisation for people with lived experience of mental health or emotional issues. Everyone who works here has a lived experience as a mental health consumer.

We provide advocacy, education, consultation and information to promote the rights of people using, or wanting to use, mental health services. VMIAC was incorporated in 1986, and over the decades we have worked closely with thousands of mental health consumers. 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 have capacity to make genuine choices, free from coercion
- People's diversity is embraced
- People should be safe, respected, valued and informed

2   BACKGROUND

International human rights movement. People using mental health services have been part of an international human rights movement since the 1970s, with some activism recorded as far back as the 1800s. Today, we commonly refer to ourselves as *consumers* or *survivors*.

The consumer/survivor movement is similar to movements by other people who have experienced systemic oppression and marginalisation, such as LGBTIQ people, women, people with disability and Aboriginal and Torres Strait Islander people, because of:

- Entrenched social, cultural and legislative discrimination
- Stigmatising myths commonly held about us
- Severe socioeconomic and health disadvantage
- Being victims of violence and abuse
- Other people frequently speaking on our behalf about 'our best interests'

Active participants for change. Today, mental health consumers/survivors are increasingly organised and vocal. We commonly work within the systems we are trying to change, as peer workers, consultants and academics, and we continue to work as advocates and activists outside the system. Like feminism and queer studies, there is now an emergent academic discipline that explores *our* perspectives, called 'mad studies'. Mad studies is in the curriculum at a growing number of universities overseas. We don't just critique the mental health system, but take an active role in changing it, and in providing outstanding alternative approaches.

How VMIAC participates. VMIAC stands proudly as an active participant in this movement for change. We advocate for individual consumers/survivors, but we also sit on government and sector committees, provide consultancy services, run campaigns, deliver training and work actively in our community to build self-advocacy skills and to constantly ask and listen to our members. We consulted with consumers/survivors from across Victoria to develop this submission, including in face-to-face sessions, phone-based consultations and on social media. This submission builds on our expertise from decades of research and advocacy.

3 SCOPE RECOMMENDATIONS

3.1 Recommendations: Themes from Terms of Reference Consultation Survey

Overall, the proposed themes contain some very important issues, however many critical issues and needs are missing, and many categories need a clearer definition, have some inherent problems or can be improved.

The rest of section 3.1 provides comments and recommendations on each proposed theme. Section 3.2 includes additional recommended themes

3.1.1 Prevention and early intervention

We'll never prevent all people from experiencing mental and emotional distress. But we can sure do a lot better.

There are very different ways of understanding prevention and early intervention, including:

- **Biomedical approaches**, which focus on medication as a primary treatment, and often include strategies which medicate children and young people.
- **Holistic, bio-psycho-social approaches**, which include understanding and addressing including social determinants of health, such as attachment, parenting, poverty, child abuse, racism, homophobia, early life wellbeing, safety, breaking cycles and other factors.

Biomedical approaches to mental health are strongly critiqued by many consumers, by recovery experts and recently, by the United Nations Human Rights Council:

The biomedical model regards neurobiological aspects and processes as the explanation for mental conditions and the basis for interventions. It was believed that biomedical explanations, such as "chemical imbalance", would bring mental health closer to physical health and general medicine, gradually eliminating stigma. However, that has not happened and many of the concepts supporting the biomedical model in mental health have failed to be confirmed by further research.[1]

We recommend that the Terms of Reference:
- Includes examining and responding to social determinants of health as part of prevention and early intervention.
- Allows for the reality that prevention and early intervention can apply to any age group (not all mental health problems commence in youth)

Theme	Priority
If this theme includes social determinants of health and looks beyond biomedical diagnoses and treatments	Very high priority
If this theme is only focused on biomedical models	Not recommended

3.1.2 Social isolation, depression, anxiety and trauma

> Causes of mental health problems, like trauma or social isolation, matter for all mental illness diagnoses, not just depression & anxiety.

Unworkable theme with serious issues. This theme includes very important issues—but we have serious concerns that it's unworkable and unreasonable because it combines two very different, complex issues: *mental illness diagnosis* and *causes of mental illness*. It also excludes many people.

a) **Trauma is relevant to all diagnoses.** Trauma is important to all people using acute services because it's the most prevalent experience shared by this group of people—around 85% have at least one of the following experiences:
   - Sexual or physical abuse in childhood
   - Sexual or physical assault as an adult [2,3,4]

   Despite this, most people are rarely asked by mental health workers about their history of trauma, let alone provided therapy to support recovery. Instead, services focus on symptoms and medical treatment, without addressing the underlying issues[5,6,7]. These types of trauma are not the only issues that impact mental health. Other types of trauma can include: childhood bullying, workplace bullying, child neglect, family violence, war and refugee trauma, racism, homophobia and many other painful experiences.

b) **Why limit the social determinants?** Social isolation and trauma are two common and critical causation factors of mental health problems, however:
   - There are other causative factors with good evidence, including many social determinants of health [8]
   - These causative factors relate to many diagnoses, not just depression and anxiety. For example:

   > Experiencing multiple childhood traumas appears to give approximately the same risk of developing psychosis as smoking does for developing lung cancer. [9]

c) **Why limit the diagnosis experiences?** Depression and anxiety are important because they are the most prevalent diagnoses. But low prevalence diagnoses, such as schizophrenia, borderline personality disorder and bipolar disorder, make up the majority of people using the tertiary mental health system, and this system accounts for:
   - The vast majority of government mental health funding
   - The people who experience the most severe human rights limits and breaches, harms and abuse, discrimination and socioeconomic disadvantage

We strongly recommend including causation factors in the terms of reference for the Royal Commission, as these are tied to prevention and effective community and health system responses. These should be in a separate theme to named diagnoses.

We recommend against limiting the scope by naming just two causation factors related to mental health problems. Instead, we recommend giving the Royal Commission scope to analyse the evidence for any and all causative factors, and to make recommendations accordingly.

We strongly recommend against explicitly naming just *anxiety and depression* as this implies the exclusion of other diagnoses.

We strongly recommend that all diagnoses are explicitly included within the scope of the Royal Commission.

Theme	Priority
The theme as currently described	Not recommended
Proposed new theme: Social isolation, trauma and other social determinants of mental health problems	Very high priority
Proposed new point in the Terms of Reference: The scope of the Royal Commission includes all mental illness diagnoses, including high and low prevalence conditions	Very high priority

3.1.3 Accessibility and navigating the mental health system

> Mental health services are impossible to find, or impossible to get into, or for some, impossible to get out of.

Consumers speak to us about many different issues with accessing and navigating mental health services. Key issues include:

Accessibility is about more than 'hospital beds'. The clinical mental health sector often argues that access issues are because there is a shortage of mental health hospital beds. We're not convinced this is a real issue. **We recommend** the Royal Commission looks at a wider range of service system options when considering accessibility.

