

A RAPID CONSULTATION WITH CONSUMERS TO INFORM DRAFTING OF THE NEW VICTORIAN MENTAL HEALTH AND WELLBEING ACT





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This consultation was commissioned by VMIAC, the Victorian peak body for consumers of mental health services. The consultations were conducted and reported between 20 April 2021 and 8 May 2021, by independent consumer/survivor consultants, Indigo Daya and Vrinda Edan.

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VMIAC, Indigo and Vrinda extend grateful thanks to all the consumers who participated in this fast-paced consultation process, bringing critical, heartfelt, embodied expertise to what we need for a mental health act which upholds our rights and choices.

We also gratefully acknowledge the support of our expert advisory group, including Wanda Bennetts and Helen Makregiorgos (Independent Mental Health Advocacy), Sonia Law and Hamish McLachlan (Legal Aid) and Dr Chris Maylea.



VMIAC is located on the lands of the Wurundjeri People of the Kulin Nation. We acknowledge the traditional custodians of the land on which we work, and pay our respects to elders, past, present and emerging.

> #AlwaysWasAlwaysWillBe #BlackLivesMatter

Contents

Conte	ents	3
Fore	vord	4
Exect	utive summary	5
List of recommendations		7
Acknowledgement of language preferences		13
Aim and methods		16
Resu	lts	21
1.	Review processes	21
2.	Seclusion and bodily restraint	24
3.	Chemical restraint	28
4.	Compulsory treatment	34
5.	Independent mental health advocates	48
6.	Supported decision making	52
7.	Information sharing	62
8.	Mental Health and Wellbeing Commission (and new boards)	70
9.	Forensic Services	76
10	. Other comments	77
Appendix 1: Act on the Act Consultation: Survey questions		78
Арре	ndix 2: Act on the Act Consultation: Focus group questions	

Foreword

Consumers with lived experience offer a unique lens to the issues that face them on a daily basis within the mental health system. This report highlights a commitment by consumers to actively participate in the development of the new Mental Health and Wellbeing Act.

The Royal Commission into Victoria's Mental Health System is an unprecedented opportunity to look at what is needed to ensure Victorian consumers get a system that honours their rights and diversity, and respects, listens, hears and values their input.

VMIAC has commissioned this report to provide an overlay of consumers' thoughts, comments and views to add value and direction to the current discussions around the development of the new Mental Health and Wellbeing Act, Mental Health and Wellbeing Commission, and regional boards. The report recognises that consumers are extremely diverse—that many such as Aboriginal and Torres Strait Islander, culturally and linguistically diverse, and GLBTIQ+ communities are silenced by legislation that is disempowering, and that further work is required by government to ensure an inclusive approach.

The report provides guided direction to what consumers say is needed to happen to change the system and legislation we currently have. It is not about reproducing the previous Act within a different framework but having an Act that stands up for the rights of the people it serves. An Act that has authority and accountability measures if it is breached. The report supports the development and engagement of lived experience auditors as a way of monitoring a service's work and actions. VMIAC is thrilled to have been able to produce this report in a timely manner and is confident that the information gathered from consumers will benefit and influence the development of the Mental Health and Wellbeing Act, the direction of the Mental Health and Wellbeing Commission and the regional boards.

VMIAC's commitment to raising the voice of Victorian consumers is our primary goal in all communications. We thank the many consumers who participated, including those who have been harmed by the system, and appreciate their ability to revisit circumstances that offered them little choice when framing their comments for this report.

I am pleased to say that this report has been led and driven by consumers who have a commitment to making a difference in the lives of all Victorians.

alch

Maggie Toko Chief Executive Officer VMIAC

Kathy Wilson Chair VMIAC

Executive summary

This consultation and report were commissioned by VMIAC in response to the Royal Commission into Victoria's Mental Health Services (RCVMHS) Final Report¹ recommendation to repeal the *Mental Health Act 2014* and enact a new *Mental Health and Wellbeing Act* by the end of 2021, and no later than mid-2022.

The aim of the consultation was to uphold the consumer movement principle that *"nothing about us, without us, is for us"*, to hear and elevate what matters to consumers in new legislation, and to ensure that government hears this.

A rapid, consumer-led community consultation attracted 180 responses to a survey and 39 participants in six focus groups, in less than 10 days. Consultation questions were informed by VMIAC's past advocacy efforts, consumer perspective and the RCVMHS Final Report.

During the development of the consultation process, advice and support was sought from VMIAC, sector experts and allies, and the consumer community.

This report should be seen as a significant signal for the Department of Health and the Victorian Government. In a tight timeframe, the number of people who responded, and the depth and breadth of their expertise and contributions, illustrates how important this new legislation is to consumers. The Victorian Government has a unique opportunity at this time to enact legislation that substantially improves the lives and freedoms of Victorian citizens, by upholding equal human rights, and bringing an end to coercive harms in Victoria's mental health system.

The results in this report are set out in sections addressing the key areas of recommended legislative reforms that consumers have told us are most in need of change. Each section provides an analysis of the survey and focus group responses to questions. These include:

- The elimination of seclusion and restraint: Consumer views on the best legislative options to reduce, then eliminate these harmful practices.
- Defining, then reducing, chemical restraint: Detailed consideration of different approaches to defining chemical restraint, and reasons for prioritising the *impact on consumers* rather than only considering the *intent of clinicians*.
- Reducing compulsory treatment rates and negative impacts: Consumer views about key elements to define tightly in the new Act ('serious' and 'last resort') and related expectations of the sector; and other legislative strategies to reduce compulsion.
- Opt-out independent advocates: What consumers think is needed in legislation to make this new reform effective in protecting rights.

- Supported decision-making: How to strengthen advance statements, nominated persons and second opinions so that supported decision-making can contribute to reducing compulsion and upholding rights.
- Simplifying information sharing: Detailed consideration of ways to simplify information sharing provisions in the Act which protect the privacy, selfdetermination and safety.
- Powers and transparency of the new Mental Health and Wellbeing Commission: What is needed to ensure the new Commission can bring greater transparency and accountability.
- Forensic services: What forensic consumers have told us matters most to them.

¹ State of Victoria, Royal Commission into Victoria's Mental Health System, February 2021. https://finalreport.rcvmhs.vic.gov.au

Again and again throughout this consultation, a vast majority of consumers told us how much they want binding advance care directives, so that their values, will and preferences can be upheld on an equal basis with other Victorians using the healthcare system. In multiple places, this report shares a clear message that consumers don't want to wait five-seven years for equal rights in some future legislative review; we want them now. We urge the Victorian Government to include binding advance care directives in this current legislative reform. And if there is no will to bring us equality under the law, we urge that the next review of legislation is slated for no more than three years' time.

Recommendations for the new Act are included within each section and are included as a complete list overleaf.

VMIAC urges the Victorian Government to demonstrate courageous leadership and enact legislation that is compliant with international mental health law, and that values the lives, rights and basic dignity of those of us who live with emotional distress, trauma, neurodiversity and mental health challenges.

List of recommendations

Recommendations are included in relevant sections and are repeated here in a complete list.

A. Recommendations for seclusion and bodily restraint

The new Mental Health and Wellbeing Act should:

- 1) include an objective to reduce seclusion and restraint and eliminate it within 10 years, setting an aspiration for faster elimination
- 2) include a principle that seclusion and restraint are inherently harmful practices and that all services will be committed to their elimination
- 3) include minimum targets to reduce seclusion and restraint set by the RCVMHS, linked to key performance indicators

B. Recommendation for chemical restraint

The new Mental Health and Wellbeing Act should:

- 1) include a new section to define, regulate and reduce chemical restraint
- 2) include a definition for chemical restraint, according to which, whether or not an intervention is characterised as chemical restraint is determined by the impact of the intervention on the person receiving it (either impact on their decision-making capacity and/or restraining the functioning of body, mind and/or emotion), rather than purely on the intention of the person using the intervention. Other definitional elements may also be included

C. Recommendations for compulsory treatment

That the new Mental Health and Wellbeing Act prioritises the RCVMHS recommendation to reduce compulsory treatment as follows:

- 1) Add an objective to the Act to reduce compulsory treatment rates and duration
- 2) Change the Act so that the option of voluntary treatment is strengthened and supported to happen as follows:
 - a) Add a principle to the Act which specifies that voluntary treatment is always preferred, even where someone meets the criteria for compulsory treatment.
 - b) Change the Act so that the Mental Health Tribunal:
 - i) has discretion to *not* make an order, even if the treatment criteria are met (for example, if the consumer wants to try a treatment approach that is different to the psychiatrist's recommendation)
 - ii) has discretion to approve a specific, limited treatment plan rather than an open order which allows any treatment
- 3) Tighten the criteria for compulsory treatment by adding a definition for the term "serious" in the context of harm and/or deterioration, and include the examples of:

- a) imminent death
- b) physical injury to others and/or
- c) injury to self which maims or is life-threatening
- 4) Further tighten the criteria for compulsory treatment by providing that none of the following factors can be taken as evidence of "serious harm" or "serious deterioration":
 - a) non-conforming behaviours or beliefs
 - b) financial risks
 - c) damage to reputation
- 5) Add a definition for the new recommended term of "last resort" as follows:
 - a) Specify that in determining whether compulsory treatment is a "last resort" the authorised mental health professional must evidence that a variety of different treatments and supports beyond just medication (e.g., talking therapies, peer support, specialist trauma services and/or respite services) have been offered
 - b) The above treatment and support options should be included in the Act as necessary preconditions to compulsory treatment, and as principles in the Act to support the highest attainable standard of health
- 6) Add an additional section to the definition for the new recommended term of "last resort" in relation to compulsory treatment, specifying that social issues impacting on mental health (e.g., housing, situations of violence or abuse, cultural or spiritual needs, severe financial or health stresses) have been attended to
- 7) Add a requirement that when considering whether compulsory treatment is necessary, the purported benefits of treatment must be weighed against potential harms caused by compulsory treatment (e.g., loss of rights, dignity and agency, unwanted adverse effects, retraumatisation)
- 8) Remove community treatment orders (CTOs) from the Act. If this is not yet acceptable to government, then a range of new additions are required in the new Act to address the RCVMHS recommendation to reduce compulsory treatment, such as:
 - a) Significantly shorten the permitted duration
 - b) Indicating in the Act that the number of CTOs will be reduced over time, and support this by modifying the CTO key performance indicator to include targets which reduce over time
 - c) Tightening the criteria for CTOs in line with other recommendations for reducing compulsory treatment
 - d) Expressly exclude rationales for CTOs which are based solely on consumer 'noncompliance'
- 9) Until or unless equal rights are provided to allow consumers to appoint medical treatment decision-makers (i.e., consistent with other Victorian legislation), broaden the scope of who and how many people are involved in making assessment and treatment order decisions:
 - a) Change who can make compulsory treatment orders using one or more of the options below:
 - i) Change from 'authorised psychiatrists' to 'authorised mental health professionals', and/or

- ii) Expand this further to include professional roles outside of designated mental health services (note: some respondents spoke about wanting their private psychiatrist and/or other mental health professionals involved in these decisions), and/or
- iii) Expand to include independent decision-makers.
- b) Require the involvement of more than one type of mental health professional in deciding on whether to use an order.
- 10) Include a provision that compulsory treatment must change or stop if it negatively impacts physical health or personal recovery. Require that treating clinicians and the Mental Health Tribunal review these impacts as reported by consumers, and change or cease compulsory treatment when negative impacts occur.
- 11) Include a new safety condition for compulsory treatment which prohibits the use of high risk treatments (e.g., very high medication doses or electroconvulsive therapy) and/or off-label medication use, within compulsory treatment, unless the person gives free and informed consent without duress.

D. Recommendations for independent mental health advocates

That the new Mental Health and Wellbeing Act expressly protects the right of access for independent advocates and ensures that notifications and responses are provided by services within prescribed timeframes and give further consideration to the right to communicate.

- 1) Specifically, where the consumer consents, an independent advocate:
 - a) cannot be prevented by a service from meeting with a consumer
 - b) cannot be prevented from attending a service meeting with a consumer
 - c) can access consumer records
- 2) In addition, the Act must expressly protect these rights of access for independent advocates (consent is not relevant here):
 - a) A right of access to all authorised mental health services
 - b) Access to the mental health system database to see who is on an order under the Act and (only) their contact details.
- 3) The independent advocacy service must be notified:
 - a) within 24 hours when a person is subjected to compulsory treatment
 - b) when a registered advocacy client is subjected to seclusion or restraint, including chemical restraint.
- 4) Services must respond to requests by advocates within three days.
- 5) The new Act should strengthen the current *Mental Health Act* 2014 right to communicate.

E. Recommendations for supported decision making

That the new Mental Health and Wellbeing Act strengthens supported decision making as follows:

- 1) Add an objective that supported decision making should be part of standard clinical practice in mental health settings.
- 2) Add a definition for supported decision making based on international disability standards.
- 3) Amend the informed consent provisions to provide that treatment cannot be given unless supported decision making processes are followed.
- 4) Store advance statements or directives on a new centralised database managed by the new Mental Health and Wellbeing Commission.
- 5) Include binding advance care directives in the new Act, consistent with the Medical Treatment Planning and Decisions Act 2016, adapted for a mental health context (see preferences by consumers in section 6.3.1 of this report).
- 6) If there is not yet government will to introduce binding advance care directives, we strongly recommend a review date of not more than three years to reconsider.
- 7) Until such a time as the new Act is reviewed to include advance care directives in alignment with the MTPD Act, the new Act should strengthen advance statements as follows:
 - a) Change the requirement regarding reading advance statement from 'give regard to' to 'give all due consideration to advance statements
 - b) Require all staff to give all due consideration to all advance statements regardless of whether the consumer is on a compulsory treatment order or not
 - c) Require mental health services to carefully document and evidence how they have given all due consideration to a consumer advance statement
 - d) Give in writing to all consumers reasons for not complying with their advance statement
 - e) Report on measures to address above
- 8) Change the Act to specify that the role of nominated person is separate from that of carer.
- 9) Strengthen the description of nominated person to ensure there is a requirement that:
 - a) the nominated person understands the role to be one of supporting the consumer's rights, views and preference, and not their own
 - b) all nominated persons sign a statement on accepting this role that they:
 - i) have an obligation to uphold the consumer's rights, views and preferences
 - ii) agree to promote the consumer's personal social wellbeing and to have regard to the need to respect their individuality
 - iii) agree to read and understand any advance statement the consumer makes
 - iv) agree to provide consumers with support to make their own decisions
- 10) If either recommendation 9(a)(i) or 9(a)(ii) in the section on compulsory treatment are adopted, then provision of a second mental health opinion should be conducted by a person in line with that recommendation.
- 11) If the recommendation options in 9(a) of the compulsory treatment section are not adopted, then strengthen the provision of second psychiatric opinions as follows:
 - a) Ensure the service is completely independent of clinical mental health services

- b) Provide for consumers to attend a private psychiatrist at no cost
- c) Copies of the second psychiatric opinion are to be given to the consumer within a timely period
- d) Specify that the treating mental health service should not get a copy of the second opinion unless the consumer gives consent for this to happen

F. Recommendations for information sharing

That the new Mental Health and Wellbeing Act includes changes to information sharing to protect both privacy and safety of consumers, as follows:

- 1) The Act should provide for:
 - a) real time access to medical files by consumers
 - b) right to make changes and corrections to medical files by consumers
 - c) right of consumers to add information to their medical file
- 2) The Act specifically states that consumer consent is required for the sharing of any information outside of the following circumstances:
 - a) The consumer is unable to consent due to physical incapacity (i.e., coma)
 - b) When children are at risk from a mental health consumer, and mandatory reporting is necessary, only the information that is necessary and legally required should be shared, and what is shared:
 - i) must be reported to the consumer
 - ii) entered into the medical record (who, when and why)
- 3) The Act specifically states that the sharing of medical information on the grounds of imminent harm to others is not permitted. In these circumstances only the information necessary to keep the other person safe is required and:
 - a) must be reported to the consumer
 - b) entered into medical record (who, when and why)
- 4) The Act provides for consumers to nominate excluded persons, and mental health services are precluded from receiving or giving information about a consumer to an excluded person.

