

2019 Submission - Royal Commission into Victoria's Mental Health System

Organisation Name

N/A

Name

Miss Elinor Jack

What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

"The Victorian Community can be narrow minded and this is due to the lack of education and training, whether it be in society or in the workplace. Creating more opportunities of education would be to have workshops like Understanding Mental Illness, Well Together and other community based workshops and presentations for the community to not only learn and understand Mental Illness, but to hear from someone with a lived experience of mental illness. Workshops should in compass how they, the community, see mental illness in the community, what would they like to see change and then how would they implement that change. Then all the feedback from those workshops could then be collated into a written paper to be submit to the Government to discuss ways to implement positive changes. Our society whether it is hear in Victoria or abroad rarely hear what would be considered a positive story about mental illness. We hear about how someone was violent and going through psychosis which communicates through the media that all people with mental illness and those that go through psychosis are dangerous and violent when many times that is not the case. Many that go through psychosis are disorientated or alternatively attempting suicide due to the chaotic mindset that a psychotic episode is. We need to hear of the more positive stories that are in our community. For Example, there are many consumers that work in the community that do some wonderful things and even get awards from the mental health community about the marvellous work they are doing, but you never hear of it in the media. It's rare to hear stories of people with lived experience of mental illness, alcohol and other drugs that are giving back to the community through their own organisations, workshops or their own work. We need the media to publicize more positive stories about mental illness as well as the challenges they have faced. This shows many people in the community about a person's resilience and mindset when facing adverse challenges and difficulties. We don't ask to get a mental illness. It occurs through a lived experience of life itself. Many people who are diagnosed with a mental illness are treated a second class citizens, with less respect than the average person because it is seen as if it is their fault for becoming mentally ill. We need to support people with a lived experience in mental illness, alcohol and other drugs in their road to recover whilst they take self-responsibility, the community needs to allow for their space and time to recover. We don't heal overnight, it can take months or even years before someone sees a change in their recovery to move forward in their life. The community needs to have patience. They need to understand that the person that has just gone through psychosis isn't just going to bounce back up into life and continue where they left off. That it will take time for them to do what we take for granted, like having a shower, going out or even riding on public transport. People look down at them when they see them not realising what trauma they have just gone through. There is prejudgment which is based on misconceptions by the media and the general public. We need better communication. We need to start talking about this issue, not hiding it under the table. We need to inform the public whether it's a story in the newspaper or a tv series like how mad are you which tries to decipher who has a mental illness, proving that you

can't pick it based on first glance. We need to make the public aware of what we are capable of. Not what we can't do to reduce stigma and discrimination. We shouldn't have to go for jobs where we are asked if we have a psychological impairment. People should be judged on the competency of how they will perform or can perform in the job, not that they have a mental illness therefore they are seen as incompetent. Employers need to train their staff to deal with mental health due to the fact that 1 in 4 people are likely to have mental health issues. Employers need to remind staff about appropriate language in the office and also ensure that people feel safe. Employees themselves would benefit from a mental health workshop to discuss and be educated about mental health, the risks, and to treat someone unbiasedly. There should be posters and flyers in the office to remind people. With regards to social stigma and discrimination people need to hear stories that those with a mental illness are competent in their lives, they have families, relationships, friends and some go to work whether it is paid or unpaid. The community needs to open up their minds to the possibility that someone with a mental illness whilst are limited can function in their life. The community needs to be educated and informed the change in someone's journey. The best way to promote a story might be to have 2 photos, to show the difference between when someone is unwell and when they are well. To visually demonstrate change in someone's life through their road to recovery. The community needs to start a conversation. We don't talk about mental illness. If you bring it up at a party or social gathering you can be guaranteed to have eyes daggering at you, however if you were to talk about someone been in a car accident or about a terrorist incident on the other side of the world, no one would blink an eye. We need to change how we talk about mental illness and also what is the language to use. We need to change people's attitudes through community discussion and engagement at meetings open to the public. People with lived experience with mental illness need to be heard in a safe place that will identify to the community how someone is discriminated or stigmatised and group activities and engagement need to create awareness to the community. "