Views about access vary by experience. People will give very different advice about accessibility issues, depending on their experience. People who have been trying to get into services without success will naturally argue for more services, but many people who have used those services will argue for different, more helpful services:

'Do we need these services, or different ones that will include us as humans, e.g. places of humanity?' (Consumer)

Consumers have consistently told us about these accessibility issues:

People who've never been able to access services	People who have accessed services
• Desperately need access to help but can't get any • Want the services that other people seem to be getting	• *Crisis-driven:* Too hard to get help unless you're in absolute crisis • *Over-supply:* people who have received compulsory treatment, sometimes for years, will argue the opposite of accessibility—they want less services and to be left alone: 'once in the system, almost impossible to get out of it...' (Consumer) • *Discriminatory, judgemental staff blocking access:* Many people diagnosed with Borderline Personality Disorder speak about being treated like a 'time waster' and sent away from EDs without any support[10]. Yet up to 10% of patients with this diagnosis die from suicide (a rate 50 times higher than the general public)[11]. • *Fear of access:* Needing help, wanting to ask, but being afraid of compulsory or restrictive treatment.
Everyone	
• Information about mental health services is complex and confusing. • It's really hard to know where to go.	

It will be important for the Royal Commission to consider all of these views, in the context of people's experience, and without just deferring to the majority view. A much greater number of people have NOT accessed services, compared to those who have – but both sets of views are important, because the underlying experience and expertise is different.

Navigation: The mental health system is indisputably difficult to navigate. There is no central source of information, many online information sites are out of date, and continual reform and funding changes add to the confusion. Consumers tell us they want a single number to call, and a single website to visit.

We recommend that the Terms of Reference include additional considerations for this theme (see box below).

Theme	Priority
Accessibility and navigating the mental health system	High priority
Recommended improvement: • Explicitly examine the experience of people who have, and not, used services • Impact of diagnosis, gender, sexual orientation, culture and disability on access and navigation • How access varies for different service types (e.g., acute services, community services, peer support, respite and therapy)	

3.1.4 Integration between AOD and mental health services

> People with acute intoxication should NOT be admitted to mental health units—it's unsafe for them, other patients and staff.

Definition concern. This theme is important, but there are other types of services that should also be better integrated with mental health, such as housing, child protection, aged care, sexual violence and family violence services. Integration between clinical and MHCSS is often poor. We recommend expanding this theme to include other services that are related to mental health services.

AOD and mental health have overlapping, but different skills & knowledge. There is a long history of arguing for dual diagnosis (mental health + AOD) services, but this doesn't mean that the treatments for AOD and mental health are always the same, even when both issues have the same underlying cause. Specialist skills and approaches are used for each, and staff in each area are not always trained in the other area.

Acute intoxication and hospital. People with acute intoxication are often admitted to mental health units, rather than specialist AOD units. This is a serious problem that puts patients and staff at risk and should be examined by the Royal Commission. Typical psychiatric unit staff are ill-equipped to respond to people with intoxication needs, so AOD patients are not receiving the specialist care they have a right to. Acute intoxication is linked to increased violence[12], whereas acute mental health crisis is much less clearly associated with violence (see section 3.2.7). Putting these two groups of people together puts everyone at unacceptably greater risk.

We recommend that this theme is expanded (see box below)

Theme	Priority
Integration between Alcohol and Other Drugs and mental health services	High priority
Recommended improvement: Integration between mental health and other related services such as Alcohol and other drugs, housing, aged care, family violence, sexual violence and child protection.	

3.1.5 Community mental health services

> For many people, community services were the best part of the mental health system—
> **now they've been decimated.**

Definition concern. We assume this theme refers to Mental Health Community Support Services (MHCSS, previously known as the PDRSS sector), however it might also refer to clinical community services, and so it requires clarification in the Terms of Reference.

Major funding changes to community services have increased distress. Community (non-clinical) mental health services have been decimated by state government de-funding following the NDIS bilateral agreement. Consumers tell us daily about devastating impacts of losing these support services.

Community services and rehabilitation. Community services and the NDIS are two different things:

- Great community support services can help people recover at least as much as an acute service. Traditionally these services have focused on habilitation and rehabilitation services, along with a supportive relationship, with the aim of personal recovery.
- The NDIS does not provide these services—instead it provides more practical supports to alleviate functional impairment from permanent disability. NDIS guidelines explicitly exclude rehabilitation services as a mainstream system responsibility.

Most people understand rehabilitation in relation to a physical injury. But people get confused about rehabilitation for mental and emotional health problems, even though the broad principles are the same.

The right to rehabilitation. The UN Convention on the Rights of Persons with Disability (CRPD) includes the positive right to habilitation and rehabilitation, but it's almost impossible to have this right met now in Victoria, because few services are really funded to provide it. This is a sad irony given that the NDIS was supposed to improve compliance with the CRPD. It is imperative for the Royal Commission to investigate the needs, rights and gaps relating to community services, rehabilitation and support services.

We strongly recommend the inclusion of this theme, with some improvements (see box below).

Theme	Priority
Community mental health services	High priority
Recommended improvement: • Clarify definition to be non-clinical services. • Include rehabilitation (access and human rights)	

3.1.6 Acute mental health services

Acute mental health services cost the most money and get the worst outcomes– this must be at the heart of the Royal Commission.

There is strong evidence that acute services are very limited, and do not address the underlying issues of people's mental health problems. Acute services require urgent investigation and reform. Acute services:

- Consume the bulk of state government mental health funding
- Come under restrictive legislation which has serious rights implications
- Are where many serious human rights issues occur
- Are where the potential for reform is most significant
- Have poor accountability for many of the issues, (eg. rates of restraint are not publicly reported, memory damage from ECT is not required to be assessed or reported, and some clinical guidelines are often ignored)

Expensive system with little evidence and frequently poor outcomes. Acute mental health services do not have strong evidence for their treatment practices. While some people experience positive clinical outcomes, many do not. For example, only 38% of people diagnosed with psychosis report 'good' clinical recovery outcomes[13]

'System locks up and medicalises rather than looking holistically i.e. what happened to the consumer rather than what's wrong.' (Consumer)

'Current treatment for mental health is not adequate.' (Consumer)

Critical additional sub-themes. Acute mental health is a very complex system. Accordingly, we recommend some sub-themes that should sit within this theme for the Royal Commission. None of these were made explicit in the consultation survey, however each is a very high priority for VMIAC and its members. Each proposed new sub-theme is outlined further in section 3.2, and they include:

a) **Services systems and models of practice (section 3.2.3)**
   Medical approaches to social & psychological problems: The foundations of the acute system are problematic. Located within hospitals, they use primarily medical approaches to problems that are inherently social and psychological in nature.

   It's well accepted that mental health problems are related to a range of social determinants, such as parenting or trauma, however mental health treatment largely ignores this. The first, and often only, line of mental health treatment is medication. While medication is helpful for some people, for some experiences—it is never a cure, and it usually comes with serious side effects. Many other, improved models exist for service delivery systems and models of practice. Read more in section 3.2.3.

b) Harms and abuses (section 3.2.1)

Acute services can lead to poorer mental health because of the many harms and abuses that occur behind locked doors: sexual violence, seclusion, mechanical restraint, physical restraint, chemical restraint, coercion and unlawful human rights breaches.

c) Legislation and human rights (section 3.2.2)

Acute services come under the Mental Health Act, which intentionally places major limits on many human rights. Legislation is a major component of issues faced by consumers, and can even stand in the way of getting better outcomes for people and the community. Legislation should form part of the Royal Commission Terms of Reference.

d) Recovery (section 3.2.4)

Recovery IS the outcome that a good mental health system should be seeking. But despite years of plans and frameworks and training, it has never been effectively implemented. Recovery remains a high priority for consumers, but not for services.

e) Police (section 3.2.5)

Many consumers have interactions with the police, most commonly as part of welfare checks or being transported to hospital. There are many serious and complex issues related to police interactions.

f) Physical health and early death (section 3.2.6)

People using acute services are most at risk of developing serious illness, disability and large reduction in life expectancy.