G. Recommendations for Mental Health and Wellbeing Commission (and new boards)

That the new Mental Health and Wellbeing Act includes the following with regard to the new Mental Health and Wellbeing Commission:

- 1) The Act provides for the Mental Health and Wellbeing Commission to have the following powers:
 - a) Formally review services and make recommendations
 - b) Undertake sanctions in the event a service or practitioner does not comply with the Act or recommendations from the Commission, that include but are not limited to:

- i) Refer to police for possible criminal investigation
- ii) Deregistration of services
- iii) Recommend deregistration of professional person
- iv) Application of fines
- v) Other sanctions as appropriate (e.g., reduced funding)
- 2) The Act requires a minimum of annual, and where feasible quarterly, public reporting by the Commission that specifies the performance of services and includes but is not limited to:
 - a) Non-compliance with Victorian Charter of Human Rights and Responsibilities (2006)
 - b) Analysis of reductions in seclusion and restraint
 - c) Analysis of reductions in compulsory treatment
 - d) Analysis of grounds for compulsory treatment including:
 - i) evidence of serious harm and last resort
 - ii) records of capacity assessments and informed consent processes
 - e) Any investigations, including recommendations and outcomes
 - f) Sector-wide and individual service compliance with the principles and objectives of the Act.
- 3) The Act provides for the necessary powers for the Commission to intervene when the Commission becomes aware of an imminent breach of the Act.
- 4) The Act requires that at least 50% of the Commissioners are consumers.

Acknowledgement of language preferences

We acknowledge that as people who have experienced the mental health system, we have a wide range of preferred language choices about how we, and our experiences, are described and understood. These preferences are grounded in life experiences which can be painful and deeply significant to us.

In this report we have used the term 'consumer' because the primary audience is the Department of Health, and it is important that we communicate clearly and as concisely as possible. However, we acknowledge that this language choice will not feel respectful to everyone.

While originally the term 'consumer' was chosen by our own lived experience community as being preferable to 'patient', it no longer has widespread support. Many of us prefer terms such as 'survivor', 'lived experience expert', 'person with lived experience' and for people at Forensicare services, 'patient' or 'client'. We don't have a consensus on respectful language choices that describe us in relation to our experiences in the mental health system, but we wish to acknowledge how difficult it can be to read language about ourselves which we would not choose. This page left intentionally blank.

Aims & Methods

Nothing about us, without us, is for us.

Aim and methods

Consultation

The Royal Commission into Victoria's Mental Health Services (RCVMHS) recommended that the Victorian Government "repeal the Mental Health Act 2014 (Vic) and enact a new Mental Health and Wellbeing Act, preferably by the end of 2021 and no later than mid-2022". This is a quick timeline for reviewing legislation, and that raised concerns for us at VMIAC.

VMIAC believes it is imperative that consumer voices are heard loud and clear in any review of mental health laws, but with such tight timelines it was possible that our voices might not be heard.

Given the impact of mental health laws on our fundamental human rights, and the principle of *"nothing about us without us is for us",* VMIAC commissioned this rapid consultation and report. We will submit this report to the Victorian Government to inform drafting of the new Mental Health and Wellbeing Act, and use it in our ongoing advocacy for the rights of all consumers.

We engaged expert consumer/survivor consultants, Indigo Daya and Vrinda Edan, to lead this consultation and develop this report.

We asked for the consultation process and report to be completed within a 2.5 week timeframe, to give us the most possible time to influence change.

Aims

The aims of this consultation were to:

- 1) Reach as many diverse consumers as possible within the deadline
- 2) Find out what matters most to consumers about potential legislative changes recommended by the RCVMHS (taking account of what we already know from past advocacy with and for consumers)
- 3) Write and publish a report that can be used in advocacy by VMIAC and all consumers to ensure the new Mental Health and Wellbeing Act respects and upholds our rights.

Methods

The consultation process included an online survey and six focus groups.

The survey was open from 7pm, 20 April 2021 until 1.30pm, 30 April (10 days). It included 35 questions, both closed and open-ended. The survey questions were developed based on a combination of Royal Commission recommendations, historical advocacy information from VMIAC, and consumer perspective philosophy and knowledge. Support in drafting questions was received from Victoria Legal Aid, the Independent Mental Health Advocacy Service, and Dr Chris Maylea.

The survey was established on the online Survey Monkey platform, and convenience sampling was used with snowballing. The survey was promoted on social media and the VMIAC website, in VMIAC newsletters, via a direct email to members of the VMIAC consumer register, on the online consumer workforce Basecamp platform, and through consumer leadership networks. Consumers were asked to share the survey and focus group invitation with their networks, consumer consultants were encouraged to speak with consumers in their advisory groups, consumer workers were encouraged to share with their colleagues and networks.

Six focus groups were run, including:

- One for the consumer workforce
- One for consumer leaders
- One for Forensicare patients
- One for members of the Speaking From Experience consumer advisory committee at IMHA/VLA
- Two open for any consumers

Focus groups were promoted using the same methods as the survey and by invitation. Focus groups were run during daytime and evenings to allow maximum flexibility and were facilitated over Zoom video conferencing. The Mentimeter online platform was used for voting and comment collection during the focus groups. Comments were also collected from the 'chat' function within Zoom. Participants were reimbursed with a \$50 voucher.

In the report, when discussing qualitative responses, we have used the following unique identifiers:

- (R#): Survey respondent: where the # denotes a unique respondent.
- (P#/#) Where the first # denotes focus group and the second # denotes a unique participant.
- (C#) Zoom chat comments where the # denotes the focus group.

Participants

The Act on The Act consultation process included a total of 219 responses which consisted of:

180 survey respondents
 Although 251 people consented to begin the survey, 71 records were deleted during a process of data cleaning. Deletion reasons are listed below:

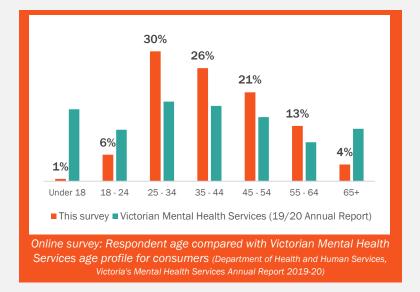
- x69: No question data beyond initial consent question
- x1: Duplicate with another record
- x1: Not eligible (identified as a case manager not a consumer/survivor)
- 39 focus group participants, including:

Focus group #	Target group	Date	Participants
1	Consumer workforce	27 April, 1.00pm	9
2	Any consumers or survivors	27 April, 6.00pm	8
3	Consumer Advisory Group at IMHA	28 April, 1.00pm	6
4	Consumer/survivor leaders by invitation	28 April, 6.00pm	10
5	Any consumers or survivors	29 April, 1.00pm	4
6	Forensicare	29 April, 3.30pm	2
Total focus group participants			39

Respondent demographics

The consultation intention was to reach as many consumers as possible, with as much diversity as possible, within a short timeframe. It was recognised during the design phase that the fast consultation approach would not be inclusive for many people, and we acknowledge that we were unable to address some issues of accessibility and cultural safety within such an urgent timeframe.

Demographic data was not collected at the focus groups; however, all participants were encouraged to also complete the survey.



2.8% of survey respondents

identified as Aboriginal people

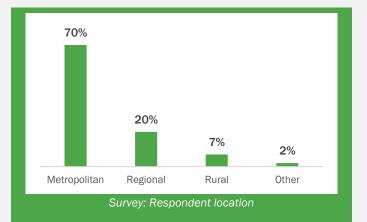
15%

of survey respondents identified as culturally or linguistically diverse

Gender identity	%
Agender/non-binary	1%
Binary	1%
Female	64%
Female-ish	1%
Gender fluid	1%
Male	24%
Non-binary	6%
Not identified	3%
Transgender	1%
Transmasculine	1%
	(n=180)

Notes

 Categories are self-identified
 Some people answered in more than one category



16.7%

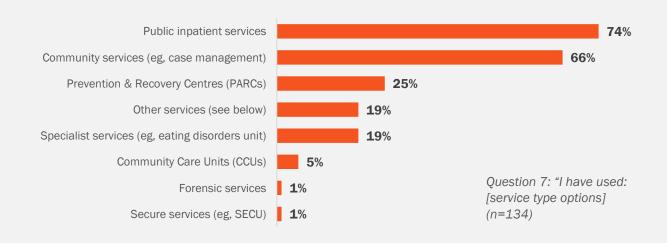
of survey respondents identified they had a disability other than psychosocial

31.1%

of survey respondents identified as LGBTIQ+

Experiences of mental health services

Respondents in the online survey had collectively experienced a wide range of Victorian public mental health services, with 74% having been in public inpatient units, and 69% having experienced case management.



Other Victorian services that were identified by respondents included:

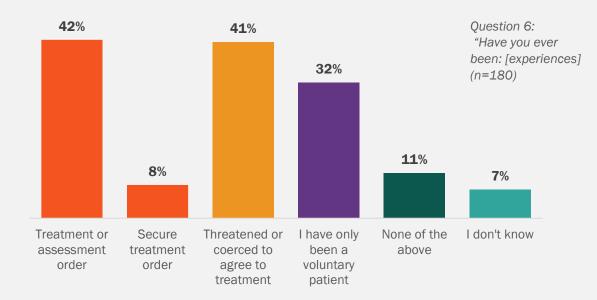
Public child / adolescent services (e.g., CAMHs)	2%	Private services (inpatient and outpatient)	5%
Crisis Assessment and Treatment Team (CATT)	2%	Private psychologist, therapist, social worker	3%
Hospital Brief Intervention Team	1%	Private psychiatrist	2%
Psychosocial rehab services (NGOs)	3%	Laurundal mental asylum	1%
Intensive care unit	1%	NDIS	1%

As these additional service types were volunteered rather than explicitly asked for, this data should be taken as a minimum of service type experience.

Experiences of compulsory treatment

46% of survey respondents had experienced one or more kinds of compulsory treatment or assessment order.

It is notable that 7% of respondents did not know whether or not they had been on a formal order under the Act. This confirms what we hear in our advocacy work at VMIAC, that some people are not properly informed about their legal status, and accordingly, not even aware of rights protections they may be able to access.

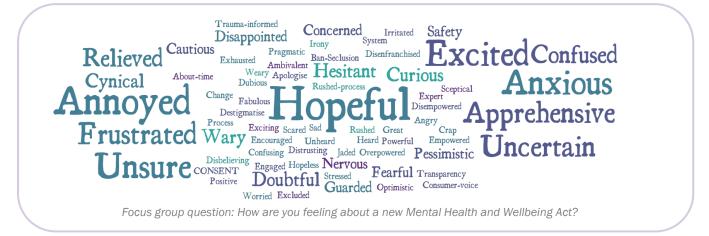


Results

1. Review processes

1.1 Review process for the Mental Health and Wellbeing Act

At the beginning of each focus group, participants were asked to share how they were feeling about a new Mental Health and Wellbeing Act. The word cloud below is a compilation of results across the groups. Many participants shared conflicting feelings: a combination of being hopeful or excited, but also feeling annoyed, anxious, apprehensive or unsure about the outcome.

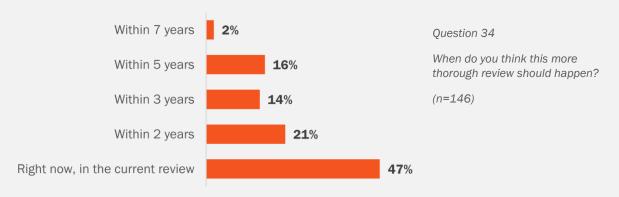


1.2 Next review of the Mental Health and Wellbeing Act

The Royal Commission has recommended that the new Mental Health and Wellbeing Act be independently reviewed in five to seven years, with a 'terms of reference' that is codesigned with consumers. That review will look at ensuring the law is contemporary, effective and responsive to people's needs. Other recommendations to enhance human rights are suggested for this review.

We were cognisant that a great many consumers were hoping to see far reaching reforms in this first review of the Act. While the Royal Commission recommended aligning the Mental Health and Wellbeing Act with other legislation such as the *Medical Treatment Planning and Decisions Act 2016*, it has slated this for future review. However, delaying binding advance care directives will be devastating for many consumers, and is a lost opportunity for Victoria to enact the most innovative and progressive mental health laws in Australia. The right to choose what happens to our bodies is what has galvanised consumer advocacy for decades. Including these changes in new legislation would be a major advancement in consumers' pursuit of equal rights.

Given this context, the online survey asked respondents when they think this more thorough review should happen; 47% said right now, and 82% collectively said in less than 3 years.