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

"Having a Peer Workforce already works well in the mental health community, whether it is in the hospitals or in out-patient/outreach services or in the community. When someone who is acutely unwell talks to someone who has been through what they have been through, there is hope that things can get better. It shows someone that life can improve. Also it means that you as a consumer can talk to someone about your struggles and challenges which they can immediately relate to and identify with because they have been through a similar situation themselves and it means that you as a consumer can become empowered because you see what they are doing and it helps you aspire to your own goals in life. To have someone understand the trauma of what it's like not only to be unwell but to be in an inpatient unit in hospital means there is a unique level of empathy and compassion because they themselves have lived it. They understand where you are coming from. Having a supportive Case Manager and team is imperative in someone's road to recovery. Sometimes there is a calculated risk that needs to be taken for me to move forward in my recovery and that can only happened if the medical team are open minded to try new things, even if there is a risk involved. Whilst it may seem as a risk up front, the rewards are sometimes far greater where it improves the quality and functionality of my life. It's important to have someone behind you to support you in your ideas that may or will provide a better outcome more so than the one that has been presented by the medical team themselves. If I come to you with my own research on medication that I think will work for me, you need to give me the scope to try it, even if there are consequences as it ends up providing a more life fulfilling result, reducing the side-affects. Having an early prevention plan I believe is something that everyone should discuss with

their Case Management or GP. I have found my early prevention plan very beneficial as it provides me with insight into my mental illness and allows me to take calculated risks and identifies behaviours that would put me at risk of harm. It discusses behaviours and strategies when those behaviours occur so I know what plan to put into action. For example, A Green Light (good day) is doing all the normal things. A Yellow Light (bad day) is when I am feeling paranoid and need to take time out for self care like going window shopping or having a cup of tea. On A Red Light (acutely unwell) when I need to call the CATT team or dial 000. By having a plan in place I know what to do in an emergency or alternatively when the warning signs start to show so I limit my exposure to becoming acutely unwell by putting strategies outlined in my Early Prevention Plan in place. The Mental Health Community Support Services are imperative to my road to recovery. It provides me with an environment where I am surrounded by others with similar lived experiences in mental illness and have a supportive caring team of social/support workers. I am able to participate in activities without judgement. I can feel normal again. If I am having a bad day, I can talk about it and others around me will support me and understand where I am coming from. It shows a sense of camaraderie. If I need to talk to someone, I can instantly walk over to a support worker and ask to speak to them whether it's open or private. Having that extra support provides comfort and peace of mind that if I feel I need help, I know that there is someone there to support me. In community based groups you don't get that because the facilitator is not trained in mental health. If you have a bad day in a community based group you feel isolated because the people around you haven't gone through the same experience as you have. There are not the same types of supports in a community based group whether it be at a TAFE or Community House. In a sense you feel alone in a community group if you are having a bad day because you know that the people around you may not want to hear about it. Unfortunately the NDIS has taken away the funding to Mental Health Community Support Services, meaning that many have now folded and people can't go to their usual activity like art, music, mytrainer, social outings, cooking sessions and many more. It means that services now have to be more selective with the programs that they provide. There needs to be more funding provided to these organisations. Funding needs to be put back to ensure that these programs still run and not create uncertainty, stress and anxiety for the consumer because they are not sure if they will get the NDIS to fund for the program that they want to do and if it will be available to them. By going to a mental health support service activity on almost every day of the week, it gives me something to look forward to. It creates a routine for me. Then once I have a routine, I can then move forward to try other things to create other routines, like going shopping, travelling on public transport, volunteering or going to work. The NDIS has caused acute amount of anxiety and stress. A design by the government that was meant to give people more choice in their services which assists in early treatment as going to programs and activities and Mental Health Support Services supports and provides engagement and assists in supporting someone's day to day living. However it has been met with political red tape. It is stressful to obtain medical reports from doctors and mental health practitioners which has derogative language that doesn't talk about recovery but what you can't do. This causes conflict in recovery which is used in mental health. By been informed by the NDIA that from the information that I provided I don't meet the Early Intervention requirements because the early intervention support I require is more appropriately met through mainstream services. Meaning that the supports I use to receive are no longer accessible to me because they were replaced by the NDIS and were meant to be funded by the NDIS. Also it means that the mental health support services that I use to receive are no longer applicable to me even though I needed them as early treatment and support in the past and still require them now to maintain my mental health. The NDIS fails to identify and understand the complexities of mental illness known to them as psycho-social disabilities. The NDIA has created a gap where I can't access their funding for