We strongly recommend that the Royal Commission include this theme, as well as the additional related themes (see box below).

Theme	Priority
Acute mental health services (mental health assessment and treatment both in hospital and in the community)	Very high priority

Recommended improvement: Include the following sub-themes (more information in section 3.2)
    a. Harms and abuses in services
    b. Legislation and human rights
    c. Service systems and models of practice
    d. Recovery
    e. Police
    f. Physical health and early death
	Very high priority

3.1.7 Forensic mental health services

The terms of reference must include prisons, forensic services, and post-release/discharge services, including rehabilitation, support and housing programs.

Acute services issues matter here as well. Almost all the issues in acute services also apply to forensic services, however there are some additional issues that a Royal Commission

should examine, most particularly about protection of human rights and independent oversight.

Better options for people in prison. People in prisons with mental health issues have poor experiences, and there is scope for considerable innovation in providing compassionate and effective supports and services. There are examples of much better prison support programs overseas, like the Voices Unlocked program in the UK, which is voluntary, low cost and achieving great outcomes. We also note that many people will naturally experience worsened mental health in a prison environment because of issues like:

- Forced withdrawal for substance users, potentially with no AOD counselling
- Violence
- Complex emotional impacts from crimes, court experiences, conviction and future prospects
- Lost relationships, liberty and dreams

Human rights issues are complex. It is often assumed that forensic services are better than prison, or vice versa, but in fact there are serious issues in each. We note the questionable view that transferring a person from prison to forensic services upholds their right to health. This is often assumed to be the case because compulsory treatment is not possible in prison, but it is in forensic services. However, the right to health includes informed consent—so these transfers actually breach the right to health, rather than uphold it.

We recommend inclusion of this theme.

Theme	Priority
Forensic mental health services	High priority

3.1.8 Preventing suicide

> Suicide will not be prevented with more medication or more beds. We need to focus on ways to reduce emotional pain and increase hope–across communities, not just in mental health services.

Suicide is not necessarily tied to mental illness. We note that suicide is not necessarily because of mental health problems, but more accurately, because a person is experiencing both *unbearable pain* plus *hopelessness*. The big question for Victoria is to understand what we can do—as a society— to reduce pain (emotional, physical, spiritual, cultural, social) and increase hope. We cannot rely on doctors and nurses, or services, to do this—it is a whole of community problem.

Increasing access to current services is unlikely to prevent suicide. It is important that the Royal Commission does not simply connect suicide prevention with accessing mental health services—the reality is far more complex. For example, it cannot be claimed that existing services are necessarily successful in preventing suicide:

> '...adverse experiences in psychiatric units such as trauma, stigma and loss of social role might precipitate some in-patient suicides.' [14]

> '...people are about 100 times more likely to die by suicide after a psychiatric hospital admission' [15]

Consumers tell us that fear of compulsory detention and treatment in acute services becomes a barrier to help-seeking when feeling suicidal. Many people want to seek help, but can't find a safe place:

> 'Suicide = difficult emotions. Can we have places to share difficult emotions without fear?' (Consumer)

Further, there is poor evidence that psychiatric risk assessments can usefully guide clinical practice:

> 'The overwhelming majority of people who might be viewed as at high risk of suicide will not die by suicide, and about half of all suicides will occur among people who would be viewed as low risk.' [16]

We recommend that the Royal Commission investigate suicide prevention, but, as with all topics, listens to consumer's experiences about the issues, as well as reviewing the evidence. In this instance, it is essential to hear from people who have survived suicidal feelings, urges and attempts.

Theme	Priority
Suicide prevention	High priority
Recommended improvement: • Look at suicide as a whole of community concern, rather than a mental health system issue • Learn from people who have survived suicidality—and why	

3.1.9 Workforce development and retention

> Workforce development and retention is important, but **it's even** MORE important to think about what the right mental health workforce should actually look like.

Acute services workforce

Workforce composition: We think the most important issue for workforce has been missed. This theme must be expanded to consider what an ideal mental health workforce would look like—there is no point in trying to keep and train a workforce that is not the right one.

As at 2014/15, the acute workforce was 56% nurses, 11% doctors, 20% allied health—while the lived experience workforce was just 0.5%[27]. Based on the kinds of issues raised in this submission, we could easily see a very different workforce, one that includes a much higher percentage of therapists and counsellors, peer workers and other allied health.

Workforce development. Workforce development is a high priority; it's arguable that mental health nursing skills have declined over recent years since Australia changed the qualification pathway for mental health nursing. This used to require three years of specialist undergraduate study in mental health nursing. Today, people do three years of undergraduate general nursing, then one year of postgraduate training in mental health. Further, not all nurses in acute services have even completed mental health studies. On face value, we fail to see how so little training can provide adequate knowledge or skills to support people in the most complex and painful moments of their lives.

Does working in a coercive, harmful system impact staff compassion? Some consumers spoke to us in consultations with deep compassion for nurses. These consumers acknowledged a lack of skills and compassion in nurses, but they also expressed concern for why some nurses are like this, and what might help:

> 'Does the system squeeze compassion out of staff? Are staff members victims of the system? The system constrains the staff to the extent it damages humanity.' (Consumer)

> 'Needs to be more debriefing, especially for nurses' (Consumer)

We also note these workforce development issues:
- The increasing use of online qualifications for nurses and psychiatrists, and the potential impact on developing good interpersonal and therapeutic skills.
- The lack of counselling and therapy skills in most nurses and psychiatrists
- The lack of expert knowledge in many nurses and psychiatrists about trauma, social determinants, recovery, emotions, human rights, power, interpersonal connection, and consumer perspectives.

Workforce retention: This is less of an issue for consumers. We argue that retention issues represent an important opportunity to start diversifying the mental health workforce beyond psychiatrists and nurses, and to begin an influx of counsellors, therapists and peers.

Community services workforce

Workforce development: The community sector lacks funds for upskilling staff: MHCSS services have been essentially de-funded and the shift to NDIS has tightened margins which means less investment in staff development. Historically, staff in this sector have had stronger skills in recovery, trauma informed practice, peer support, and working in non-coercive ways.

Workforce retention: De-funding, the NDIS and a trend towards shorter funding contract has had a devastating effect on workforce retention. Redundancies are common, many others are leaving because of uncertain futures or being discouraged by the directions of the sector, or not being willing to work for what is increasingly lower pay and shorter term or casual positions.

Primary health workforce

We note that the lack of mental health knowledge and skills of General Practitioners is concerning to many of our members, however this is probably outside the scope of a Victorian Royal Commission.

We recommend that this theme is modified to include workforce composition, and with less emphasis on workforce retention (see box below)

Theme	Priority
Workforce development and retention (as is)	Not recommended
Proposed modified theme: Workforce composition and development	Very high priority
Other recommended improvement: • Consider acute and community services • If possible, also consider primary and secondary health workforce needs	

3.1.10 Deliverable reform to improve outcomes for people living with a mental illness

> This is a critical element for the Royal Commission, and there would be little point in proceeding without it.

Mental illness affects almost everybody. So, good outcomes for consumers means good outcomes for all of Victoria.