1.4 From our hearts to yours

At the close of each focus group, participants were invited to think about the people who will be writing the new Act, and to send a message from their own hearts to the hearts of the writers. The word cloud below is a compilation of messages from participants:



Focus group question: Tell us 3 words you want the people writing the new Act to hold in their heart

Seclusion and restraint

Many people are not violent until threatened with compulsory treatment or restraint.

> The 'tool' of seclusion creates aggression situations." (P1/7)

2. Seclusion and bodily restraint

2.1 Recommendations:

The new Mental Health and Wellbeing Act should:

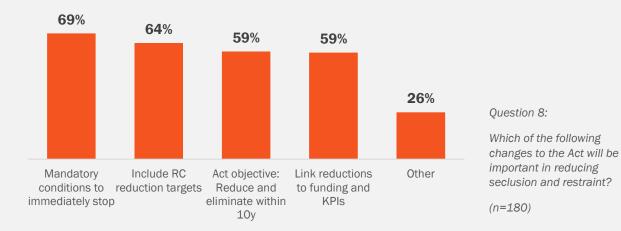
- 1) include an objective to reduce seclusion and restraint and eliminate it within 10 years, setting an aspiration for faster elimination
- 2) include a principle that seclusion and restraint are inherently harmful practices and that all services will be committed to their elimination
- include minimum targets to reduce seclusion and restraint set by the RCVMHS, linked to key performance indicators

2.2 Strategies to reduce, then eliminate seclusion and restraint

Seclusion and restraint are arguably some of the most traumatising experiences for consumers in mental health services, and eliminating these practices has been a priority for VMIAC for many years now. The Royal Commission into Victoria's Mental Health Services (RCVMHS) has recommended the elimination of seclusion and restraint over 10 years, beginning with immediate reductions in key performance indicators of 50% in adult services, and by two-thirds in child, adolescent and aged services.

The elimination of seclusion and restraint is very positive news for most consumers (except for the inordinately long timeframe), however how we get there will be important. It is clear that past efforts to reduce seclusion and restraint, while once having some impact, are no longer working.

We asked consumers how the new Act could help to reduce seclusion and restraint. All four of the suggested options (see graph below) had majority support, with 69% of respondents supporting the idea that legislation must require seclusion and restraint to immediately end when someone is asleep or becomes otherwise unconscious.



2.3 Qualitative responses to eliminating seclusion and restraint



2.3.1 Survey comments on seclusion and restraint

Faster | Many survey respondents said the timelines provided by the Royal Commission are too generous, with many suggesting that no more than one year should be allowed.

Staff skills & alternatives | There were comments that consideration should be given to retraining staff and the provision of alternatives to seclusion in order to achieve the culture change necessary for everyone.

The new act should include something about acute management of people that ensuring preventative measures ... & supports that are alternatives to those currently used. (R33)

Traumatic | Some respondents took this opportunity to talk about the personal consequences of seclusion, including the trauma and re-traumatisation they experienced. For several people this was emphasised in situations where, as females, they were subjected to restraint by males, or with the use of security guards. Some people expressed this in terms of human rights while others spoke about not being prisoners.

We are not prisoners. We are patients (R76)

Provocation | While the overwhelming message from respondents was one of the potential damage and trauma that can be experienced, several people acknowledged that staff often don't know how else to respond to situations of violence, or to the consequences of illicit drug use, and further, that staff may often inadvertently provoke aggressive responses through disrespectful and/or coercive practice.

Specific strategies | Strategies to reduce the use of seclusion included the use of body cameras, citing some evidence that this also contributed to a de-escalation of aggression, CCTV of all seclusion episodes for investigation purposes, consequences for services including tying funding to reducing rates, authorising specific staff to use seclusion and restraint, and better documentation.

2.3.2 Focus group reflections on seclusion and restraint

Dehumanising | The focus groups added depth of understanding of the impact of seclusion and restraint, with numerous reports of being denied access to toilets or water, and the traumatising and dehumanising impact of its use. Sometimes physical harm was reported.

I'm tired of seeing consumers with marks from restraints in the emergency department. Bracelets stuck under restraints almost puncturing skin. (P4/35)

Punishment | Also, the use of seclusion as punishment is reported several times.

Seclusion and restraint are driven by fear and unfortunately have been abused/have been used as a go to, rather than as the exception. There hasn't been appropriate accountability or acknowledgement of the damage inflicted (P4/32)

Provocation | Several participants spoke about the impact of being in hospital and the system's responsibility in sometimes provoking aggressive responses.

These comments are clear examples of the kinds of issues described in the Victorian Safewards training handout on *'Cultures of Control, Cultures of Care'*², where a coercive, controlling system is described as triggering understandable fight/flight/freeze fear responses, which may perpetuate cycles of violence in coercive services.

The system is often the cause of people's actions that lead to seclusion and restraint. Can we somehow have nurses and doctors understand patients more than locking them up. (P 4/36)

If someone's coming at you, attacking you, a self defence (C/3)

Many people are not violent until threatened with compulsory treatment or restraint. The 'tool' of seclusion creates aggression situations. (P1/7)

Fight or flight is a natural response to being held against your will (C/4)

As in the survey, questions were raised in the focus groups about why it would take 10 years to eliminate seclusion and restraint:

It shouldn't take 10 years to find a less degrading way to help manage distress and maintain safety (P2/15)

² Department of Health. (2017). Moving from cultures of control to a culture of care: Positive words reflections, Safewards Victoria. Victorian Government, unpublished. (Available via Office of the Chief Mental Health Nurse).

Chemical Restraint

 We are your mothers, fathers, children, family and friends.
 Do not other us." (C/4)

3. Chemical restraint

3.1 Recommendation for chemical restraint

The new Mental Health and Wellbeing Act should:

- 1) include a new section to define, regulate and reduce chemical restraint
- 2) include a definition for chemical restraint, according to which, whether or not an intervention is characterised as chemical restraint is determined by the impact of the intervention on the person receiving it (either impact on their decision-making capacity and/or restraining the functioning of body, mind and/or emotion), rather than purely on the intention of the person using the intervention. Other definitional elements may also be included.

3.2 Defining chemical restraint

On the matter of chemical restraint, the RCVMHS recommended to:

"regulate the use of chemical restraint through legislative provisions in the new Mental Health and Wellbeing Act" (Recommendation 54, v4, p297).

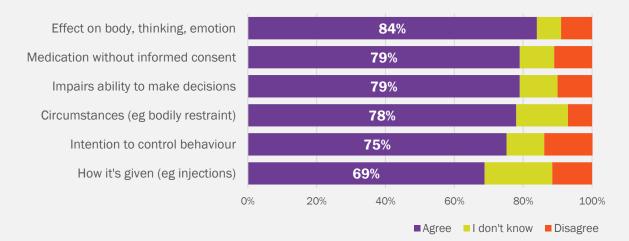
This recommendation was expressly linked to recommendation 42.2(e) regarding a new Mental Health and Wellbeing Act. This section states:

"[ensure the new Mental Health and Wellbeing Act] specifies measures to reduce rates and negative impacts of compulsory assessment and treatment, seclusion and restraint" (v4, p11).

The RCVMHS final report noted that:

"...consumers and clinicians may hold different views about how it [chemical restraint] should be defined and whether it is necessary to regulate it through legislation" (v333,p332).

The survey asked consumers how they think chemical restraint should be defined. The survey results indicated a majority of respondents supported all of the options proposed, with positive responses ranging from 69% to 84% (see graph below). The most preferred option was *"effect on body, thinking, emotion"* at 84%, however the differences were not large, and so focus groups were used to seek further clarification on which definition option is preferred if only one was possible (see section 3.3.2).



Question (9): What factors should be considered when defining chemical restraint in the new Act? (n=177)

3.3 Qualitative responses to defining chemical restraint



3.3.1 Survey comments about chemical restraint

Impact, not intent | Respondents to the survey commented on the significant impact that the use of medications has, particularly without consent and in the presence of coercion. There was overwhelming support for the chemical restraint definition to include the *impact* of the medication, with several people saying they believed that if *intent* was used it was too open for services to just say it was treatment, not for control of behaviour.

Few practitioners will admit that they intend to control a person's behaviour: this is much more likely to be described as medically treating symptoms, though it may not be truthful. The Act should focus on the effects of medication, including decision making capacity, cognitive processes, memory, and physical impacts. (R18)

Compulsion | There was similar support for the definition to include any treatment that was compulsory, including in the community setting. where it was felt that CTOs are used to "sedate people into compliance" (*R*171):

Chemical restraint is used in the mental health arena like a gun.... It is an unfair contest. Should not be a contest but in my experience it was, as you fight for your life. (R179)

Easy option for staff | Several people spoke about chemical restraint where medications are used for convenience by staff who may not have the necessary resources or training to assist people in extreme distress. Some respondents spoke about the potential of someone being traumatised by actions they may take when they are in distress:

I live everyday with my trauma; I do not want the unconscionable trauma of hurting someone else whilst in psychosis added to that. (R114)

Strategies | In these situations, some suggestions were made to ensure good practice such as attending to issues of staff gender and impact this may have on the person (particularly for consumers with a trauma history involving gender-based violence); having the person's medical power of attorney (medical decision maker) consent; increasing documentation; and videoing interactions that led to the restraint to inform an investigation process.

Maybe another way to measure is dose or if there is no upper limit. (C/2)

3.3.2 Priority ranking of chemical restraint definitions (focus groups)

In the focus groups, the question of defining chemical restraint was raised again, with the aim of clarifying which option was preferred for a chemical restraint definition given that all the options in the survey had broad support.

The focus groups used a ranking question to identify preferences between the types of definition, and discussion to elicit further explanation. The following slide was used to prompt discussion about different ways of conceptualising chemical restraint, and potential implications of these varying definitions.



The slide was developed following reflection of the survey results. As we were seeking clarification, we simplified the survey options into four broad categories.

In presenting the above slide, each option was described as shown below. These descriptions help to frame participant responses:

(1) **'Intent of clinician'** is the subjective view of a clinician but is a common, consistent definition across other sectors:

I have some concerns around relying on the use of 'clinician intention to control behaviour' in a definition as there is great scope for the 'restraint' to be defined as 'treatment by the clinician, and placed them in the position of power to be defining, even if the consumer perceives the treatment as chemical restraint. More so than treatment (C/5)

- (2) **'How the drugs are given'** may be more objectively observable by clinicians and consumers, such as using bodily restraint to give drugs, or a rapid sedation injection without consent, but it may not be broad enough to capture all forms of chemical restraint.
- (3) **'Impact on the person'** may be the subjective view of the consumer identifying impacts on body, mind and emotion, but maybe it can be objectively observed through independent capacity assessments:

I think that grounding the question of chemical restraint on whether it supports or removes someone's decision-making capacity is important, because it acts as a safeguard: a clinician would find it difficult to justify that something is NOT chemical restraint, if it results in a person being unable to make decisions for themselves consistently. It means that it would look bad if someone continued to not have "capacity". (C/4)

(4) 'Nonsense': we discussed how, for some consumers, chemical restraint can feel like a 'nonsense' concept, indistinguishable from all compulsory treatment.

The whole process from hospital to home is varying shades of chemical restraint. (C/3)

When an inpatient has akathisia and is shifting from foot to foot, and dyskinesia and is grinding their teeth, it is definitely chemical restraint. (C/1)

I think it has to have something about consent in the definition. (C/2)

Participants were asked to rank the different options for defining chemical restraint, following the above discussion. The collated results express a clear preference for definitions which focus on the *impact* of chemical restraint on the consumer, rather than the *intent* of the clinician or the *process* of drug administration (see table below).

Definition options	Priority ranking (mean)*	Priority ranking (median)*
Impact on consumer: Restrains capacity	1.8	2
Impact on consumer: Restrains body/mind/emotions	1.8	2
How it is done: Using bodily restraint	2.2	3
Cannot separate from compulsory treatment	2.9	4
Intent of clinician to control behaviour	3.0	4
How it is done: Use of IM injections	3.0	5
(n=35) * Rankings were from 1 (highest priority) to 6 (lowest priority)		

Some participants talked about the potential of a definition for chemical restraint to include more than one of these concepts:

Is it possible to include multiple definitions for the department? Important for accountability of services and safety and human rights of consumers...(C/1)

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Compulsory treatment

"But nothing damages your reputation like people finding out you've been a compulsory patient."

> (Participant C/2, following a discussion about how the fear of "damage to reputation" is sometimes used as justification for compulsory treatment)

4. Compulsory treatment

4.1 Recommendations

That the new Mental Health and Wellbeing Act prioritises the RCVMHS recommendation to reduce compulsory treatment as follows:

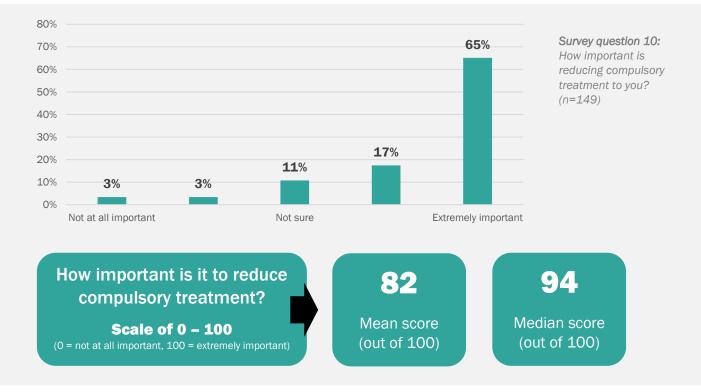
- 1) Add an objective to the Act to reduce compulsory treatment rates and duration
- 2) Change the Act so that the option of voluntary treatment is strengthened and supported to happen as follows:
 - a) Add a principle to the Act which specifies that voluntary treatment is always preferred, even where someone meets the criteria for compulsory treatment.
 - b) Change the Act so that the Mental Health Tribunal:
 - i) has discretion to *not* make an order, even if the treatment criteria are met (for example, if the consumer wants to try a treatment approach that is different to the psychiatrist's recommendation)
 - ii) has discretion to approve a specific, limited treatment plan rather than an open order which allows any treatment
- 3) Tighten the criteria for compulsory treatment by adding a definition for the term "serious" in the context of harm and/or deterioration, and include the examples of:
 - a) imminent death
 - b) physical injury to others and/or
 - c) injury to self which maims or is life-threatening
- 4) Further tighten the criteria for compulsory treatment by providing that none of the following factors can be taken as evidence of "serious harm" or "serious deterioration":
 - a) non-conforming behaviours or beliefs
 - b) financial risks
 - c) damage to reputation
- 5) Add a definition for the new recommended term of "last resort" as follows:
 - a) Specify that in determining whether compulsory treatment is a "last resort" the authorised mental health professional must evidence that a variety of different treatments and supports beyond just medication (e.g., talking therapies, peer support, specialist trauma services and/or respite services) have been offered
 - b) The above treatment and support options should be included in the Act as necessary preconditions to compulsory treatment, and as principles in the Act to support the highest attainable standard of health
- 6) Add an additional section to the definition for the new recommended term of "last resort" in relation to compulsory treatment, specifying that social issues impacting on mental health (e.g., housing, situations of violence or abuse, cultural or spiritual needs, severe financial or health stresses) have been attended to
- 7) Add a requirement that when considering whether compulsory treatment is necessary, the purported benefits of treatment must be weighed against potential harms caused by

compulsory treatment (e.g., loss of rights, dignity and agency, unwanted adverse effects, re-traumatisation)