supports and early treatment like the mental health nurse incentive scheme which ceased due to the NDIS. As a result I have been in an 8 month review process with no outcome and my case has been escalated because I also can't access other early treatment and support models like the step-care model in my region. I would have to be identified as someone that doesn't qualify for the NDIS today or in the future to be granted access to the step-care model. Due to this clause, I can't access any funding and are relying on a stressed medicare system where 10 sessions for the 12 month period is simply not enough to ensure my needs are met for my mental health. The NDIS needs to take in all cases given that I have a complex physical and mental health issues and what is classified as a disability under the NDIA. The NDIA lack the competency, understanding, compassion and knowledge of what is needed for early treatment and supports for someone that has a psycho-social disability, a person with a lived experience of mental illness. The NDIA need to educate themselves on the complexities of mental health to gain a better understanding how these early supports and treatment assist in someone's functionality in staying well and prevent someone from turning up in the emergency department. It communicates to me that in order to gain access to early treatment, whether it be a treating psychologist, mental health nurse or a mental health support service, I would have to be either declared psychotic or suicidal in order to access funding. The NDIS indicates that I have the capacity in one or more areas, communication, social interaction, learning, mobility, self-care and self-management. However when I become acutely unwell and go through a psychotic episode I can't perform any of these tasks. It is something that the NDIA fail to recognise what incidents and events occur when someone becomes unwell and it doesn't just happen overnight, it happens gradually over time. The NDIA need to review their processes and their judgement on anyone with a psycho-social disability or mental illness because it causes anxiety, fear and a determinant to my mental health and wellbeing as I'm uncertain what services and supports I will have to rely on in the future. Medication has played an integral part in my road to recovery. The medication, including Saphris and Epilim that I am on now means that I can function more normally in society. I can interact and communicate better. However been on medications in the past and present which have included anti-depressants, anti-psychotics and mood stabilisers have interfered with other treatments to my physical health like cortisone injections and have had an adverse effect on my mental health which assisted in spiralling out of control. All treating doctors across both my physical health and mental health need to communicate with each other to ensure that there is not detriment to me when prescribing these medications. I was trialled on over 30 different medications in hospital when I first went through psychosis in 2006 and because I was near catatonic I could not communicate properly what was wrong with me. There needs to be a better way of ascertaining a diagnosis and prescribing medication rather than making someone a human guinea pig of medication to see if something works. At the time my father claimed that doctors were killing me because of all the different medications I was trialled on. It caused acute amount of distress for my father. He felt at the time that he was not been heard and kept a record of all the medications that I had been on to keep track to ensure that I was ok as he had grave concerns over what was happening. I have had adverse side- affects to older medication like risperidone and paliperidone. These included visual impairments, tremors down the right side of my body and my menstrual cycle ceasing. It meant that I could not function properly and impaired my road to recovery. I'm now taking the contraceptive pill for medical reasons to ensure that I have a menstrual cycle and are regular tested to ensure that I have normal levels of prolactin. This has caused me distress and added an additional complication to my existing complications to my physical health. There were other medications out there that I could have been on that would have prevented this however these were not considered at the time I was prescribed risperidone and pailperidone. In hospital for some reason my medical history was not communicated well and I was never placed back on

abilify which was somewhat successful in maintaining my mental illness in the past. It is imperative that communication is made and the medical history comes from treating doctors. I was labelled psychosomatic by hospital staff, that what I was experiencing was paranoia. It wasn't until another patient sprayed something that gave me an allergic reaction that they realised that I had a problem and became anxious and agitated as well as sick. This interfered with my road to recovery as I felt like I wasn't believed in. Medical staff need to be aware of medical conditions that may seem rare and not treat as if it's just in my mind. In early treatment where I was seeing a psychiatrist, unfortunately the traumas in my life of being a flood affected victim, a legal case with the Transport Accident Commission and moving 9 times in 9 months and enduring physical and emotional pain was too much to bear which resulted in attempting suicide during a psychotic episode. I lost some support worker as I became an infrequent user of services. It meant that I was on my own most of the time with family, my ex-boyfriend and my psychiatrist as the supports. This means that other than one external support I was relying on a friendship with family and my ex-boyfriend as a support through these times which provided a burden. If I still had had the support worker from the mental health community support services to check in on me to see if I was ok, it may not have felt as if I was alone. We need more access to supports to have someone check in on me to ensure when I am at a time of being unwell that I have someone to talk to other than family to ensure my safety and mental health. I know we have Brief Intervention Teams these days, something which was not around when I became acutely unwell. There should be early intervention teams as part of early treatment and support to assist before someone becomes unwell. Having a CATT team check up on me assists me in my road to recovery as it ensures that I am taking the right dose of medication and ensure my safety. They are crucial in the road to recovery and also they are there if I ever start to become unwell again. The uncomfortable part was having the CATT team come to my home. Since the staff rotated it meant that I was letting in a stranger every time they came. I would like to see a more routinely roster of staff so you get to see the same group of people. This means that you don't have to retell your story. When you are unwell it's an anxious meeting letting in strangers to your house, even though you know they are medical staff and are not there to harm you."