There may be different outcomes for different people. We highlight that the experience of people using the acute system, those labelled with 'severe' or 'serious' mental illness, have very different experiences to those at the mild to moderate end of the spectrum—this

means that the outcomes might be different. For example, legislative change is a very high priority for the first group and possibly irrelevant to the second group. Nevertheless, every person, regardless of their experience, deserves improved outcomes.

'We need to know the real outcomes (and impacts) on lives. Improving outcomes means 'BIG REFORM so "every person matters" (Consumer)

Potential for worse outcomes. We recognise there are other drivers for the Royal Commission which could lead to worse outcomes for consumers, such as balancing the community right to safety against consumers' rights to liberty and informed consent. However, we strongly believe that these rights are not incompatible at all. With improved services and legislation, this shouldn't have to be a trade-off in rights.

We recommend that the Royal Commission includes this theme. We recommend the following aspirational outcomes:

- People feeling and being personally safe (freedom from harms and abuse)
- Equal rights (including health equity and freedom from coercion)
- Freedom from discrimination, welcoming communities
- Diverse range of flexible, quality treatment and support services, accessible to all
- Specialist supports that address the underlying social determinants of mental health problems, with particular focus on trauma
- Personal recovery, as defined by each person, being the highest priority

Theme	Priority
Deliverable reform to improve outcomes for people living with a mental illness	Very high priority
Recommended improvement: Specify aspirational goals for outcomes such as those listed above.	

3.2 Recommendations: Additional themes

3.2.1 Harms and abuses

It's a tragic irony that so many people leave mental health services more distressed than when they arrived. Sexual violence, restraints & coercion have no place in a health service.

For many people, the most critical aspect of this Royal Commission will be the investigation of harms and abuses that occur within acute mental health services. Most of these harms and abuses also relate to human rights issues. For many people, this theme would provide a powerful, affirming opportunity to be witnessed and believed.

Like many other large and powerful institutions, there are countless hidden and devastating harms in the mental health system.

'Who investigates the abuses? The Mental Health Act missed an opportunity to put checks and balances in place. It failed.' (Consumer)

'Violence and the impact on consumers (and workers) come in many forms.' (Consumer)

Just some of the harms and abuses include:

- **Seclusion**: Seclusion can be a terrifying experience: locked in a small, cell-like room. A plastic mattress and a cardboard bedpan on the floor. With nothing to distract from mental and emotional distress.

  Seclusion may be a lawful rights limitation in Victoria, but it is internationally recognised as a severe and harmful breach of fundamental rights, including by the United Nations[1]. Seclusion and other restrictive practices will come under increasing scrutiny with Australia's ratification of the Optional Protocol for the UN Convention Against Torture (OPCAT).

  We are particularly concerned with the growing seclusion rate of adolescents (which grew by 371% since January 2017[17]), and the enormous variations in seclusion between hospitals[17]. Victoria secludes people for an average of 10 hours, the worst rate in Australia[18]. By comparison, New Zealand has set an aspirational goal to end all seclusion by 2020[19].

  Anecdotally, we have heard many consumers speak about extreme uses of seclusion such as it being used as a punishment for 'breaking rules' on the unit.

- **Restraint**: Victoria has more than double the number of restraints compared to other states[18] with 7,215 Victorians being restrained during 2016/7 [20]. Victoria doesn't even count or report chemical restraint (which, anecdotally, is common). The Victorian government annual report on mental health does not break down data between physical (being held down) and mechanical (being strapped down) restraint.

Restraint is a frightening and very extreme experience, especially in the midst of a mental health crisis.

> The experience of seclusion o**r restraint results in the subjugation of one's own self to the will and the power of another person. The forceful assertion of another person's will over one's own, along with the loss of control over one's body and environment, can** generate very negative emotions and have deep psychological and traumatic impacts on people.
>
> Many people experience feelings of loss of dignity, degradation, demoralization, dismissal, humiliation, anxiety, disempowerment, helplessness and rejection by the healthcare staff, which can aggravate the situation further.
>
> Seclusion and restraint can also re-traumatise people who have a past history of sexual or physical abuse, or past psychological trauma.[21]

- **Sexual violence**: Last year the Mental Health Complaints Commissioner released a report[22] that investigated 90 complaints about sexual violence in acute services. Tragically, this issue was highlighted 25 years ago in the Burdekin report[23] and little has changed. The mental health sector is clearly unable or unwilling to prevent this issue, and it is wholly unacceptable and profoundly harmful.

  We have numerous concerns about sexual violence in hospitals, but of particular concern for a Royal Commission are the following issues, which appear tragically similar to behaviour by other powerful institutions, investigated in other Royal Commissions:

  - Sexual assaults by staff (and the lack of transparent consequences)
  - Negligence by staff who prevent or discourage patients from being able to keep bedroom doors locked, despite knowing the risks of sexual violence in bedrooms
  - The practice of locking aggressive males and sexually vulnerable females together in High Dependency Units
  - The long-standing failure of services to implement changes that improve safety. There are many practical measures that could dramatically reduce sexual violence, but they never actually happen[24]. A Royal Commission needs to investigate why this change is not happening.
  - The lack of transparent data and service accountability relating to sexual safety and violence.

- **Coercion**: Coercion occurs across a spectrum and can include more than just compulsory treatment under the Act. It includes:
  - Lawful compulsory treatment (limiting rights through compulsory detention and/or treatment, compliant with the Act)
  - Unlawful compulsory treatment (breaching rights through acting inconsistently with the Mental Health Act or other laws)
  - Lawful but unethical actions like undue influence or punishments
  - Unlawful actions like assault

  We have heard hundreds of stories of people being coerced by mental health clinicians, and the lasting, negative impacts on mental health. More examples are provided in the next section on rights.

- **Treatment harms:** Too often, psychiatric treatments are assumed to be very effective and largely benign. In reality, psychiatric medications can have extremely serious side effects, including suppressing the ability to feel emotions, limiting cognitive abilities, and a range of serious physical health impacts outlined in section 3.2.6. Electroconvulsive Treatment cause some memory loss in most people, and for some this can be extensive and permanent. It is not uncommon for consumers to tell us that the side effects of psychiatric treatment are worse than their original mental health problems. This harm is more significant than harms from other medical treatments, because the majority of inpatients have these treatments forcibly administered.

- **Other harms and abuses:** Consumers tell us about many other issues, including assaults by security guards and clinical staff, strip searches, punishments / punitive measures, emotional abuse and/or threats by staff.

Impacts of institutional power. There would be value in the Royal Commission using a lens of power to consider many of these issues. Tragically, acute services can have more in common with prisons or detention centres than with places of respite and healing.

Several things contribute to the excessive power imbalances in acute services, including mental health legislation, the relative status of medical specialists versus vulnerable distressed people, the hidden nature of these services (including poor provision of public data), and probably much more.

Emergency Departments and restrictive practices. Emergency departments use seclusion and restraint as well, but outside of the Mental Health Act. Often their seclusion rooms are called 'Behavioural Assessment Rooms'. There is no public data or independent oversight.

Lack of accountability. Many of these issues have existed for decades, despite multitudes of state and national plans, consultations, frameworks and inquiries. We suggest that part of this lack of change is because of the lack of accountability on services.

'Psychiatrists just need to be accountable. This Royal Commission needs to decrease the power of the mental health psychiatrists and increase the power of the users/victims.' (Consumer)

We recommend that the Royal Commission investigates harms and abuses to mental health consumers, with a broad scope, as well as the evidence for safer, more rights-based and therapeutic alternatives[25,26]—of which there are many.