- 8) Remove community treatment orders (CTOs) from the Act. If this is not yet acceptable to government, then a range of new additions are required in the new Act to address the RCVMHS recommendation to reduce compulsory treatment, such as:
 - e) Significantly shorten the permitted duration
 - f) Indicating in the Act that the number of CTOs will be reduced over time, and support this by modifying the CTO key performance indicator to include targets which reduce over time
 - g) Tightening the criteria for CTOs in line with other recommendations for reducing compulsory treatment
 - h) Expressly exclude rationales for CTOs which are based solely on consumer 'noncompliance'
- 9) Until or unless equal rights are provided to allow consumers to appoint medical treatment decision-makers (i.e., consistent with other Victorian legislation), broaden the scope of who and how many people are involved in making assessment and treatment order decisions:
 - a) Change who can make compulsory treatment orders using one or more of the options below:
 - i) Change from 'authorised psychiatrists' to 'authorised mental health professionals', and/or
 - ii) Expand this further to include professional roles outside of designated mental health services (note: some respondents spoke about wanting their private psychiatrist and/or other mental health professionals involved in these decisions), and/or
 - iii) Expand to include independent decision-makers.
 - b) Require the involvement of more than one type of mental health professional in deciding on whether to use an order.
- 10) Include a provision that compulsory treatment must change or stop if it negatively impacts physical health or personal recovery. Require that treating clinicians and the Mental Health Tribunal review these impacts as reported by consumers, and change or cease compulsory treatment when negative impacts occur.
- 11) Include a new safety condition for compulsory treatment which prohibits the use of high risk treatments (e.g., very high medication doses or electroconvulsive therapy) and/or off-label medication use, within compulsory treatment, unless the person gives free and informed consent without duress.

4.2 Importance of reducing compulsory treatment

The RCVMHS has recommended that compulsory treatment be reduced over time. Respondents were asked how important this objective was to them. The results were consistent with the Royal Commission final report and VMIAC's advocacy over recent years, with a large majority of 82% saying that reducing compulsory treatment was *important* to them (above 60 on a sliding scale from 0 to 100). See graph below.



Consumers have spoken to VMIAC over many years about the unacceptably loose and variable way that different clinicians interpret the criteria of the Act. These differences are evident in the variation in compulsory practice across services. It may also be a function of the Act lacking clear definitions, and in some cases, an absence of definitions at all.

The Act on The Act survey and focus groups explored definitions with consumers to identify if tighter definitions might be helpful in reducing compulsory treatment, and to understand what should be included and/or excluded from these definitions. The focus was on the term "serious" in the context of "serious harm" and "serious deterioration", and the new term recommended by the Royal Commission, "last resort". The additional concept and term of "harm to self" was further explored in focus groups to clarify what this should and should not mean in the context of compulsory treatment.

4.2.1 Qualitative reflections on compulsory treatment from focus groups

During the focus groups, participants were asked to *"tell us about any strong feelings you have about compulsory treatment - whether it's for or against".* They were offered the opportunity to respond in 250-character paragraphs and could enter responses multiple times. In total 88 responses were entered, and themes are outlined below.

Impact of compulsory treatment | Participants shared the impact of compulsory treatment:

There were 3 occasions that compulsory treatment saved my life, but I was severely traumatized by being in hospital and I was poisoned by the heavy drugs! The heavy drugs were torturous! I felt like I was being tortured from the inside out! Nightmare (P1/9)

It made me feel so hopeless and not worth anything that I found it hard to believe I had the right to live. It was only When I left the system that I found recovery and meaningful life - joy of life (P2/14)

Heavily sedated 24/7, life felt hopeless, pushed into a corner, attempted suicide for the first time in my life at age 31. Only felt like I had a future when the order was lifted. (P3/23)

Sign of a failing system | Some participants spoke of understanding the justification for compulsory treatment's use when a person is at imminent risk of significant harm or death, but some also spoke about the failure of the system as a reason for the use of compulsory treatment.

Adult Acute Unit care is trigger (P5/42)

You can't see eye to eye with the dr so instead of working through it he simply medicates you (P4/39)

Stark result of system failure to help earlier (P4/34)

Mental Illness shouldn't be treated like a CRIME! "Beyond reasonable doubt" standard required. (P5/43)

4.3 Tightening compulsory treatment criteria: Defining serious harm or deterioration

4.3.1 Defining serious harm or deterioration: survey results

More than 50% of respondents identified three factors which should be specifically <u>excluded</u> from any definition of 'serious harm' or 'serious deterioration':

- 1. Non-conforming behaviours or beliefs (69%)
- 2. Taking financial risks (54%)
- 3. Damage to reputation (54%)

At the other end of the scale, respondents identified three factors that should be <u>included</u> as examples of 'serious harm,' or 'serious deterioration', including:

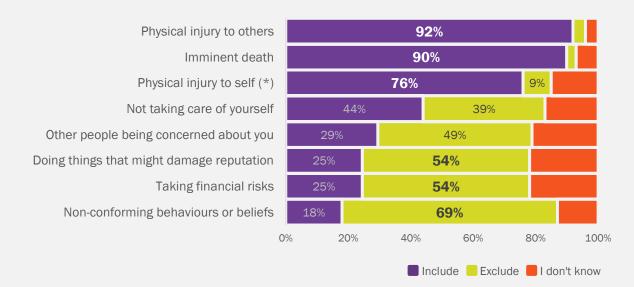
- Physical injury to others (92%)
- Imminent death (90%)
- Physical injury to self (76%)

It is important to note that focus group participants clarified that these factors are only potential reasonable preconditions for compulsory treatment, however they should not automatically be a justification.

Instead, participants said that even when these conditions apply, voluntary practice should always be preferred, and that other treatment options should be offered before compulsion was

used. The current *Mental Health Act 2014* already requires this, however it has not translated into practice. We encourage the Department to consider ways to strengthen this expectation.

The remaining two options for defining "serious" had unclear results. While only a minority (29%) agreed that "other people being concerned about you" should be justification for compulsory treatment, only 49% agreed that it should be excluded as a justification. The option of "not caring for yourself" (i.e., not eating, showering, or sleeping) was even less clear, with similar numbers supporting inclusion (41%) and exclusion (39%). Further research and consultation are required on these two areas.



Question 11: What, if any, of the following factors should be included or specifically excluded from a definition of "serious deterioration" or "serious harm".

4.3.2 Defining serious harm or deterioration: Qualitative responses (survey)

The comments following this question provided some clarification on what consumers considered important about defining this term.

Respondents generally agreed that the word 'serious' was problematic as it was too subjective, with several people suggesting that it needs to be defined by the person themselves. Minority-Report Criminalises False-predictions Abuse-of-power Who-decides Mistrust Scepticism Targeted Pre-crime Self-defined Devastating Too-subjective

Who defines what the meaning of the word "serious" is? Is it clinicians or people with a living experience of mental distress? There's a big difference! (R64)

There was also scepticism that changes to the act, short of banning such practices, would make any difference at all:

The lack of practice change generated by the 2014 Act provides sufficient evidence that (some) MHS staff will always abuse their power and penalties under the Act will never be

enforced. The MH service system can't be trusted to wield such potentially devastating power against individuals. (R113)

Concern was also raised about the 'predicting' nature of using the term 'risk'. Several people noted the lack of evidence to support risk assessment with one respondent drawing on principal of 'innocent until proven guilty' and another on the story line of the film 'Minority Report'

Psychiatry is not a version of pre-crime and should [not] have powers to criminalise an individual before an event. This principal of 'serious' places an individual outside of the realm of proven innocence, and places abstract mind determinations as a guiding principle towards forceful control of a targeted social group (R172)

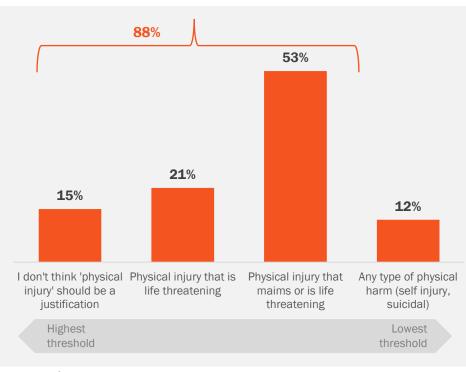
We are not living inside the film 'Minority Report' and actually risk assessments are not at all reliable (R180)

4.3.3 Defining serious harm or deterioration: Clarifying threshold of harm to self (focus group)

Given the potentially broad way in which "physical injury to self" could be interpreted, in the focus groups we sought clarification about what types of injury would be a threshold for considering compulsory treatment.

Participants were presented with four possible thresholds for when 'physical injury to self' could be considered 'serious harm' in the context of compulsory treatment and were only able to choose one. Inappropriate Risks-with-compulsion Maims Mistrust Uphold-choices Misunderstood Too-much-power Threatening Death Respect Coping Not-for-self-injury

88% of respondents chose thresholds higher than 'any type of physical harm'. A majority of 53% said that physical injury which 'maims' (i.e., explained in the groups as injury which creates a permanent impairment) or is life threatening would meet this threshold, while 21% said that the higher threshold of 'life threatening' was more appropriate, and 15% said that harm to self should never be an acceptable criterion. See graph below.



Focus groups

If 'physical injury to self' was included as a criterion for compulsory treatment, what does that mean to you?

(n=34)

Participants discussed experiences like self-injury which may fall under these definitions, and shared that this experience is frequently misunderstood and inappropriately responded to by mental health staff:

Self injury gets misinterpreted a lot by clinicians, as being the same as suicidal. But it's not. People use it as a coping mechanism. Don't tell people we can't use our coping mechanism. Threatening us with hospital never resolves the need for self injury, it just means we don't trust the clinicians any more. (C3)

4.4 Reducing compulsory treatment: Defining "last resort"

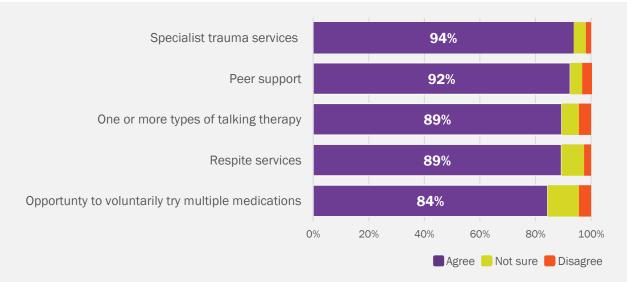
4.4.1 Treatment/support choices and defining last resort: Survey results

The Royal Commission has recommended that compulsory treatment be used as a "last resort". "Last resort" commonly means that all other options have been offered and/or tried. In the survey respondents were asked what "last resort" means to them, in two questions.

The first question asked, from a list of five commonly accepted options, which types of treatments should be offered and/or tried before compulsory treatment could be considered a "last resort". These included:

- Trauma specialist services
- Peer support
- One or more types of talking therapies
- Respite
- Opportunity to voluntarily try different medications

All options were rated highly by respondents, ranging from 84% to 94%. See graph below.



Survey question 12: Which of following should the Act say must be offered and/or tried before compulsory treatment was really a "last resort"?

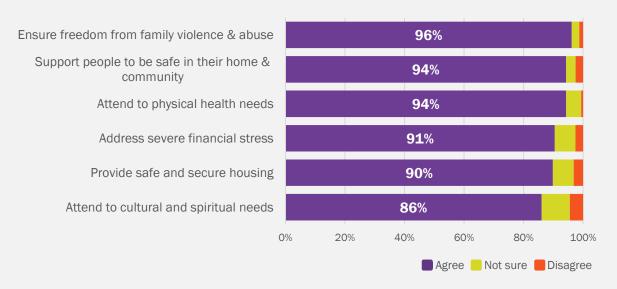
4.4.2 Social determinants and defining last resort: Survey results

Respondents were also asked to choose which, if any, social determinants issues should be attended to before compulsory treatment could considered a last resort. These were drawn from issues which are highly prevalent amongst mental health consumers, and clearly linked to mental health challenges and psychological distress.

These included:

- Providing safe and secure housing
- Ensuring people are free from family violence and abuse
- Supporting people to be safe in their home and community
- Addressing severe financial stress
- Attending to physical health needs.

All options ranked extremely high, ranging from 86% to 96%. Results are shown in graph below.



Survey question 13: Should the Act require any of these social determinants be addressed before compulsory treatment is considered? (n=159)

In comments, participants clearly acknowledged the importance of responding to the social determinants of health:

Without the above options being addressed you cannot reasonably support someone's mental health - more often than not a combination of the above are a significant cause, so treating those underlying issues will go much further toward improving a person's mental health that forcing them into "treatment" which only addresses the symptoms (which is almost guaranteed to result in one or more relapses). (R10)

Recognition that if the above factors are or were addressed, compulsory treatment may never have been necessary to consider. (R88)

There was a particular focus on housing needs in the comments:

...people need to know they can access a safe roof over their heads each night consistently. If a client has no where to go after initial intervention on any level, this will result in them being stuck in the ever-revolving door of mental health... (R99) The provision of health food options was also highlighted:

Access to fresh food products (R124) and Low-cost fresh food (R127)

4.4.3 Defining last resort: Qualitative survey responses



Offered, **not tried** | Many of the comments following these questions supported the definition of last resort including the offering of multiple treatment options in addition to the social determinants. Several people cautioned that it should be restricted to the documented 'offering' of options rather than an obligation of 'tried' as this too may lead to coercion.