What is already working well and what can be done better to prevent suicide?

"People attempt suicide because they can't see an answer or a future that will solve their issues. To prevent suicide you need to look at the causes as to why people are dying by suicide. There are a range of reasons. Our lifestyles also play a part where we have an instable cost of living that fluctuates and cause increasingly amount of stress. There are other factors like relationship breakdowns, ill health and many other factors that result in suicide. We need to have programs, support groups in the area. Having intervention teams are helpful because they can assist and provide support at a crucial time when someone is acutely vulnerable. They need to be in each area. The language used by the government is not something that the community in general would understand. It needs to be simplified to language and communication to educate the community on a basic level. There are apps from Beyond Blue and Black Dog Institute that follow your mental health and if you are at risk of suicide. Allows you to put a plan in place of what behaviours to look out for and what actions need to be taken when certain suicidal thoughts or behaviours occur. Men sit at a higher rate of suicide than women yet there is very little supports like all the helplines, which are inundated and there is very little awareness about it. I have recently seen a more growing presence on social media, like facebook about youth mental health. The same should occur for other aspects of mental health and also suicide. Creating awareness about the issues needs to occur, whether that be flyers, social media, websites and community

hubs."

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

"It is a hard to have a good mental health experience when you present in front of Victoria Police, then taken to emergency department, assessed and then placed into an Inpatient Unit. Whilst all my experiences have been positive with Victoria Police, it is still a traumatic experience because I was unwell at the time. The Victoria Police were very respectful, called an ambulance for me, drove me to hospital without handcuffing me and let me ride in the back seat like a normal passenger. There was a sense of care, calmness and duty. I know that not everyone has had the same positive experience that I have had when dealing with Victoria Police. When taken to an emergency department it is hard to have a good experience as there is lots of noise and distractions. To someone that is going through a psychotic episode, the emergency department is not an ideal place to be. It is frightening and traumatic because I am going through a chaotic mindset in a foreign high stimulus environment. It is not until you get passed triage and are in a quieter space that it is less traumatic and intimidating. In an inpatient unit, if I have to share a room with another patient, this can cause distress, conflict and arguments with the other person that I have to share with. Having my own room which likely to occur more these days means that you avoid or minimise conflict with others. Seclusion as a form of treatment is worse than going to jail. It hinders the recovery process. I was given a petri dish as a toilet and four cups of water to stay hydrated. I had one mattress on the floor for a bed and three walls and a heavy door with a twenty by twenty centimetre window to look out of. Occasionally staff would come by to check on me. When I needed to go to the toilet I feared that if I missed the petri dish, I would pee all over the floor which was embarrassing and demoralising to contemplate. I felt I was penalised for been unwell. I had been taken out of a high stimulus environment and placed in a cold low stimulus environment which was a mental shock to me. I was not given food and the main reason I was placed in seclusion was because I kept absconding the ward on at least three occasions. This was not due to my fault as there was poor security at [REDACTED] Psychiatric Hospital Inpatient Units. The fence which was backed onto the main road was the same material and design as a normal household fence to keep all the patients in. Due to poor weather the fence became flexible and as a former gymnast I had the capacity to use the fence like a springboard to escape the ward. Since many patients were absconding the ward due to this it is uncertain whether other patients were placed in seclusion for the same reason I was. Had there been better security I would have not been able to abscond the ward and on one occasion attempt suicide during psychosis. I am aware as I have visited for interviews in recent years that the design of the [REDACTED] Psychiatric Hospital Inpatient Units no longer reside close to the road and are now enclosed away from any roads and traffic. I was not violent or aggressive when placed into seclusion. I believe that we need the basics like a proper bed and toilet. Also staff needs to be with the patient, not just the occasional check in for support. With the first hospitalisation, there were no peer workers such as consumer consultants and carer consultants. This made the experience all the more difficult not just for me but also for my family. Having someone to talk to and be heard is vital for both the consumer like myself and the carer, whether it be my mum or dad. When I had my relapse it made it easier having a peer worker on the ward to talk to. When I was placed on a Temporary Community Treatment Order whilst in hospital I had to face the Mental Health Review Board. Having Victorian Legal Aid represent me took away some of the stress and anxiety in that process. They provided support throughout my hearing. Been able to privately discuss my case with someone meant that Victorian Legal Aid could better articulate my opinions, emotions and state