The traumatic impact of these harms and abuses are sometimes so severe that we also recommend the Royal Commission use approaches similar to those used in the Royal Commission into Institutional Responses to Child Sexual Abuse.

3.2.2 Legislation and human rights

We've stopped valuing human rights—and it costs dignity, humanity and lives.

Human rights are mentioned in lots of mental health policy documents, but the real world experience for many consumers is that rights are largely absent. It's not uncommon for consumers to contact VMIAC to ask if they even have any human rights.

Most rights issues are in the acute system. The most serious and frequent mental health-related human rights issues occur in the acute system, where the Mental Health Act allows for the lawful limiting of different rights, under specific conditions.

Mental Health Act: Protecting or limiting rights? The current Act is only five years-old, and includes an objective to:

> 'protect the rights of persons receiving assessment and treatment' (MHA, s10.c)

This is a challenging and arguably contradictory objective given that the bulk of the Act contains conditions and processes for limiting rights.

In fact, it's not uncommon for consumers to be told that the Mental Health Act is the place that lists their human rights—with no mention of all the fundamental rights in the Victorian Charter and the UN Convention on the Rights of Persons with Disability (CRPD) that are being limited or breached.

> As a consumer, it's useful to have the right to appeal compulsory treatment at a Tribunal, but it would be so much better to just have the right to informed consent upheld, like everyone else. (Consumer)

The Act includes elements that aimed to achieve greater protection of rights, including *presumption of capacity* and mechanisms to enable *supported decision making* (like advance statements and nominated persons). These elements have significant potential to protect human rights, but in practice they have never really been implemented, and they are poorly understood in the sector, let alone commonly practiced.

Rights limits and breaches are common. Many rights issues are permitted limitations under the Mental Health Act, but still constitute a serious problem, because they negatively impact emotional wellbeing:

- Compulsory detention and treatment (more than 50%)
- Compulsory treatment in the community (more than 11%)
- Restrictive practices (seclusion and restraint)

Other rights breaches contravene the Act:

- The right to communicate is protected by the Act, yet many services confiscate mobile phones as a matter of standard practice, in stark violation of the Act.
- Electroconvulsive Therapy can only be a compulsory treatment under very specific conditions relating to capacity. Last year's Supreme Court case for two Victorian consumers (PBU & NJE v Mental Health Tribunal) confirmed human rights breaches when acute services tried to administer ECT against consumers' wishes, and the

Mental Health Tribunal imposed higher standards for capacity than would occur for the general public

Other rights breaches occur as a consequence of overly coercive and paternalistic service delivery:

- All people have a right to be informed about medical treatment benefits and risks, yet very few consumers are provided full and frank information, despite many treatments carrying serious health risks.
- Denying leave to voluntary patients is not permitted by the Act. This unlawful detention, however, happens all the time, with little consequences for services.

VMIAC hears about these and many other rights limits and breaches on a daily basis.

Human rights not understood or valued by services. Clinical staff appear to have little understanding of human rights, which is in stark contrast to the powers they have over consumers' lives. There are no standards for training or accreditation of staff on human rights knowledge. Human rights breaches have become so common in this sector that they are often not even noticed.

'Human rights are surely fundamental to any care system. This current system is far from accountable. Users are more likely to come out of the system de-humanised.' (Consumer)

'Human rights need to be given higher priority than funding, expediency and convenience.' (Consumer)

Protections and oversights not working.

- Only a minority of consumers are able to access an advocate, and very few people can access legal counsel for Tribunal hearings.
- The uptake of advance statements and nominated persons is very low at less than 3%. [27]
- The use of 'urgent ECT' hearings (which make it almost impossible for people to access any procedural fairness) is more common than standard ECT orders [28]. After years of steady decline, seclusion and restraint now seem to be increasing [18]. These and other issues point to the need for a review of protections in the Act, along with associated oversights, measures and accountability.

Questionable evidence base for the Act. Some foundations of the Act, and the rights limits it permits, have questionable evidence, for example:

- *Community Treatment Orders (CTOs)* are permitted by the Act, and about 11% of consumers each year are under one of these orders [27]. However, research suggests that CTOs have little if any beneficial effect [29].

The criteria in the Act are also deserving of inquiry by the Royal Commission, for example:

- *One criterion requires a person to be at risk of harm* to themselves or others, in spite of research suggesting that clinicians have a very poor ability to reliably predict either of these risks [16,30]. The ineffectiveness of risk assessments was discussed at a forum hosted by Victoria's Chief Psychiatrist last year—yet people's rights continue to be limited on the basis of unreliable psychiatric predictions.

Rights issues in other systems. While acute services contain a high volume of human rights issues, they are not the only place where the Royal Commission should examine mental health and human rights:

- **The right to rehabilitation** (CRPD) is problematic now that community services are no longer funded to provide many, if any, rehabilitation support services
- **Forensic services and prisons** can involve more complex and long-term human rights issues which are deserving of their own investigation
- **Discrimination in broader society**, on the basis of mental illness and psychosocial disability, is far too common, particularly in the areas of insurance, physical healthcare, emergency services, employment and housing.

We recommend:

- That the scheduled Mental Health Act review is included as part of the Royal Commission. This should include investigating:
    – Whether the Act is meeting its stated objectives
    – How the Act impacts human rights and consumer outcomes
    – Whether services and statutory bodies are performing in compliance with the Act
    – Evidence supporting the Act
    – How the Act is performing in relation to other state and Commonwealth rights legislation, and to international human rights conventions including the CRPD and the Convention Against Torture (particularly given Australia's recent ratification of OP-CAT and upcoming obligations).
    – Effectiveness of the Act's protections and oversight mechanisms
    – Concerns by consumers, carers and clinicians
    – Opportunities for amendments to the Act
    – Opportunities to protect and promote human rights
- That the Royal Commission investigate human rights breaches in acute services more broadly (beyond just the Mental Health Act)
- That the Royal Commission investigate other human rights issues affecting people diagnosed with mental illness, including: Discrimination in the community, forensic services and access to rehabilitation services

3.2.3 Service systems and models of practice

Victoria's mental health system is outdated and flawed. There are many innovative approaches that could save lives and money.

The acute mental health system has not changed, except superficially, in the 30 years or so since deinstitutionalisation. Many aspects of the old institutions are still evident in current practices, and consumers have told us that they are still institutionalised, but in poverty and CTOs instead of in old buildings.

A Royal Commission is the ideal time to look seriously at genuinely innovative and transformative new approaches to the service system, and the practice models within those systems.

There is an abundance of improved, innovative and effective approaches to systems, services and practices in other countries, and here at home. Many already have good evidence, while others are still emerging but have enough evidence to warrant serious consideration and piloting. Some of these innovative approaches include:

1. The Open Dialogue approach (Western Lapland, UK)
2. Intentional Peer Support (US, Australia)
3. Peer zone (New Zealand)

4. Peer-run services:
   Including crisis services, respite services, drop-in services and phone lines. There is good evidence for peer-run services. A leading review into consumer-run services, commissioned by the Mental Health Commission of NSW [31] recommended:

   'Greater investment in consumer-operated services be considered, with consumers centrally involved in conceptualising, designing, operationalising and evaluating these services.'

   and reported:

   … that people who accessed consumer-operated services experienced improved levels of empowerment, social inclusion, well-being, housing, employment, hope and program satisfaction, than those who accessed only traditional services.