People will feel coerced into trying things they may not feel they want or need (R9)

I think that offered and tried are really different. I think people should be offered everything they could possibly have before compulsory treatment, and even then, I am not sure compulsory treatment in its current form should be administered. Also, if the law says things need to be tried before compulsory treatment is administered, then that in itself is compulsory treatment (R63)

Harm to others | There was also support that 'last resort' be tied to the risk of harm to others:

Only if all of the above have failed, and only then if the person is at risk of harming themselves or other people (R88)

Should also be an imminent risk if the person is not made compulsory, and the compulsory treatment must be capable of addressing that risk, and not be simply preventative detention (R81)

Lack of skills | Of particular interest is the message from respondents that currently they experience the use of compulsory treatment as a result of staff not having the necessary skills to offer anything else. It is not experienced as either least restrictive practice (as the current Act says) or as a last resort as is recommended for the new Act.

If we didn't have compulsory treatment... staff may (with support) improve their skills in working alongside consumers rather than dominating them. (R113)

We are ... left at the mercy of clinicians who are frankly, often biased by a medical lens, and little knowledge of what else might help. (R180)

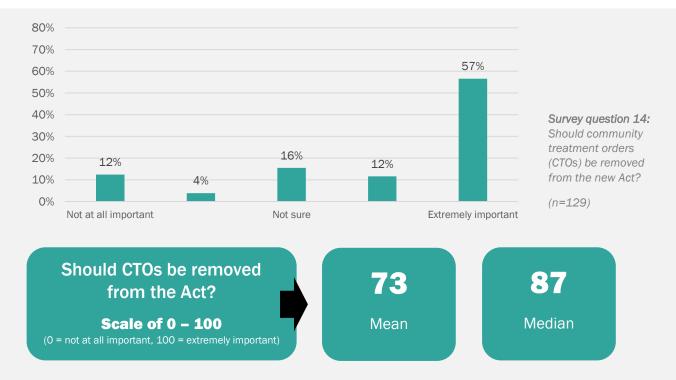
signal to you that what's in the law is largely irrelevant for as long as the people administering it don't give a shit. (R158)

that it is not referenced to convenient use of staff or impatience with the person's ongoing distressing behaviour (R107)

4.5 Reducing community treatment orders

Respondents were told that the final report by the Royal Commission into Victoria's Mental Health Services included the following quote about community treatment orders: *"the sum of evidence does not support their effectiveness in preventing relapse and readmission"* (v4, p375).

Respondents were asked whether it was important that community treatment orders were removed from the new Act; 69% of respondents said this was important, with a median score of 87 out of a possible 100.



4.6 Other strategies to reduce compulsory treatment

4.6.1 Other strategies to reduce compulsory treatment: survey responses

Respondents were presented with a list of possible additions to the new Mental Health and Wellbeing Act which might aid in reducing compulsory treatment. Respondents were asked to select which options they thought would help to reduce compulsion.

All options were supported by a majority of respondents, with support ranging from 69%–90%. Complete results are reported in the table below. The three most strongly supported options were:

• **90%** Require the involvement of other mental health professionals in deciding on an order (not just a psychiatrist)

- 87% Compulsory treatment must change or stop if it negatively impacts physical health or personal recovery
- 84% High risk treatments and/or off-label use of medications should not be permitted for compulsory treatment

There needs to be an upper limit, they can't just drug people into oblivion. It must be reviewed often. People can't end up in fistfuls of drugs without upper limits. That makes no form of informed consent possible, if you're so drugged you can't give consent. (C/2)

If included in legislation, all three of these options would support other policy and legislative goals, including:

- Addressing the severe life expectancy gaps for mental health consumers
- Addressing the 'negative impacts' of compulsory treatment (see RCVMHS recommendation 42.2[e])
- Creating a more diversified workforce (see RCVMHS recommendation 57.1, and chapter 33, p496).

What would help to reduce compulsory treatment orders?	Positive responses (%)
Require involvement of other mental health professionals in deciding on an order (not just a psychiatrist)	90%
Compulsory treatment must change or stop if it negatively impacts physical health or personal recovery	87%
High risk treatments and/or off-label use of medications should not be permitted for compulsory treatment	84%
Treatment orders should specify what the treatment will be (e.g., types and doses of drugs)	82%
Include an official objective and targets to reduce compulsory treatment	76%
Concerns about "compliance" can't be justification for an order	76%
Shorten the maximum duration of treatment orders, including CTOs	69%
Other (see comments below)	29%

Survey question 15: Which of the following changes to the Act do you think would help to reduce compulsory treatment orders (including in the community, hospital and forensic settings)?

4.6.2 Other strategies to reduce compulsory treatment: qualitative survey responses

Many comments supported the statements about eliminating compulsory treatment.

Expanding beyond psychiatrists as substitute decision-makers | Comments suggested that an increase in peer workers and the addition of alternative and complementary treatments could reduce the use of compulsory treatment. VMIAC does not support the inclusion of consumer peer support workers in any aspect of compulsory treatment decision-making without a thorough process of investigating ethics and consequences with the consumer workforce. However, it is consistent for consumer peer workers to support the consumer to be present during decision-making and to express their views in these processes.

There was also the suggestion that beyond one or two psychiatrists making an order, the entire treating team should be involved, and a suggestion about expanding compulsory treatment decisions to an advocate role.

Include the perspective of peer/consumer workers to share their perspective on the impact this action may have on a person's recovery. Should require consultation with entire care team and input of service user. (R35)

Mental professionals should include a peer support worker, and a client advocate provide at the Service's expense. (R25)

Mandatory training | There were also comments on the need to introduce mandatory training in human rights and supported decision making before being able to make a compulsory treatment order.

Mandatory training in human rights, supported decision making ... should include all staff, especially psychiatrists. (R181)

Advocacy | and that the Act should be written in such a way as to support advocacy:

The principles underpinning the Act should be written in such a way that they can be used for systemic advocacy. (R13)

Prescriptive guidelines | Finally, there was strong support for having more prescriptive guidelines concerning what can be treated compulsorily.

should be stated maximum dosages of all drugs used for CTOs that cannot be exceeded under any circumstances (R67)

CT should never be compulsory (R183)

Consent can't be given without choices free of punitive consequence, without knowledge of side effects, long term effects or reasonable and less restrictive alternatives (C/2) This page left intentionally blank.

Independent advocates

⁶⁶ There are rarely any alternatives and options given to us"

5. Independent mental health advocates

5.1 Recommendations for independent mental health advocates

That the new Mental Health and Wellbeing Act expressly protects the right of access for independent advocates and ensures that notifications and responses are provided by services within prescribed timeframes, and give further consideration to the right to communicate.

- 1) Specifically, where the consumer consents, an independent advocate:
 - a) cannot be prevented by a service from meeting with a consumer
 - b) cannot be prevented from attending a service meeting with a consumer
 - c) can access consumer records
- 2) In addition, the Act must expressly protect these rights of access for independent advocates (consent is not relevant here):
 - a) A right of access to all authorised mental health services
 - b) Access to the mental health system database to see who is on an order under the Act and (only) their contact details.
- 3) The independent advocacy service must be notified:
 - a) within 24 hours when a person is subjected to compulsory treatment
 - b) when a registered advocacy client is subjected to seclusion or restraint, including chemical restraint.
- 4) Services must respond to requests by advocates within three days.
- 5) The new Act should strengthen the current *Mental Health Act 2014* right to communicate.

5.2 Ensuring opt-out advocacy is successful: survey responses

The Royal Commission recommended that Independent Mental Health Advocacy (IMHA) will become an 'opt out' service. This means every person subjected to compulsory treatment will be offered an advocate, rather than having to ask to get one. The survey asked respondents what the new Act should include that will support this recommendation to be successful.

All options in the survey had strong majority support, ranging from 73% to 95%, see table overleaf.

The most strongly supported options related to clear rights of access by independent advocates: to meet with consumers, to enter authorised services, and not being prevented from attending meetings. We recommend that the new Act contains all of these protections.

Category	Answer choices	Responses (%)
Right of access	IMHA advocates cannot be prevented by a service from meeting with a consumer or survivor, unless the person does not want to meet with them	95%
Right of access	IMHA advocates must have a protected right of access to all authorised mental health services	94%
Right of access	IMHA advocates cannot be stopped from attending meetings with consumers, unless the person does not want them there	93%
Notification	IMHA must be notified when a person is subjected to a treatment or assessment order within 24 hours	93%
Response to requests	Services must respond to IMHA advocates' requests within a maximum of 3 three days	92%
Notification	IMHA must be notified within 24 hours when a person is subjected to seclusion or restraint	91%
Right of access	IMHA advocates should able to access consumer medical records if the person consents	90%
Right of access	IMHA must have access to the mental health system database to see who is on an order and their contact details	73%
	Are there other circumstance in which IMHA should be notified?	22%

Survey question 16: The Royal Commission has recommended that Independent Mental Health Advocacy (IMHA) will become an 'opt out' service. This means every person subjected to compulsory treatment will be offered an advocate, rather than having to ask to get one. Which of the following options should be included in the new Act to support this: Please select all that apply. (n=153)

5.3 Ensuring opt-out advocacy is successful: survey comments



Respondents wanted IMHA to have the ability to be involved prior to compulsory treatment being implemented or when the person is feeling coerced.

Would also be amazing in outpatient, and in voluntary inpatient (because this can be very coerced) (R63)

If someone is being told they will be subjected to compulsory treatment at some time in the near future, an IMHA should be provided beforehand to ensure all other options have been tried (and have been tried for a reasonable amount of time), to potentially prevent the compulsory treatment to begin with. (R10)

Some participants spoke about needing phone lines and phone access to contact independent advocates. While opt-out advocacy should reduce the need for phone access to make initial contact with an advocate, it may still present issues for when consumers need to contact their advocates with new issues or changes.

IMHA should have a phone line so people who are made compulsory can phone them to get the process started (R131)

Service must be required to provide access to phones and or computers in order for the person to contact IMHA or VLA (R88)

Consumers have repeatedly informed VMIAC that mental health services are not upholding the right to communicate as it is described in the *Mental Health Act 2014*. This becomes a barrier to upholding other rights. We are aware there have been ongoing issues in getting the sector to respect and uphold this right, and so we recommend that the Department give consideration to strengthening the current right to communication.

People subjected to compulsory treatment should be offered an advocate within 24 hours of admission. People should be provided with information and be informed that if they say no to an advocate, they can change their mind at any point. This will be life saving. (R18)

There were also suggestions that when circumstances change IMHA should be notified for example when guardianship is considered (R62), physical health (R67) or when the person wants to leave treatment (R51)

Supported decision-making

"My body, my right" (C/4)

6. Supported decision making

The RCVMHS final report said that "the aspiration to embed supported decision making into treatment, care and support has not been realised" (v4, p393). This section includes a series of questions about supported decision making mechanisms including advance statements, nominated persons and second psychiatric opinion, with the aim of identifying changes in the new Act which will strengthen human rights.

These changes will enable the recommended reduction of compulsory treatment and facilitate a greater focus on rights and dignity.

6.1 Recommendations for supported decision-making

That the new Mental Health and Wellbeing Act strengthens supported decision-making as follows:

- 1) Add an objective that supported decision making should be part of standard clinical practice in mental health settings.
- 2) Add a definition for supported decision making based on international disability standards.
- 3) Amend the informed consent provisions to provide that treatment cannot be given unless supported decision making processes are followed.
- 4) Store advance statements or directives on a new centralised database managed by the new Mental Health and Wellbeing Commission.
- 5) Include binding advance care directives in the new Act, consistent with the Medical Treatment Planning and Decisions Act 2016, adapted for a mental health context (see preferences by consumers in section 6.3.1 of this report).
- 6) If there is not yet government will to introduce binding advance care directives, we strongly recommend a review date of not more than three years to reconsider.
- 7) Until such a time as the new Act is reviewed to include advance care directives in alignment with the MTPD Act, the new Act should strengthen advance statements as follows:
 - a) Change the requirement regarding reading advance statement from 'give regard to' to 'give all due consideration to advance statements
 - b) Require all staff to give all due consideration to all advance statements regardless of whether the consumer is on a compulsory treatment order or not
 - c) Require mental health services to carefully document and evidence how they have given all due consideration to a consumer advance statement
 - d) Give in writing to all consumers reasons for not complying with their advance statement
 - e) Report on measures to address above
- 8) Change the Act to specify that the role of nominated person is separate from that of carer.
- 9) Strengthen the description of nominated person to ensure there is a requirement that:
 - a) the nominated person understands the role to be one of supporting the consumer's rights, views and preference, and not their own
 - b) all nominated persons sign a statement on accepting this role that they:
 - i) have an obligation to uphold the consumer's rights, views and preferences

- ii) agree to promote the consumer's personal social wellbeing and to have regard to the need to respect their individuality
- iii) agree to read and understand any advance statement the consumer makes
- iv) agree to provide consumers with support to make their own decisions
- 10) If either recommendation 9(a)(i) or 9(a)(ii) in the section on compulsory treatment are adopted, then provision of a second mental health opinion should be conducted by a person in line with that recommendation.
- 11) If the recommendation options in 9(a) of the compulsory treatment section are not adopted, then strengthen the provision of second psychiatric opinions as follows:
 - a) Ensure the service is completely independent of clinical mental health services
 - b) Provide for consumers to attend a private psychiatrist at no cost
 - c) Copies of the second psychiatric opinion are to be given to the consumer within a timely period

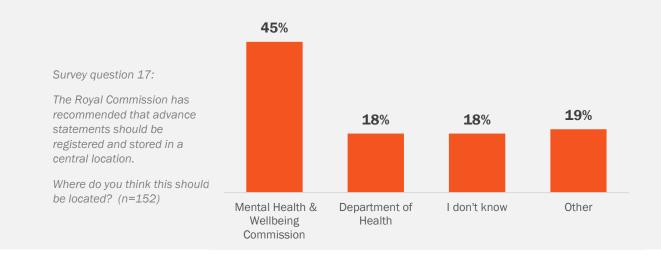
Specify that the treating mental health service should not get a copy of the second opinion unless the consumer gives consent for this to happen

6.2 Strengthening advance statements

Under the current Act, advance statements are documents in which consumers can write their treatment preferences in the event that they have a compulsory inpatient admission. Services currently don't have to uphold preferences in advance statements, they only have to 'have regard' to them.

6.2.1 Storage of advance statements

The RCVMHS acknowledged that services regularly could not locate advance statements and recommended a centralised register. The most strongly supported place to centrally store advance statements was the new Mental Health and Wellbeing Commission, however no option had majority support.