that I wanted to communicate because I was quite unwell and didn't have the same level of capacity for communication. This service is imperative as they represented me with regards to what I thought my rights were in the community. It is a service that should be accessed to all. PARC (Prevention Acute Recovery Care/Centres) are integral service to step down out of hospital and is a better service than CREST/SHADES that use to exist in the community. With PARC it is like a communal home, you have your own room and a communal area for meals and activities. I learnt basic living skills that I forgot when I was unwell like cooking, cleaning, shopping and going out. PARC has clinicians and support staff so if I have an issue, a bad day or need to ask questions about my medication I can chat to someone. With CREST/SHADES, I was on my own living with another out-patient. Not having support staff around 24/7 meant that it could take days to communicate to support staff of any issues that was occurring. I had to fend for my own. There seemed to be a seamless transition between hospital and the community based clinic like [REDACTED] and [REDACTED] House. I was instantly set up with a Case Manager as soon as I was about to be discharged from hospital. This made the experience of support staff less stressful. Initially in 2006 when I was about to be discharged, support workers from EACH came to hospital to introduce me to their services. This encouraged me to come on board because I got to see what was involved and the type of activities. When I relapsed in 2013 there were walking activities and other activities like tai chi on the ward, yet there were no support workers from places like EACH to link in with services. Services need to be available for those that are about to be discharged so they can interact in community activities with Mental Health Support Services to have support and ensure that they don't go back into isolation. It is difficult to have a good mental health experience when I was going through a legal case with the Transport Accident Commission and was unwell. At the time my ex-boyfriend was liaising with my solicitor which brought in an additional stress. If the case was able to be placed on hold, so I could deal with it when I was well and not straight after I had just come out of hospital after enduring psychosis where I was not in the right mindset. After I was discharged from [REDACTED] Clinic, I was placed in a private doctor's clinic under the Mental Health Nurse Incentive Scheme, which has since ceased due to the NDIS. This service and support provided was an integral part in maintaining my self-care especially when I incurred stresses with the mandatory legal processes with the Transport Accident Commission. My mental health was monitored and my medication was changed to protect me from becoming unwell during this stressful time. By not having the Mental Health Nurse Incentive Scheme it means that there is no support that is free and at regular intervals to monitor my mental health. If I want to get support these days, I either have to find the money to pay upfront for my psychiatrist or find a bulk billing psychologist which are few and far between. We need more bulk billed psychologists so I don't have to try and find the money upfront to pay and then have to wait to be reimbursed by Medicare. Also my intervals with my psychologist is monthly so there is a longer period of time between appointments to monitor my mental health to ensure that I stay well."

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

"There are some communities and locations that are in isolation themselves due to where they are located. There is a lack of services and supports in those regions. There is only one hospital and probably only a handful of services to divide over a vast range of the region so they are stretched more so in rural areas than in city areas. There are certain communities whether it be Aboriginal, LGBTIQ+ and Cultural Linguistic Diversity where mental illness maybe seen as shameful or their recovery may have different meaning and way. "

What are the needs of family members and carers and what can be done better to support them?

"Family members and carers need their voice to be heard. Before Advanced Statements, Nominated Persons and Carer Consultants they had to navigate through a complex system without any or little help. Support Groups are helpful for Carers to get together and share their experiences. Workshops like Wellways Build A Future plays an integral part of educating Carers about mental health. Understanding Mental Illness workshops for the region educates Carers on the Services and supports in the area, there needs to be more of them. Respite for a Carer is needed as they are an unpaid worker. Making the language simpler for them."

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

"Peer workers need to be paid and awarded for their work. They shouldn't be treated as tokenism. Peer Workers need to have a proper position description outlined so they aren't teaching clinicians what their role is about. More education and training is needed along with supervision to retain and better support the mental health workforce. More doctors, psychiatrists and nurses are needed for the over populated hospital system to cope with the needs and demands of patients."