   These are great examples of peer run services, including:

   Residential services:
   - Piri Pono (New Zealand)
   - Afiya Peer run respite (USA)

   Non-residential service:
   - The Leeds Survivor-Led Crisis Service (UK)

5. Safe Haven support cafes (UK) and other types of community hubs for both crisis and non-crisis
6. The Power Threat Meaning Framework (British Psychological Society, UK)
7. Hearing Voices Approach (Intervoice, UK; Voices Vic, Victoria, Maastricht, NDR)
8. Alternatives to Suicide (Western Mass, US)
9. Many different specialist trauma interventions, including the Practice Guidelines for treatment of complex trauma (Blue Knot, Australia)
10. Alternatives to Coercion in Mental Health Settings, a substantial recent literature review by the Melbourne Social Equity Institute,[26] also provides a comprehensive overview of non-coercive alternatives to mental health settings.

We recommend that the Royal Commission investigates local and international innovative approaches to mental health systems, services and practices, rather than focus only on addressing gaps and issues within an existing, flawed mental health system.

3.2.4 Recovery

> Personal recovery has long been cited by government as a critical outcome from mental health services**—yet it doesn't really** happen in services.

The concept of *recovery* originated in a movement by mental health consumers during the 1980s and 90s. It's epitomised in Patricia Deegan's well-known talk '*Recovery and the Conspiracy of Hope*'.[32] Recovery is different to 'clinical recovery', which is all about the remission of symptoms. Instead, recovery in mental health means having a good life, and the CHIME acronym (Connectedness, Hope, Identity, Meaning, Empowerment)[33] is often used to explain the different elements of recovery.

> We need to feel loved and to be able to contribute to society. (Consumer)

> 'It is important that people with a mental illness need pathways and support to participate in community life such as employment, education and volunteering opportunities. The terms of reference should also include people with a mental illness to be encouraged to access leisure and cultural activities, supportive social relationships and make connections in their respective communities.' **(Consumer)**

Victoria committed to recovery-oriented mental health services in its 2011 Framework for Recovery-Oriented Practice, and again in its recent 10 Year Mental Health Plan—yet there is no evidence of recovery-oriented work being implemented in practice, certainly not in acute services. Recent government reports of sector performance use HONOS ratings (a measure of clinical recovery) as indicators of recovery, which is patently inappropriate.

> Because of biomedical bias, there exists a worrying lag between emerging evidence and how it is used to inform policy development and practice. For decades now, an evidence base informed by experiential and scientific research has been accumulating in support of psychosocial, recovery-oriented services and support and non-coercive alternatives to existing services. Without promotion of and investment in such services and the stakeholders behind them, they will remain peripheral and will not be able to generate the changes they promise to bring.[1]

We strongly recommend that the Royal Commission Terms of Reference include scope to investigate recovery-oriented practice, why it is has not been successfully implemented, and make recommendations for improvement. Aside from ensuring that people are alive and safe, recovery is surely the most important outcome of the mental health service system.

3.2.5 Police interactions

Police interactions can be scary, and quickly escalate to becoming unsafe.

Police are often involved in consumer transport to hospital, or in welfare checks—and many issues occur during these interactions. We argue there are much better approaches to these situations, particularly involving peer workers.

Lack of skills can escalate situations rather than help. While we have heard many encouraging stories of positive change in Victoria Police officers over recent years, consumers still tell us that police lack skills and knowledge that can cause situations to escalate:

> Police often escalate a person's situation and people suffering trauma end up assaulted by police. Do no harm. Police violence and victim blaming consumers for reacting re this process. (Consumer)

Attitudes about consumers. It is clear that at least some police officers tend to view consumers as potentially violent perpetrators and treat people accordingly—which results in escalating situations. They do not:

- Understand that most consumers are victims of violence, not perpetrators
- Know how to speak to people when they're in crisis (particularly if the person is hearing voices or expressing unusual beliefs)

Lose-lose situations. Police are often the 'middle-people', between consumers and hospitals. They do not necessarily understand reasons why some people will resist being taken back to hospital (ie, sexual violence, seclusion, compulsory treatment), and may employ unnecessary and harmful force that causes trauma.

Clara[1] told VMIAC about her experience of sexual violence by a nurse in a psychiatric unit:

> 'The next day, distressed, I absconded from the ward. I walked, without shoes, for three hours. I was picked up by the police…handcuffed…and driven back to the psych ward.' (Consumer story)

Inequities. There is a serious imbalance in societal and media views about violence between consumers and police, and inequities in government and legal responses:

- There was months of media attention last year on mandatory sentencing, about citizen violence towards emergency services staff
- But comparatively little attention on the Melbourne man who was beaten and humiliated by a group of police on his front lawn

We recommend that the Royal Commission investigates the role of police in patient transport and welfare checks, including adequate skill and knowledge, safety and risks for all parties, and better alternatives.

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[1] *Pseudonym*

3.2.6 Physical health and early death

It's a disgrace that mental health consumers die 20 years younger than other people.

As consumers, we live with the knowledge we will die sooner and have poorer health[34], and the health inequality gap is growing[35]. This is clearly unacceptable.

Mental health consumers die, on average, 10 – 20 years younger than other people[36]. There are many contributors to early death, however the following issues need to fall within the scope of the Royal Commission:

- **Serious side effects from mental health medications:** All psychiatric medications have potentially serious risks, however evidence suggests that antipsychotics have the highest risk[37]. Polypharmacy and high doses of medication may increase the risks[38,36] and our members tell us these practices are common. This requires investigation of actual prescribing rates compared to evidence and best practice, and informs thinking about the need for less risky (and often more helpful[1,39]) treatment alternatives like counselling, therapy and peer support.
- **Compulsory treatment:** Many other medications have serious side effects (eg, chemotherapy) but the difference in acute mental health is that treatment is mostly compulsory. There are serious ethical issues in the forced administration of treatments which can contribute to an increased risk of death.
- **Lack of informed consent:** Even when mental health treatment is voluntary, our members tell us constantly about the lack of *informed* consent, ie, consumers are often not being told about the real risks of the treatment they are agreeing to take. We know from conversations with clinicians that some psychiatrists never tell consumers about the risks of treatment, because they are fearful of 'non-compliance' (people not taking their medication). This kind of paternalistic and risky practice would be scandalous in any other health system.
- **Discrimination, particularly diagnostic overshadowing:** It is well documented[40] that health practitioners commonly ignore physical health concerns and screening when working with mental health consumers. At best this is poor practice, at worst it is discriminatory.

We recommend that the Royal Commission investigates the evidence of poor physical health and reduced mortality for people with mental illness, and develop policy recommendations to prevent increased disease, disability and early deaths.

3.2.7 State government responsibilities and therapy

> People desperately need more access to counselling and therapy. **It's pointless to** argue about which government should pay**—it's costing Victoria millions anyway** in greater demand on expensive hospital-based services.

There is a striking lack of counselling and therapy for people with mental health problems:

- Counselling and therapy are rarely provided by acute or community mental health services, and many acute service clinicians don't have the necessary skills
- Access to therapy through Medicare is far too limited to be useful for people with moderate or serious mental health problems
- The cost of accessing private counselling or therapy is prohibitive for most people, and particularly for people at the more serious end of the mental health spectrum (when unemployment and socioeconomic disadvantage are common)

Historically, state governments have avoided investing in counselling and therapy in mental health, claiming this funding responsibility rests with the Commonwealth Government. Regardless of who should be responsible, it is clear that emotionally distressed Victorians are often unable to access the support they need.