Comments generally supported copies of a person's advance statement being in multiple places, including with family and carers, other support people and GPs. In addition, *My Health Record* was suggested with the commentary that it was important that advance statements be available online to ease real time access, however past VMIAC advocacy suggests this option will not be favoured by many consumers who have opted out for privacy reasons. Other places suggested were IMHA and the new consumer-run agency recommended by the RCVMHS. The lower support for the Department of Health holding advance statements may be explained by this comment:

Perhaps the Department of Health....as long as they're transparent and can be trusted (R127)

6.2.2 Binding advance care directives

In its final report, the RCVMHS recommended that mental health laws be aligned "over time with other decision-making laws with a view to promoting supported decision-making principles and practices" (v4, p362). The principal reason for doing this is to dramatically decrease compulsory treatment through the introduction of binding advance care directives.

Unlike advance statements, binding advance care directives are a genuine supported decisionmaking mechanism which ensure that the person's written values and preferences about treatment and care will be upheld by health services. On the other hand, advance statements as established in the current *Mental Health Act 2014*, are not binding and legislation only requires psychiatrists to 'give regard' to them.

The survey asked respondents what "over time" means to them; for 69% of respondents this meant within 12 months, and for an additional 24% it was within three years.

Survey question 18: The Royal Commission recommended aligning the Mental Health Act with other similar laws 'over time'.	Answer choice	Positive responses (%)
This means we will eventually get binding Advance	Within 12 months	69%
Care Directives where our health care choices must	Within 3 years	24%
be upheld.	Within 5 years	7%
How soon should this happen? (n=147)	Within 7 years	0%

There was overwhelming agreement that people do not want to wait for equal decision-making rights in the mental health system, and that the sooner mental health legislation was aligned with other similar Victorian legislation, such as the *Medical Treatment and Decisions Act 2016*, the better. Comments included:

We do not want sweeping statements & empty promises. We need action. People are dying. (R99)

If it doesn't happen fast it won't happen at all (R178)

Feedback on this question aligns with that on question (34) about the next review of mental health legislation. If binding advance care directives are not delivered in this current review of the Act, then there is greater urgency to ensure that the next review is sooner, and within three years at the most.

6.2.3 Service compliance with advance statements: survey results

Survey respondents showed strong support for all legislative options suggested to strengthen service compliance with advance statements, with two options selected by 92% of respondents, three between 80–90% and one at 79%. The two highest ranking options were:

- 92% Services required to provide written reasons to consumers when they do not comply with an advance statement
- **92%** Psychiatrists required to read advance statements when consumers are admitted, not only when compulsory treatment has occurred

Complete results are in the table below.

What would help to increase mental health services' compliance with our advance statements?	Positive responses (%)
Written reasons provided to consumer when advance statement is over-ridden	92%
Psychiatrist must read advance statement on admission (not just during compulsory treatment)	92%
Staff must document how they comply with our advance statement and give reasons	89%
Copies of our advance statements should be available to the Independent Mental Health Advocacy service (IMHA)	87%
Staff must regularly review our advance statement	85%
Services must report publicly on compliance with advance statements	79%
Other (see comments below)	22%

Survey question 19: The Royal Commission has recommended changes to improve the compliance of mental health services with our advance statements. Which of the following changes to the Act do you think would make a difference?

6.2.4 Service compliance with advance statements: qualitative comments

Make them binding | In relation to increasing service compliance with people's advance statements, the strongest themes were in relation to making them binding:

If you just try to make advance statements stronger, I guarantee at the next review of the act we'll all still be wondering why advance statements don't work. They don't work because they are not binding. And not being binding, it is easier in a busy system to ignore them and just force drugs on people (R180)

there is no such thing as compliance with Advance Statements because they are not binding. They are persuasive at best and usually taken no notice of. (R158)

Not worth it | Some respondents told us they don't bother to complete advance statements because they are not binding and can be so easily ignored:

I myself have not completed an advanced statement due to the fact that having only ever been treated involuntarily, I know that it only has to be consulted, not adhered to. (R114) These comments align with findings and recommendations in VMIAC's³ prior consultation on advance statements and nominated persons. This consultation found consumers had a high level of mistrust in advance statements because services were under no obligation to uphold them. Some consumers in the report described their experience of having advance statements ignored. The consultation report recommended:

"... legislative change during the 2019 Mental Health Act review: including changing from advance statements to directives, allowing the nomination of excluded people, and strengthening safeguards for human rights" (2018, p18)

Respondents expressed strong support for having accountability for services through reporting requirements, both at an individual service level and at an individual staff level:

anyone involved with patients in compulsory holding should have to carefully document and prove how they have honoured, considered, and actualised the patient's wishes (R8)

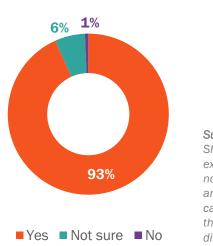
There was some commentary regarding making an advance statement compulsory, however while this is problematic from a human rights perspective, it was also suggested that adequately documenting why someone has refused to write an advance statement would be useful.

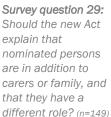
Four respondents made suggestions about services approving advance statements before they then are required to comply with them. We do not recommend this approach, however, since it would be in contradiction with the spirit and intent of advance statements as a method to ensure people's preferences can be expressed and known.

6.3 Strengthening nominated persons

Survey respondents strongly supported these next two potential legislative changes to improve the effectiveness of nominated persons:

 Different to carers: 93% of respondents agreed that there should be an explanation in the Act that nominated persons are a different role to carers or family, and in addition to those roles (see graph below for question 29)

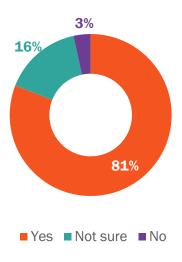




³ VMIAC (2018) Advance statements and nominated persons survey report. Downloaded from <u>https://www.vmiac.org.au/wp-content/uploads/VMIAC</u> - Advance-statements-Nominated-Persons_Consumer-Survey_2018.pdf

• **Documented service compliance:** 81% of respondents agreed that the Act should require public reports on whether services are involving nominated persons in consumers' care according to their documented preferences (see graph below for question 30)

Survey question 30: Should services be required to report on whether nominated persons have been involved in our care, according to our preferences? (n=147)



6.3.1 Clarifying the role of nominated persons in the Act

Past consultations by VMIAC³ have highlighted that, for some people, there is a lack of clarity about the role of nominated persons. In particular, consumers have reported that sometimes carers or family members in the role of nominated person sometimes speak about what they want for the person, rather than taking on the intended role of nominated person, to advocate for the person's will and preferences.

This survey asked respondents to rate some specific options for the new Act which may help to define the role of nominated persons more precisely, avoiding current conflicts. The suggestions in the survey were adapted for a mental health context from the *Medical Treatment Planning and Decisions Act 2016*. All suggested options had strong support, ranging from 82% to 95% (see graphs below).



6.3.2 Clarifying the role of nominated persons: Qualitative responses

It is clear from responses to this question that people's experiences with nominated persons have not been consistent with the supported decision-making intentions in the Act. Several people spoke about experiences where the nominated person represented their own needs to the mental health service rather than the person's:

My father was listed as a nominated person for me, and I revoked him, because he was advocating for his opinions to the treatment team, and not my preferences. I was very powerless. (R18)

NP's should not be asked for their opinion. They should be there solely to support/enhance the person's own opinion. (R36)

There was also a suggestion that nominated persons undertake training and have supports for them in that role:

should be made aware that there are boundaries around what the nominated person can disclose and to whom. A nominated person needs to be an appropriately trained person and carefully selected. (R107)

6.4 Strengthening second psychiatric opinions

The survey asked people about two areas which may improve the effectiveness of second psychiatric opinions as a supported decision-making mechanism.

6.4.1 Getting a second opinion: Survey responses

Respondents were asked if there should be other options for getting a second psychiatric opinion than the current service, which is managed by an existing designated mental health service. The results are shown in the table and comments below.

Option	Positive responses (%)
The Second Psychiatric Opinion Service should be run independently of public mental health services	75%
We can see a private psychiatrist of our choice for a second opinion, for free (gov. funded)	90%
Other (see comments below)	11%

Survey question 32:

The new Act might make changes to how the right to a second psychiatric opinion operates, to try and strengthen our rights. Which of the following options do you think would improve second psychiatric opinions? (n=146)

6.4.2 Strengthening second psychiatric opinions: Qualitative survey responses

Second 'mental health' opinion | The comments on second psychiatric opinions were strongly supportive of having a profession other than psychiatry involved in providing second opinions, including psychologists, social workers and psychiatrists who work privately at no cost.

It was also suggested that people should be able to access psychiatrists outside of their normal geographic area:

Telehealth should be leveraged to obtain second opinions outside the Melbourne psychiatric fraternity, which will always support the initial diagnosis. (R178)

Independence and impact | Respondents said there must be processes to ensure independence and that the second opinion is properly considered and included in future treatment and care decisions:

With consumer consent 2nd opinions are included in care rather than completely ignored (R181)

6.4.3 Who sees the second opinion? Survey responses

Respondents were asked who they want to be sent a copy of their second psychiatric opinion. Options scored between 80%–92%; the table below shows options in preferred order as scored by respondents.

Option	Positive responses (%)
Independent Mental Health Advocacy Service	92%
Nominated person (if there is one)	88%
Lawyer (if there is one)	83%
Mental Health Tribunal	80%

Survey question 33:

If you get a second psychiatric opinion, and you give consent, should a copy be sent to (please select all that apply). (n=145)

With respect to who should receive copies of second opinions, comments reflected that the person should receive a copy and then decide who it should go to. One respondent suggested that the Mental Health and Wellbeing Commission receive a copy if the opinion is different to that of the treating psychiatrist. (R81)

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Information sharing

If a family member or organisation can access my medical information for free then I should be able to as well. Why do I have to apply for FOI but everyone else can have it at their leisure?" (P4/35)

7. Information sharing

Information sharing intersects with the right to privacy, to self-determination, to freedom from discrimination and can often be a serious safety issue. It has been a high priority issue for consumers for many years, and it has historically been a common reason for consumers to contact our advocacy service at VMIAC. We recognise this can be a difficult area to legislate in because, on some matters, there is conflicting advocacy from consumers and carers.

It was encouraging to see the RCVMHS recommend to simplify information sharing, but also to acknowledge the importance of consumer consent and our right to privacy.

During the consultation we explored several issues related to information sharing, and this part of the report includes a section on each of the following:

- Real-time access to records
- Modifying health records
- Information sharing and the right to privacy
- Information sharing and safety

7.1 Recommendations on information sharing

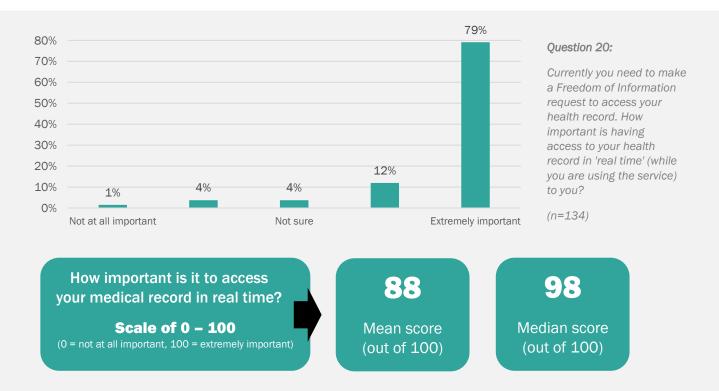
That the new Mental Health and Wellbeing Act includes changes to information sharing to protect both privacy and safety of consumers, as follows:

- 1) The Act should provide for:
 - a) real time access to medical files by consumers
 - b) right to make changes and corrections to medical files by consumers
 - c) right of consumers to add information to their medical file
- 2) The Act specifically states that consumer consent is required for the sharing of any information outside of the following circumstances:
 - a) the consumer is unable to consent due to physical incapacity (i.e., coma)
 - b) when children are at risk from a mental health consumer, and mandatory reporting is necessary, only the information that is necessary and legally required should be shared, and what is shared:
 - i) must be reported to the consumer
 - ii) entered into the medical record (who, when and why)
- 3) The Act specifically states that the sharing of medical information on the grounds of imminent harm to others is not permitted. In these circumstances only the information necessary to keep the other person safe is required and:
 - a) must be reported to the consumer.
 - b) entered into medical record, (who, when and why)
- 4) The Act provides for consumers to nominate excluded persons and that this precludes receiving or giving information to excluded persons.

7.2 Real-time access to health records

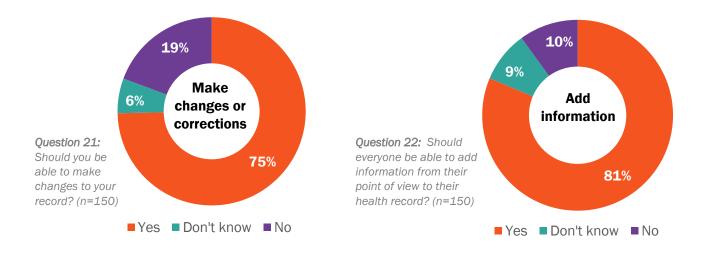
There is no legal prohibition to showing someone their health record outside the Freedom of Information Act 1982, however consumers report having to make Freedom of Information (FOI) requests to access their records, which can cause a range of issues.

The survey asked respondents whether it was important to have real-time access to their records while they are using the service, rather than having to use the FOI process. It was very important to 79% of respondents (>80 out of 100), and important (>60/100) to 91% of respondents. See graph below.



7.3 Modifying health records

Respondents were asked how important it was to be able to modify their health record. 75% of respondents said they want to be able to make changes or corrections (question 21), and 81% want to be able to add information to their health record (question 22). Results are in the two graphs below.



7.4 Information sharing and the right to privacy

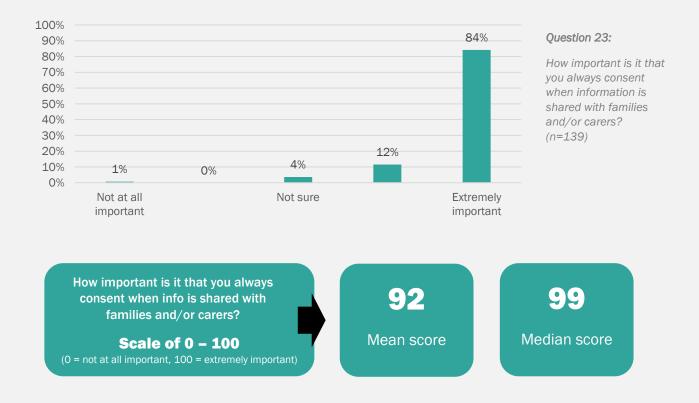


The RCVMHS has recommended that current legislative requirements for the sharing of consumers' private medical information with families and carers be simplified and also "...support and respond to consumer consent to share information with other service providers, families, carers and supporters" (v4, p523).