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

"Social participation comes from being able to engage in activities provided by mental health support services where they can engage and feel welcome and then able to go out in the broader community to do things like play sport, exercise, participate in programs or go back to study or work. It's important to provide environments that are non-threatening. Mental Health Support Services are losing programs and some are stepping away from the NDIS as well. We need to keep these programs as opportunities as stepping stones back into the community. Economic participation occurs only when someone feels ready to commit to work whether it be volunteering or paid employment. Volunteering is a good avenue to start the process of economic participation as it can lead to paid work. Also volunteering allows flexibility so if someone is having a bad day, there is less reliance on commitment and fewer penalties. Volunteering acts as a stepping stone into paid work as the individual gets to learn about the working environment, responsibilities, meeting people whilst maintaining flexibility. The workforce needs to allow job-sharing as many people with mental illness are not able to work full time, but can work in some sort of capacity. "

Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

"Seclusion should be phased out. If someone needs to be isolated it should be in their room where they have a proper toilet, bed and have support staff around them in a critical time of need. If someone comes violent then I believe that is when security should be called. Mental Health Professionals shouldn't have to wear it. More staff both Peers Workers as well as Doctors, Nurses and Psychiatrists. Peers workers connect with consumers as they have been through it themselves. To have a peer workforce union to advocate change to the workforce and what is needed for them. More clinicians so you aren't a number. To have the Inpatient Units not to feel so cold and clinical. If I was in a Breast Cancer Centre, it has warm coloured walls, inviting architectural design, artwork painted on the walls. Inpatient Units need more than just a garden. It needs to feel warmer rather than staring at a grey concrete wall. You can still have furniture and

an architectural design suited to the safety measures of a mental health ward that look aesthetically pleasing and more welcoming not only for consumer but for the families and friends that come and visit them. To put funding back into Mental Health Support Services that provide daily activities for the mental health community like art, crafts, cooking, social outings, walking and many more. To educate the NDIS in the totally lack of regard of understanding of what is a psycho-social disability (mental illness)."

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?

"Put back the funding that was taken out of services and treatment schemes like the mental health nurse incentive scheme and mental health community support services. A shift of thinking needs to occur in how patients are treated with regards to seclusion and physical restraint. We need to get away from the primal way of dealing with things to a more humane way of dealing with things. Plans need to be set in place on how to track someone that needs to be alone and away from other patients, but still have the required support and not just a look in every few hours. Give Peer Workers a bigger voice as they hold the key to relating to consumers and carers that are going through this traumatic experience. Provide more training and education, expand the workforce so there is someone in every hospital and outreach/outpatient service or clinic. A bolder move would be to have a peer worker in local General Doctor Practices, so the patient can have someone to talk to and provide early intervention. "

Is there anything else you would like to share with the Royal Commission?

"Communication between medical practitioners and mental health professionals. To ensure that when dealing with someone's mental health and physical health combined that there is little to no interference when dealing with treatments and medications to avoid adverse side-effects and a decline in my mental health. That Mental Health Professionals should be aware of the Transport Accident Commission's processes. I felt like someone was watching me and I reported it to police but it was never followed up. When I was discharged from hospital in 2013, I was repeatedly assured by mental health professionals that no one was watching me or following me. In 2017, my solicitor disclosed photographic evidence and material to prove that I was actually been investigated by the Transport Accident Commission. This angered me because what was considered as a psychosomatic reasoning turned out to have truth in it. As a result I lost confidence and trust in mental health professionals as I was cautious to believe in them if they were telling the truth. It took extra time to regain trust and confidence with mental health professionals and hindered my road to recovery. Also what many family and friends believed to be paranoia was actually truth, which made me very distrustful and paranoid about my environment. It has taken time to trust my social and professional environments again. It is unwise to ask someone that is in a psychotic state to tell mental health professionals the names and phone numbers of their loved ones, family and friends and emergency contacts. I was never in a coherent enough state to memorise all the numbers and names and I am sure I got probably fifty percent wrong. An advanced statement and nominated person provides those details if in the event I go to hospital. I am hoping that we don't have to wait to have another Royal Mental Health Commission to change the mental health system and the community at large. These changes should have already occurred. The next time you have a Royal Mental Health Commission for mental health, it should include a Carer and Consumer Consultant representative from organisations like Tandem and VMIAC. They're the advocating bodies that represent all of us and would understand the stories and language. I thank the Royal Mental Health Commission for

taking on board my suggestions for terms of reference and for changing the language for the online submission form questions. The feedback that I provided was the original questions had language that was too clinical and a consumer wouldn't understand or be able to provide feedback if they didn't understand the questions. I would also like to thank the Royal Commission in taking on board my feedback to have the Royal Mental Health Commission Panel attend at least the consultation that I was present for in Box Hill, I'm not sure if they attended others. I did mention at the Royal Mental Health Commission that I was interested in the hearing but I am unsure who they would select to testify. "