This is where they are really dropping the ball. (Consumer)

This costs Victoria in increasing demand on expensive acute services and emergency departments, and it has a much bigger cost in the socioeconomic consequences of ongoing mental and emotional distress.

We recommend that the Royal Commission investigate the relevant state and Commonwealth responsibilities in mental health service provision, and specifically make recommendations about the provision of counselling and therapy.

Issues with GPs. We note that consumers speak to us with concerns about the knowledge and skills of GPs in relation to mental health, particularly, but not only, in relation to the prescribing of psychiatric medications:

Informed consent should be needed at a GP: if I knew all the kinds of side effects, I would not have gone on them, they minimise the side effects. (Consumer)

This is a considerable issue, but we are unsure if it would be appropriate for primary health to fall within the provisions of a state-run Royal Commission.

3.2.8 Violence and mental health

> No mental health myth causes more harm than the nonsense that people living with mental illness are violent.[41]

Myths about social violence and mental illness. Beliefs about violent perpetrators with mental illness are fuelled by the media, and this feeds into stigmatising attitudes in the community, police, justice systems, child protection, employment, housing and more. These community-held myths then 'justify' the use of coercive and restrictive acute services.

> Persons with psychosocial disabilities continue to be falsely viewed as dangerous, despite clear evidence that they are commonly victims rather than perpetrators of violence. [1]

Mental illness is <u>not</u> a major contributor to societal violence. The research debates many factors related to violence and mental illness, however a few facts are quite clear:

a) The vast majority of people with mental illness are <u>victims</u> of violence, not perpetrators

> Individuals in this sample were at least 14 times more likely to be victims of a violent crime than to be arrested for one. In general, the risk associated with being in the community was higher than the risk these individuals posed to the community. [42]

b) People with mental illness are more likely than the average person to be a victim of violence

c) Despite the above points, the vast majority of people using acute services, or having contact with police, are treated like perpetrators—not victims

d) Some people with mental illness do commit violent crimes, however it's likely this is not at a much higher rate than other people

e) When people with mental illness commit violence, it's not necessarily because of mental illness (ie, violence is more strongly related to other factors)

> Although offenders with mental illness are overrepresented in the criminal justice system, psychiatric symptoms relate weakly to criminal behavior at the group level…. crimes rarely were directly motivated by symptoms…. Specifically, of the 429 crimes coded, 4% related directly to psychosis, 3% related directly to depression, and 10% related directly to bipolar disorder. [43]

f) Psychiatrists cannot reliably predict violence by people with mental illness (this was a key topic presented at a quality and safety forum in 2018, hosted by the Chief Psychiatrist of Victoria).[30]

Recent major incidents. We remind government that, despite the very great tragedy of recent violent events in Flinders Street and Bourke Street, that in the larger context it is important to not make generalisations that will result in unjust restrictions against a group of people who are largely victims themselves. These incidents should be examined by the Royal Commission, within the larger context of violence outlined above.

Violence in acute and emergency services must be viewed in the context of self-defence and provocation. In recent years many mental health and emergency services staff have raised concerns about violence by consumers. This issue concerns us as well, but our take on it is different to that of the workforce and unions.

We do not condone violence, by anyone. However, we do believe that consumers in inpatient settings are being unfair characterised as violent. The important context is that, very often, consumers are violent towards staff as a natural and predictable self-defence response to coercion and force.

Consumers in these situations are frequently subject to restrictions and force. It is entirely predictable that if an already distressed person is held down by a whole team of staff and forcibly injected, that sometimes they will hit out. It is predictable that people who've experienced abuse in a psychiatric service will be aggressive if police try to force them back to the place they were hurt.

'Police often escalate a person's situation and people suffering trauma end up assaulted by police.' (Consumer)

'…violence is done to consumers in the guise of treatment.' (Consumer)

These examples don't explain every situation, but they are important and not uncommon. The concept of consumer aggression being understood as a normal and predictable response to mental health services is explained in a Victorian Government resources from the Safewards program[44].

We argue that the over-use of coercion, force and restrictions in mental health services is the real cause of violence, and that these issues are deserving of investigation by the Royal Commission.

We recommend that the Royal Commission investigate the myths and facts about mental illness and violence, its consequences, and make recommendations accordingly. This should include consideration of violence in a broader society setting, and violence in acute mental health services. This theme should link to others, including acute services and discrimination.

3.2.9 Gaps in care for abuse and trauma survivors

We think many people would never need mental health services if they could access specialist trauma services instead.

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.[45]

As we outlined in section 3.1.2, an overwhelming majority of people using acute mental health services have a history of serious trauma. 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.

Mental health services are not trauma services. Trauma is not addressed by mental health services, which tend to provide almost exclusively medication and electroconvulsive therapy. Counselling and therapy are rarely provided, and mental health clinicians have little expertise about trauma.

Mental health services can cause trauma. Worse, many people have their trauma worsened by the coercive and restrictive practices that are common in mental health services. Trauma-informed practice is an important concept for mental health services, however it is impractical and contraindicated while these services continue to use coercive and restrictive practices so frequently.

Failure to acknowledge the reality of trauma and abuse in the lives of children, and the long-term impact this can have in the lives of adults, is one of the most significant clinical and moral deficits of current mental health approaches.[46]

Trauma services often aren't available. A better alternative to a mental health service that may try to be trauma informed, is to go straight to a service that specialises in trauma instead. However, specialist trauma services only exist for some experiences (eg, sexual assault, family violence services), and not for others (eg, child neglect, severe bullying, racist violence) and there are no services for people who've experienced multiple and complex traumas. Further, some trauma services reject people with diagnoses like schizophrenia.

'Trauma and mental health issues go together the majority of the time so it is about time system reform happened to acknowledge this and to take it into account in services and new design too.' (Consumer)

This means Victoria channels thousands of people through an expensive health system that is not addressing the real need. We waste time, money—and people don't recover.

We strongly recommend the Royal Commission investigates the care and support needs for survivors of abuse and trauma, how the mental health system can and should respond to trauma and identify any gaps in care—including the potential need for wholly different service systems.

3.2.10 Discrimination and community attitudes

Discrimination about mental illness is rife in our community and it can have devastating effects.

Discrimination, not just stigma. Stigma is about judgmental attitudes, and it matters. But discrimination is an act, not an attitude, and it's against the law. This is why any conversation about stigma must also include discrimination.

We've left people behind. Victoria has come a long way in tackling stigma and discrimination for depression and anxiety. We're not all the way there yet, but it's common to hear celebrities 'come out', and depression and anxiety are increasingly 'normalised'.

But for people diagnosed with schizophrenia, psychosis, borderline personality disorder or bipolar—it's a whole different story. If anything, these diagnoses are increasingly stigmatised in the media, and people experience discrimination across almost every aspect of their lives: employment, housing, relationships, child custody, service access, healthcare, insurance and much more.

'Exclusion and discrimination for people with mental illness exist throughout society.' (Consumer)

We recommend that the Royal Commission investigates the scope and impact of discrimination, with particular attention to the impact on different diagnoses, and across different parts of society.

4   PROCESS RECOMMENDATIONS

4.1   Privileging consumer expertise

Nothing about us, without us, is for us.