This has historically been a topic of tension in systemic advocacy by consumers and carers. In the past consumers have told VMIAC that consent for release of information is important to protect the right to privacy and self-determination, and it can become a serious safety issue for people subjected to family violence or abuse (VMIAC, 2018, p42).

7.4.1 Importance of consent before sharing information with families and/or carers

We asked respondents how important it is to give consent before information is shared with families or carers; 84% said it was very important, with a mean score of 99 out of a possible 100.

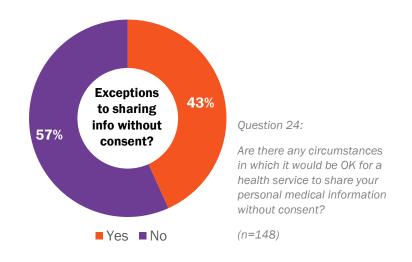


7.4.2 Are there exceptions to sharing information without consent? Survey results.

In question 24, respondents were asked if there were any circumstances when it would be OK for a health service to share personal medical information without consent.

57% of respondents said there were no exceptions to consent, however 45% said that there were.

This result is further explained in the qualitative responses below, and then clarified in the focus group responses.



7.4.3 Exceptions to sharing information without consent: Qualitative responses

High risks | By far the strongest theme in comments to this question were about circumstances with an imminent risk to self, others, or risk of death:

Limited to the most basic of information only in extreme circumstances, eg. The person was a danger or hurt someone else. That person deserves some basic information that the person is being treated, nothing more (R9)

Minimum to be safe | It was also clear that only information needed to provide a safe environment should be shared.

If another person is at risk. Only enough information should be disclosed for that person to keep themselves safe. No more! (R23)

Physically incapacitated | People made a distinction for when the person requires medical treatment, for example, if the person is in a coma, some information may need to be shared to ensure appropriate care is delivered.

If these were life threatening situations like sharing known allergies (R13)

Reasons in other legislation | Other suggested circumstances in which it may be appropriate to share information without consent are covered in other legislation, such as with the care of children, or regarding a risk of harm to a child. Several respondents mention that there are situations in which it is not appropriate to share information, this is also covered in question 25.

7.4.4 Focus groups: Clarifying exceptions to sharing information without consent

Responses to question (24) seemed to possibly be inconsistent with results from question 23. On the one hand, 90% agreed that information should not be shared with family or carers without consent. On the other hand, 45% of respondents said there were exceptions. Given these contrasting results, the focus groups sought clarification about what counts as an exception.

Not medical information | Most focus group participants agreed that medical information should not be shared without consent. Participants talked about reasons why this mattered to them, including having seen inaccurate and stigmatising, discriminating information in their records, and the implications this can have in their lives.

Yes to being able to edit records. Incorrect records can follow you around for decades with no ability to correct them. (C/2)

Only with prior consent | Many participants spoke of the potential value of having a consent arrangement made explicit in advance statements.

Never. Consent should always be given. Here's hoping that consumers can include details about who can be given their medical details in their Advance Statement. (P1/9)

Advance statements to nominate excluded and preferred sharing circumstances, but otherwise share only at same rules as other medical disciplines (P4/28)

Inappropriate & inconsistent reasons | Examples were given of inappropriate sharing of information such as a GP writing a parent's diagnosis in a referral for a child's physical health condition, as well as an inconsistent application of the 'rules':

Services also pick and choose when sharing information - my family were not informed of a lot of action and plans made when I was an adolescent inpatient and underage. However shared my diagnosis with my school without my consent, before my parents (P2/15)

Ease for families, cost for consumers | A contradiction was highlighted about the relative ease for family members to get information, but the cost for consumers navigating the *freedom of information* process:

If a family member or organisation can access my medical information for free - then I should be able to as well. Why do I have to apply for FOI but everyone else can have it at their leisure (P4/35)

Impacts of FOI | There were also concerns raised about the application of freedom of information law and the potential impact this has for consumers:

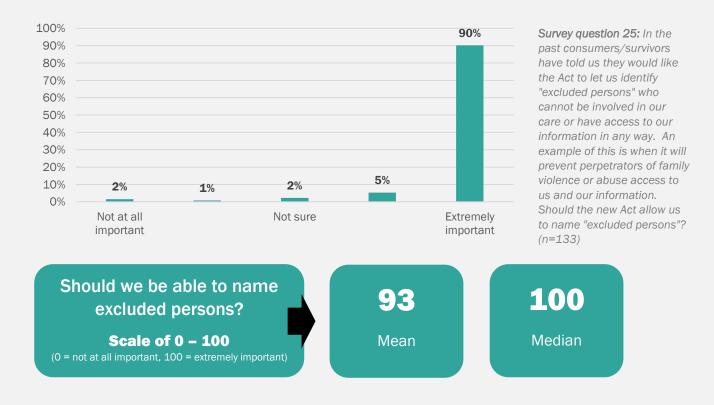
GP's should also be aware not to say "don't tell the client this" when speaking about you - FOI is telling!!! I have a new GP now :) (P5/42)

7.5 Information sharing and safety

One of the recommendations in VMIAC's survey on advance statements and nominated persons³ was for the introduction of *"excluded persons"* in the next review of the Mental Health Act. This survey identified that, particularly for consumers with experiences of family violence or past abuse by a family member, there was a need to ensure family perpetrators cannot either give or receive information about the consumer without consent. We recommend reading this previous report for further information, specifically pages 42–45.

95% of respondents in the survey agreed the next Act should allow consumers to name "excluded persons".

Family violence already has information sharing legislation re people who use violence. Recent rollout of new arrangements, started 19 April (C/3)



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Mental Health & Wellbeing Commission

There is a lack of trust, or care when forcing things upon us. I had another incident and I didn't know where to go because I didn't trust the system. That is very risky too. Have a conversation with us, rather than assume." (C/3)

8. Mental Health and Wellbeing Commission (and new boards)

8.1 Recommendations for the new Commission (and regional boards)

That the new Mental Health and Wellbeing Act includes the following with regard to the new Mental Health and Wellbeing Commission:

- 1) The Act provides for the Mental Health and Wellbeing Commission to have the following powers:
 - a) Formally review services and make recommendations
 - b) Undertake sanctions in the event a service or practitioner does not comply with the Act or recommendations from the Commission, that include but are not limited to:
 - i) Refer to police for possible criminal investigation
 - ii) Deregistration of services
 - iii) Recommend deregistration of professional person
 - iv) Application of fines
 - v) Other sanctions as appropriate (e.g., reduced funding)
- 2) The Act requires a minimum of annual, and where feasible quarterly, public reporting by the Commission that specifies the performance of services and includes but is not limited to:
 - a) Non-compliance with Victorian Charter of Human Rights and Responsibilities (2006)
 - b) Analysis of reductions in seclusion and restraint
 - c) Analysis of reductions in compulsory treatment
 - d) Analysis of grounds for compulsory treatment including:
 - i) evidence of serious harm and last resort
 - ii) records of capacity assessments and informed consent processes
 - e) Any investigations, including recommendations and outcomes
 - f) Sector-wide and individual service compliance with the principles and objectives of the Act.
- 3) The Act provides for the necessary powers for the Commission to intervene when the Commission becomes aware of an imminent breach of the Act.
- 4) The Act requires that at least 50% of the Commissioners are consumers.

The RCVMHS has recommended that a new Mental Health and Wellbeing Commission be established, with a range of statutory roles including complaints, monitoring and regulation.

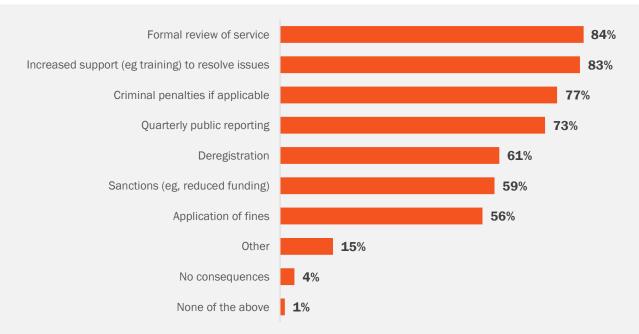
8.2 Commission powers for non-compliant services: survey results

Given the Royal Commission recommendations to reduce compulsory treatment, seclusion and restraint, and the historical challenges that mental health regulatory bodies have had in impacting these issues, we asked respondents what role they thought the new Commission

should play when mental health services do not comply with the new Mental Health and Wellbeing Act. Over many years, consumers have told VMIAC countless examples of services breaching the Act.

Respondents could choose any of the options listed in this question, and/or add their own. Only 1.33% said that none of these actions were important, and only 4% thought there should be no consequences when services don't comply with the Act.

Formal review and increased support for services were selected by over 80% of respondents. Criminal penalties were next highest at 77%.



Question 26: How should the new Commission respond to services who don't comply with the Act? (Please tick all that apply). (n=150)

8.3 Commission powers for non-compliant services: Qualitative responses

Respondents in the survey shared suggestions regarding the potential role of the Mental Health and Wellbeing Commission in monitoring compliance. It is clear that people want a better accountability structure with transparency of both issues and consequences.

Investigation and consequences | There is strong support for understanding why issues have occurred at services, investigation powers and being able to apply consequences, whether they are rehabilitative in nature or sanctions for serious breaches:

Really try to understand why they are not complying. Find out if the non-compliance is more helpful/causing less harm to the service users or if it is just biased disregard of individual rights and quality of life/freedom (R123)

Consumer audits | Two respondents suggest that independent consumer auditing of services could form part of that approach:

All services should be monitored by a Consumer LE audit team (R183)

Independent and consumer ... organisations ... should produce an annual ranking and evaluation of Services' compliance. (R90)

8.4 Commission reporting: survey responses

There has been a lack of public, transparent reporting about the mental health system, particularly on matters of high priority to consumers, like compulsory treatment, seclusion, restraint, sexual violence and other human rights and safety issues, and public data on individual services. Production of the *Seclusion Report* by VMIAC⁴ has in part been a response to these gaps. The RCVMHS also noted gaps in transparent reporting.

The survey asked respondents to select what should be included in public reports by the new Mental Health and Wellbeing Commission, from six options. All six options were rated highly by consumers, with scores ranging from 78%–92%. See table below.

Options	Positive response (%)
Actions it has taken in response to service non-compliance with human rights obligations under the Act	92%
Analysis of reductions in seclusion and restraint, including performance of individual services and the sector	89%
Analysis of reductions in compulsory treatment, including performance of individual services and the sector	88%
Any investigations, including recommendations and outcomes	88%
Sector-wide compliance with principles of the Act	82%
Individual service compliance with principles of the Act	78%

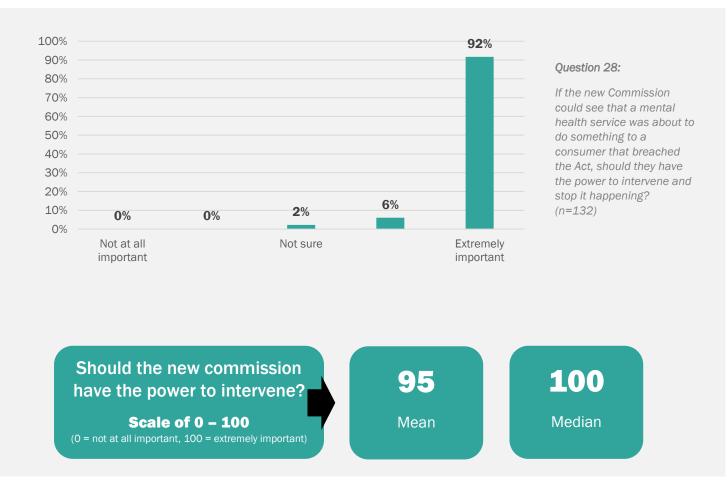
Survey question 27: What should be included when the new commission issues public reports about mental health services? (n=145)

⁴ VMIAC (2019) Seclusion Report downloaded from https://www.vmiac.org.au/wp-content/uploads/Seclusion-Report_VMIAC_Vic-mental-health-hospital-services APRIL 2019 FINAL.pdf

8.5 Commission intervention powers

Respondents were asked whether the new Mental Health and Wellbeing Commission should have the power to intervene if they could see that a mental health service was about to do something that breached the Act. Currently, this power doesn't exist at the Mental Health Complaints Commissioner,

92% of respondents said this was extremely important, with a median score of 100, on a scale of 0 to 100.



8.6 Consumer commissioners and board members: Focus groups

From consumer perspective, it is encouraging that the RCVMHS has recommended that at least one Commissioner should be a consumer, and at least one member of each new regional board should also be a consumer. However, the experience at VMIAC and in the consumer workforce strongly suggests that 'just one' is not enough to address the kinds of power imbalances in the mental health system that were noted by the RCVMHS, nor is 'just one' consumer sufficient to create cultures which embrace codesign and coproduction.

In the focus groups, participants were asked how many of the new Commissioners and new board members should be consumers. Participants voted using a sliding scale from 'one' (the minimum already recommended) to 'all'. The median result for both was 50%, which is consistent with our understanding of good practice in co-design and other participatory processes.

What should consumer leadership look like in new statutory bodies?	Mean	Median
How many of the new Commissioners should be consumers?	64%	50%
How many consumers should be on each new regional board?	65%	50%

(n=37)

Focus groups question: What should consumer leadership look like in new statutory bodies?

But I think for there to be true co-design, there needs to be a greater representation of consumer voices than not to actively redress the implicit power imbalances in LE/consumer engagements (C/2)

Other governance structures were discussed in the consumer workforce and consumer leadership focus groups, including the recommended regional multiagency panels. The discussion focussed on two points: the inclusion of an independent consumer, and of an advocate, on the panels:

"Isn't it about the principles of nothing about us without us is for us. Yes yes and yes it needs a shake up, it needs different perspectives" (C4)

Yes it's really important to have independent consumer voices (emphasis on independent) on these panels (C2)

And the panels would still be required to operate in accordance with the Act.