It's time to listen to the people themselves. Historically, society has accepted that people like psychiatrists, nurses and family members can, and should, speak on behalf of people who've been diagnosed with mental health conditions. Implicit in this norm is the belief that mental health consumers cannot speak for themselves.

Our capacity and expertise is increasingly acknowledged. However, since the 1970s there has been a growing human rights movement led by mental health consumers and survivors.

Like other marginalised and oppressed groups in society, such as Aboriginal and Torres Strait Islander peoples, women, LGBTIQ people, and people with disability, mental health consumers are increasingly saying that:

<p style="text-align:center; color:purple">We can speak for ourselves</p>

<p style="text-align:center">and</p>

<p style="text-align:center; color:purple">Psychiatrists, nurses, organisations, and even
family members, do not always know, or ask for,
what we really want and need</p>

Sometimes people speak on our behalf:
- Because they're well-meaning, but that doesn't mean they understand what we need
- Because they have vested interests
- Because they think we have no voice (but we do have a voice, we're just ignored a lot)
- Because they don't like what we say

Regardless of the reason, we know from history that letting other people speak on behalf of marginalised peoples has rarely, if ever, achieved positive social outcomes.

We recommend that the Royal Commission Terms of Reference include an aspirational and authorising statement about the inherent expertise of consumers/survivors to speak about their own issues and needs, and that the Royal Commission will seek to privilege the lived experience of consumers in all matters.

We recommend that the Royal Commission has a recruitment target for half of its staff to have lived experience as consumers. This is a positive step to embed a philosophy of valuing and respecting lived experience, and the people who the Royal Commission is ultimately aiming to serve.

4.2   Understanding consumer perspectives and diversity

We remind government there is a broad range of consumer experiences: we are not a ubiquitous group.

It will be important for the Royal Commission to ensure that the opportunity to participate in evidence gathering processes, like hearings, is available to consumers from a diverse and representative background. This should include, at minimum:

- Range of demographic experiences (age, geography, economic status, housing)
- People from CALD backgrounds
- Aboriginal and Torres Strait Islander peoples
- LGBTIQ and gender diversity
- AOD and substance use
- Justice system experiences
- People with dual disability

The Royal Commission will also need to seek a diversity of mental health and system use experiences, including:

Type of services used
- GP/primary health
- Counselling or therapy service
- Community services
- Peer services
- Private psychiatrist or hospital
- Community services (non-clinical)
- Acute services (public)
- Forensic services

Treatment and care experiences
- Voluntary or compulsory treatment
- Restrictive interventions

- Experiences of safety or harm
- Being treated with respect—or not
- Effectiveness of treatment and support
- Side effects and physical health

Mental health and related experiences
- Type of mental health experiences
- Experiences of suicidality
- Impact of mental health experiences
- Impact on socioeconomic disadvantage
- Discrimination
- Experiences of recovery

So, for example, someone with mild depression, but still employed, and who sees their GP for support and scripts, cannot speak for the person who has had two decades of regular hospital admissions for schizophrenia and is homeless. Both experiences matter but differ.

Consumers and carers are not interchangeable. We remind government that consumers and carers are not interchangeable as lived experience experts. We each have very different experiences, and while we are in agreement about many issues, there are other issues about which our perspectives differ, and are sometimes completely opposite.

4.3   Independent, expert commissioners

Considerable concern was expressed in the consumer community, and by VMIAC, about the appointment of a psychiatrist to chair the Royal Commission expert advisory group.

People expressed concern about experiences of coercive, restrictive and harmful actions by psychiatrists, and the apparent conflict of interest of a psychiatrist advising the Royal Commission. VMIAC expressed concern because, as far we know, other Royal Commissions have not appointed people from within the systems being investigated. Our view is that priority must be weighted towards the people who've experienced harm, rather than those with the power to harm.

Moving forward, it is critical that the Royal Commission maintains independence in other ways, and that it establishes processes to balance psychiatric perspectives.

Consumer commissioners. We strongly encourage the appointment of consumer commissioners, alongside others from law. There are many consumers who have exceptional skills and experience that could positively contribute to the Royal Commission.

It is no longer a new concept for consumers to take on senior leadership roles:

- The NSW Mental Health Commission has employed at least four consumers as deputy commissioners since being established.
- Victoria, and the rest of Australia, now has many consumers in senior academic, executive, governance, policy and senior leadership roles.
- Mary O'Hagan, mental health consumer leader, was one of thee mental health commissioners for New Zealand from 2000-2007, has been a consultant to the Mental Health Commission in Canada, and worked with the United Nations in the development of the CRPD.
- Louise Bradley, the president and CEO of the Canada Mental Health Commission has lived experience as a consumer

We recommend that:

- No commissioner should be appointed who has experience as a psychiatrist or doctor.
- Appointed commissioners should have expert knowledge in human rights, the law and complex systems.
- Ideally, at least one commissioner should have lived experience as a consumer.
- We recommend against appointing a commissioner with lived experience as a carer in the absence of consumer commissioners.

4.4   Expert advisory group

For an effective and fair Royal Commission, it is essential that 'expert advice' includes a broad diversity, and good number, of consumers. It is no longer acceptable to appoint a single consumer into advisory groups—this practice is tokenistic and ineffective.

We recommend that:

- A consumer co-chair be appointed to the Expert Advisory Group. This is important to counter-balance the relative power of clinical members, and provides an important message to members and the community
- At least two, and preferably half, of the Expert Advisory Group members have lived experience as consumers
- A Consumer Reference Group be established to provide advice and information to the advisory group consumer members, and that these people encompass a diverse range of consumer perspectives and experiences

We recommend against:

- A combined Consumer and Carer Reference Group, given the many areas where we typically have very different perspectives. A separate group may be formed for carers and family members if required.

4.5   Accessibility, safety and support

It is essential that participating in Royal Commission processes is accessible and safe for consumers.

We recommend the following processes:

Accessibility

- Provide choices for consumers who want to speak at hearings and other participatory opportunities to:
    - Use the same process as others
    - Have private sessions with name kept anonymous in public documents
    - Have choice of who to be heard / interviewed by
    - Access group or individual sessions
- The Royal Commission should hold both metropolitan and regional hearings, and provide accessible options for people in remote areas, such as video hearings
- There should be opportunities for submissions by consumers, on a range of topics, in a range of possible formats.
- All hearings and participatory processes should be fully accessible for people with disability
- For people from CALD backgrounds, Royal Commission information should be made available in different languages, and interpreters should be available

Safety

- The Royal Commission should ensure that the privacy of individuals is maintained whenever there are concerns about safety, and that individual consumers have choices about privacy
- There will be privacy and safety issues for some consumers to speak at hearings if clinicians are also present, especially if they come from the same service. This is a particular risk for people from regional areas and smaller communities
- Accessibility and safety will have particular requirements for consumers who want to speak at hearings, but are currently residing in forensic services, prisons, Secure Extended Care Units, or acute inpatient services. Ideally options will be provided to ensure safety and privacy for these people

Support

- The Royal Commission must ensure the provision of support during and after hearings: with options to access clinical, non-clinical and peer services depending on preference
- More generalised support should be made available for consumers impacted by Royal Commission media and publicity, regardless of whether people are directly involved. For many people, the Royal Commission will have a similar impact to the Marriage Equality vote, and the exposure will be difficult to avoid. VMIAC would be keen to provide this support to consumer if funding was available.

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