"The act needs to somehow clarify that individuals and collectives who are participating in the new multiagency panels must adhere to the principles of the legislation" (C4)

Forensic services

Long-term seclusion should be removed"

9. Forensic Services

Given the tight timeframes for this consultation, it was agreed that the forensic focus group would be led by the Senior Consumer Consultant, Thomas Embling Hospital, using a briefing by the lead consultants, and the survey questions as a guide. Two patients/clients attended the discussion with the consultant, there were also two support staff present, in line with Forensicare policy.

Not all of the questions asked on the survey had impact for the participants, and these were largely skipped (see appendix 1 for included questions), however it was clear from the feedback that there are potential intersections between the *Mental Health and Wellbeing Act* and the *Crimes (Mental Impairment and Unfitness to be Tried) Act* 1997 (*Vic)(CMIA*) and that these would need to be explored in greater depth.

This following discussion only includes points of difference with the public consultations.

9.1 Forensic participant views on seclusion and restraint

This group agreed that seclusion needs to be reduced, however they were less clear about elimination. It was stated that seclusion should explicitly be an intervention of last resort, not used as part of everyday "management" and there was also discussion about the length of seclusion and that 'long term seclusion' needs to be removed. The use of a "time out room" was also mentioned, stating that this "gives people an option for a calmer and safer environment without the restriction of seclusion"; the term "step up step down" was also used in relation to seclusion.

Several other factors were raised such as the lack of activity and subsequent boredom, learning about triggers, and the value of de-escalation in reducing the use of seclusion. While these factors are outside the role of legislation, it indicates that more work is needed in this setting.

Both participants agreed that the provided definitions for chemical restraint had a place in a definition but noted that there is a:

"big difference between having enough medication to calm you down or take the edge off and leaving you without capacity to think or act clearly".

There was support for more advocacy in forensic services including in prisons, and specifically when a person is being transferred back to prison from Thomas Embling Hospital.

There were a number of concerns raised that were not in the scope of this consultation but do warrant further exploration and advocacy.

10. Other comments

Most comments made in the final open question of the online survey, and during the focus groups, have already been addressed in the above sections of this report.

However, we have selected the comment below, from one of the focus groups, to bring this report to a close. This respondent's words capture deep concerns raised by a majority of people who contributed to this consultation. We hope they are heard.

> Never necessary... Even if a person is standing on the edge of a cliff, we don't treat them compulsorily. Coax them back from the edge and then find out what the person wants and needs. That is not a reason to then follow up with compulsory treatment.

> Treating in a compulsory way may mean you win that battle, but lose the war—lose the person forever and have a massive impact on the rest of their lives. (C/3)

Appendix 1: Act on the Act Consultation: Survey questions NB: * These questions were not asked at Forensicare.

Page 1	Welcome to this survey about the new Mental Health and Wellbeing Act.	Answer options	Comments / open response
Q1	I have read the above information and agree to completing this survey.	Yes/No	
Page 2	About you		
Q2	Can you please tell us your age group	18-24; 25-34; 35-44; 45-54' 55-64; 65+	
Q3	What gender do you identify with?		Open
Q4	Where do you live?	Metropolitan; regional; rural; other	-1
Q5	Do you identify as (please tick all that apply)	Aboriginal; Torres Strait Islander; Culturally or linguistically diverse; disabled (other than psychosocial); LGBTIQ+; Refugee or asylum seeker;	Other (please specify)
Q6	Have you ever been:	 On a compulsory treatment or assessment order On a secure treatment order Threatened or coerced to agree to treatment I have only been a voluntary patient I don't know None of the above 	
Q7	I have used:	Public inpatient services	Other (please
-		 Community services (case manager) Secure Extended Care (SECU) Community Care Unit (CCU) Forensic services Specialist mental health services such as Spectrum, dual diagnosis services, eating disorder unit PARC 	specify)
Page 3	Seclusion and Restraint		
Q8	The Royal Commission has recommended that seclusion and restraint be eliminated in 10 years. The recommended maximum rate of seclusion has been halved immediately for adult services, and reduced by two-thirds for child, adolescent and aged services. These rates will reduce again every two years until eliminated. Which of the following changes to the Act will be important in making this happen?	 The new Act should include an objective to reduce seclusion and restraint so that it is eliminated within 10 years The new Act should include the Royal Commissions targets for reducing seclusion and restraint The new Act should link reductions in seclusion and restraint to services' funding and performance indicators The new Act should make it mandatory that seclusion or restraint must end immediately when the 'imminent risk' stops (eg, the person is asleep or unconscious) 	Please tell us an other ideas you have about this:
Q9	Currently the Mental Health Act does not have a definition of "chemical restraint". The Royal Commission has recommended that "chemical restraint" be defined, reduced and eventually eliminated. What factors should be considered when defining chemical restraint in the new Act?	 The intention of the medication is to control a person's behaviour The effect of the medication is restraint on a person's body, thinking and/or emotions The medication impairs a person's ability to make decisions The circumstances in which the medication is given? eg. if bodily restraint is used to administer the medication How the medication is given, eg. Intramuscular injections Any medication given without informed consent 	Comments
Page 4	Compulsory Treatment		
Q10	How important is reducing compulsory treatment to you?	Slider from Not at all important (0) to Extremely important (100)	
Q11	What, if any, of the following factors	 Non-conforming behaviours or beliefs 	

	excluded from a definition of "serious deterioration" or "serious harm":	 Doing things that might damage your reputation Other people being concerned about you Not taking care of yourself (eg, not eating, showering or sleeping) Physical injury to self Physical injury to others Imminent death 	
Q12	The Royal Commission has recommended that compulsory treatment be used as a "last resort". "Last resort" commonly means that all other options have been offered and/or tried. Which of following should the Act say must be offered and/or tried before compulsory treatment was really a "last resort"?	 One or more types of talking therapy Peer support Providing the opportunity to voluntarily try multiple medications Specialist trauma services Respite services 	Comments
Q13 *	Should the Act require any of these social determinants be addressed before compulsory treatment is considered?	 Providing safe and secure housing Supporting people to be safe in their home and community Ensuring people are free from family violence and abuse Attending to cultural and spiritual needs Addressing severe financial stress Attending to physical health needs 	
Q14	The Royal Commission's final report says about Community Treatment Orders (CTOs): "the sum of evidence does not support their effectiveness in preventing relapse and readmission." Should CTOs be removed from the new Act?	Slider from Not at all important (0) to Extremely important (100)	
Q15	Which of the following changes to the Act do you think would help to reduce compulsory treatment orders (including in the community, hospital and forensic settings)? Please select all that apply	 Shorten the maximum duration of treatment orders, including CTOs Concerns about "compliance" cannot be a justification for an order Require the involvement of other mental health professionals in deciding on an order (not just a psychiatrist) Include an official objective and targets to reduce compulsory treatment Treatment orders should specify what the treatment will be (eg, types and doses of drugs) Compulsory treatment must change or stop if it negatively impacts physical health or personal recovery High risk treatments and/or off-label use of medications should not be permitted for compulsory treatment What else should be in the Act that could help reduce compulsory treatment? 	
Page 5	Independent Advocacy		
Q16	Which of the following options should be included in the new Act to support this: Please select all that apply	 IMHA advocates must have a protected right of access to all authorised mental health services IMHA advocates cannot be stopped from attending meetings with consumers, unless the person does not want them there IMHA advocates cannot be prevented by a service from meeting with a consumer or 	Are there other circumstance in which IMHA should be notified?

		 survivor, unless the person does not want to meet with them IMHA advocates should able to access consumer medical records if the person consents IMHA must be notified when a person is subjected to a treatment or assessment order within 24 hours IMHA must be notified within 24 hours when a person is subjected to seclusion or restraint IMHA must have access to the mental health system database to see who is on an order and their contact details Services must respond to IMHA advocates' requests within a maximum of 3 three days 	
Page 6	Advance Statements		
Q17	One issue with advance statements is that services often say they can't find them. The Royal Commission has recommended that advance statements should be registered and stored in a central location. Where do you think this should be located? Please tick all that apply	 The new Mental Health and Wellbeing Commission The Department of Health I don't know 	Other (please specify)
Q18	The Royal Commission recommended aligning the Mental Health Act with other similar laws 'over time'. This means we will eventually get binding Advance Care Directives where our health care choices must be upheld.How soon should this happen?	 Within 12 months Within 3 years Within 5 years Within 7 years 	Comments
Q19 *	The Royal Commission has recommended changes to improve the compliance of mental health services with our advance statements. Which of the following changes to the Act do you think would make a difference?	 Psychiatrists must read our advance statement when we're admitted (not just when during compulsory treatment) Staff must regularly review our advance statement Staff must document how they comply with our advance statement and give reasons When services don't comply with an advance statement they must provide us with reasons in writing. Copies of our advance statements should be available to the Independent Mental Health Advocacy Service (IMHA) and the Mental Health Tribunal Services must report publicly on compliance with advance statements 	Do you have any other ideas about improving compliance with our advance statements?
Page 7	Information Sharing		
Q20	Currently you need to make a Freedom of Information request to access your health record. How important is having access to your health record in 'real time' (while you are using the service) to you?	Slider from Not at all important (0) to Extremely important (100)	
Q21	Currently you are not able to make changes or corrections to your mental health record. Should you be able to make changes to your record?	• Yes • No • Don't know	
Q22	Depending on the service you use you may or may not be able to add information from your point of view to your mental health record. Should everyone be able to add information	• Yes • No • Don't know	

	from their point of view, to their health record?		
Q23 *	The Royal Commission has recommended that current requirements for the sharing of information with families and carers be simplified. In the past consumers and survivors have stated that consent for release of information is always important. How important is it that you always consent when information is shared with families and/or carers?	Slider from Not at all important (0) to Extremely important (100)	
Q24 *	Are there any circumstances in which it would be OK for a health service to share your personal medical information without consent?	YesNo	If you answered yes, under what circumstances do you think it would be ok?
Q25 *	Should the new Act allow us to name "excluded persons"?	Slider from Strongly agree (0) to Strongly Disagree (100)	
Page 8	New Mental Health and Welbeing Commission		
Q26 *	How should the new Commission respond to services who don't comply with the Act? Please tick all that apply	 I don't think there should be any consequences when services don't comply with the Act Increased support (e.g., training) to resolve any issues preventing good service Quarterly public reporting Formal review of service Application of fines Sanctions such as reducing funding Deregistration of services If applicable criminal penalties None of the above 	Other
Q27 *	What should be included when the new commission issues public reports about mental health services?	 Individual service compliance with principles of the Act Sector-wide compliance with principles of the Act Analysis of reductions in compulsory treatment, including performance of individual services and the sector Analysis of reductions in seclusion and restaint, including performance of individual services and the sector Actions it has taken in response to service non-compliance with human rights obligations under the Act Any investigations, including recommendations and outcomes 	
Q28 *	If the new Commission could see that a mental health service was about to do something to a consumer that breached the Act, should they have the power to intervene and stop it happening?	Slider from Strongly agree (0) to Strongly Disagree (100)	
Page 9	Nominated persons		
Q29 *	Sometimes people get confused between the different roles of families/carers and nominated persons. Should the new Act explain that nominated persons are in addition to carers or family, and that they have a different role?	YesNot SureNo	
Q30 *	Should services be required to report on whether nominated persons have	YesNot SureNo	

	been involved in our care, according to our preferences?		
Q31 *	The new Act might describe nominated persons in a different way. Please tell us which of the following descriptions would improve nominated persons:	 Nominated persons sign a statement that they understand their obligations. Nominated persons agree to express the views, preferences and values of the consumer/survivor, not their own personal views and preferences Nominated persons agree to promote our personal social wellbeing and to have regards to the need to respect our individuality Nominated persons agree to read and understand any advance statement we make Nominated persons agree to provide us with support to make our own decisions 	Other
Page 10	Second Psychiatric Opinion		
Q32 *	The new Act might make changes to how the right to a second psychiatric opinion operates, to try and strengthen our rights. Which of the following options do you think would improve second psychiatric opinions?	 The Second Psychiatrist Opinion Service should be run independently of public mental health services We can see a private psychiatrist of our choice for a second opinion for free (gov funded) 	Other
Q33 *	If you get a second psychiatric opinion, and you give consent, should a copy be sent to: Please select all that apply	 The Independent Mental Health Advisory (IMHA) service Our lawyer if we have one The Mental Health Tribunal Our nominated person if we have one 	Are there other people you think it could be sent to?
Page 11	In Closing		
Q34 *	The Royal Commission has recommended that the new Act be independently reviewed in 5 to 7 years. This review will look at ensuring the law is contemporary, effective and responsive to people's needs. Some other recommendations to enhance human rights are suggested for this review. When do you think this more thorough review should happen?	 Right now in the current review Within 2 years Within 3 years Within 5 years Within 7 years 	
Q35	Is there anything else that you would like to tell us about what the new Act should say?		

Question	Answer Options	Response Type
How are you feeling about a new Mental Health Act?		Word Cloud Single words Multiple entries allowed
Tell us about any strong feelings you have about seclusion and restraint - whether it's for or against		Free text up to 250 Characters. Multiple entries allowed
Which is the best way to define chemical restraint?	 It can't be separated from compulsory treatment Intent of clinician to control behaviour Impact on consumer - restraining body / mind / emotions Impact on consumer - restraining capacity to make decisions How it's done - using bodily restraint to give the drugs How it's done - use of IM injections 	Forced ranking 1 - 6
Tell us about any strong feelings you have about compulsory treatment - whether it's for or against.:		Free text up to 250 characters. Multiple entries allowed
If 'physical injury to self' was included as a criterion for compulsory treatment, what does that mean to you?	 Any 'physical injury' that is life threatening Any 'physical injury' that maims or is life threatening Any type of physical harm (self injury, suicidal) I don't think 'physical injury' should be a justification 	Forced choice of one
What do you think will help make the Act really clear about when our private medical info can be shared without consent?		Free text up to 250 characters. Multiple entries allowed
What should consumer leadership look like in new statutory bodies?	 How many consumers should be on each new regional board? What should consumer leadership look like in new statutory bodies? How many of the new commissioners should be consumers? 	Each option had a sliding scale of minimum 1 to a maximum of all
Tell us 3 words you want the people writing the new Act to hold in their heart		Word Cloud Single words Multiple entries allowed

Appendix 2: Act on the Act Consultation: Focus group questions

NOTHING ABOUT US WITHOUT US IS FOR US

