Royal Commission into
Victoria's Mental Health System

Outline of questions we ask as part of the Formal Submission process

We have been asked to consider some important themes relating to Victoria's mental health system.

The 11 questions set out in the formal submission cover those themes. There is no word limit and you can contribute as many times as you like. Attachments are also accepted.

You do not have to respond to all the questions. You can also make a Brief Comment submission if you wish.

To help us focus on the areas that matter most to the Victorian community, the Royal Commission encourages you to put forward any areas or ideas that you consider should be explored further.

You can request anonymity or confidentiality when filling in the cover page, which also allows us to capture details about your age, gender etc.

These are the questions that you will be asked:

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

- Positively, I have found that the public has developed a much greater understanding of generalised anxiety disorder (GAD) and Major depressive disorder (MDD) over the past decade. While this is excellent news and advocates should be congratulated, previous awareness campaigns have primarily focused on moderate severity cases, which are experienced by the majority of patients. This is not necessarily incorrect, is true to the average experience, and is naturally more accessible to the general public due a relatively high commonality in the general publication. However, care must be taken to ensure that public mental health discourse is not to the exclusion of those with more severe cases, who naturally possess a reduced capacity for advocacy when unwell. This reduced capacity for advocacy also extends to their caregivers via to increased caregiving load. It is imperative that common mental disorders such as GAD or MDD are also discussed within the context of how an individual's experience may shift with respect to the severity of their condition, and how this severity directly relates to their capacity to engage with mental health services and broader society. Critically, as severity and clinical risk increase, so do several uncomfortable questions regarding how severe mental illness is managed, such as the dynamics of involuntary treatment and who is ultimately responsible for outpatient and inpatient wellbeing in severe cases (See question 5). These questions currently possess little to no public space for discussion.

- Additionally, I have found the current focus on moderate MDD and GAD cases to be at the expense of other conditions such as bipolar disorder, schizophrenia, and cluster B personality disorders. Those with such conditions may also possess a reduced average capacity for advocacy as a direct result of their specific symptom sets, and the reduced incidence of such conditions in broader society. This is especially true for Borderline personality disorder (BPD), which is routinely and heavily discriminated against in both the public sphere and medical profession. The expansion of awareness campaigns to be inclusive of mental illnesses beyond the commonly experienced GAD and MDD at moderate severity is a natural and fundamental step to further improve the Victorian community's understanding of mental illness.

2. 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?

Mental healthcare plans

Mental healthcare plans are a very useful and widely used resource among my peer group and the peer group of who I provided care for. However, the provision of 10 free visits is often not sufficient to adequately address the core components of most mental illness, and offer no meaningful long term management for conditions where this is a clear clinical requirement (e.g. bipolar disorder, schizophrenia, and relational disorders such as BPD). This promotes consumers neglecting their genuine mental health needs following use of their 10 sessions due to financial burden, typically resulting in deterioration of their mental health. This ultimately places increased and unnecessary burden on acute services via increased crisis situations, resulting in the greater dedication of mental health resources to recover patient wellbeing then what would be required if early intervention was available. This is especially true for those experiencing complex or severe mental illness, who typically have less access to financial resources. Additionally, this 10-session limit dissuades mental health staff from attempting to treat core long term mental health difficulties that may be clinically mandated. An example of this is unresolved trauma- which may necessitate increased acute distress to the patient as component of the treatment process. Mental healthcare plans also do not support the provision of psychiatric consults, which are generally required to effectively manage severe or complex conditions. Increasing the cap on free psychological visits per year and expanding this scheme to include psychiatric consults may prove beneficial for supporting the long-term mental health outcomes of moderate to severe cases and reduce strain on acute services via flow on effects. This could be implemented generally or based on severity, diagnosis, or means testing.

Limited medium to high severity outpatient services

Public outpatient mental health services dedicated to managing severe and complex cases such as Orygen Youth health (OYH) have proved extremely valuable for who I have provided care for. The integration of this service with Headspace (which openly states that they are not designed or capable of providing care to high risk or complex cases and have offered no meaningful help to myself or who I provided care for) have proved invaluable in supporting 'the missing middle' of mental healthcare. I have no doubt that without this space being filled by OYH, who I provided care for would not be alive today. The integration of OYH with headspace centres also allows for clients to be referred between the two services- An invaluable measure to promote appropriate service dedication for clients presenting at either institute. Further expansion of outpatient programs dedicated to support severe cases are a vital necessity to prevent those with severe conditions deteriorating the point of crisis. I strongly support the Labour party's commitment to the 'Headspace Plus' initiative as a component of their 2019 federal election campaign, which directly addresses this lack of services for severe mental health cases. Please note that I have found that there is currently an abundance of low care and early intervention support services. As such, I would find additional funding for low care services welcome but non-urgent. However, given that I am a former carer of a high risk and complex patient living in a metropolitan area, my perspective may not be applicable for all communities.

In our case, the case management model at OYH has proved very effective and allowed for the integration of acute inpatient admissions, outpatient services, the promotion and monitoring of lifestyle factors supportive of good mental health (e.g. secure hosing, jobseeker programs for those experiencing disadvantage, physical health support). In my opinion, this has resulted in much more effective long-term outcomes for who I provided care for. Expansion of this healthcare model which addresses common social factors affecting mental health and maintains continuity of care during inpatient admissions is likely to prove ultimately more effective for moderate to severe cases and reduce overall strain on the acute system.

Variations in private and public models of inpatient care

It is very important to recognise that public and private inpatient units currently operate offer varying models of mental healthcare, which greatly affects how they interact with patients and conceptualise their role within the healthcare system. Private hospitals such as [redacted] typically utilise a welfare model of mental healthcare- favouring early inpatient interventions for patients in declining but non-critical states. Such admission typically are very low care, restrict patient intake to simple cases, and are completely exclusionary of involuntary patients (the latter enforced via internal policies). This is in sharp contest with the public inpatient units, which typically only admit under crisis circumstances and favour quick admissions focusing solely on crisis containment before discharging to outpatient teams, with little regard to long term support. As I have found the early intervention and welfare model to only be present within the private sector, this therapeutic tool is currently only accessible for those with substantial private health insurance and is otherwise entirely cost prohibitive (In our case, a 3 week stay at the [redacted] inpatient unit was priced at $17,273). Individuals managing severe or complex mental illness are far more likely to have limited incomes or be in financial distress and are thus far less likely to posses private health insurance. Additionally, the social support networks of those with severe or complex illness are also more likely to have reduced financial resources to assist the patients obtaining private health insurance or paying out of pocket if required. This due to the fact that most mental illness intergenerationally propagate through families, often leading to carers stretching their resources across multiple individuals. Additionally, the carer role often requires carers to pay out of pocket for other associated medical costs and reduce their work commitments, directly reducing carer disposable income and overall carer career prospects (See question 5 for further discussion). These factors lead to the systemic exclusion of those with complex or severe mental illness from welfare models of hospitalisation due to their limited financial resources, regardless of their potential clinical utility. Implementing programs to allow public patients access to such private hospitals (or limited duplication of this model within the public sector) may prove a useful early intervention for public patients who may be experiencing a deteriorating mental health condition but do not require immediate presentation to an emergency department.

3. **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**.

Current Stigma exhibited by frontline mental health staff

Frontline healthcare workers such as paramedics, police, and emergency department personnel frequently exhibit stigmatising, dismissive and belittling attitudes towards patients with mental illness. This is especially true for cluster B Personality disorders such as BPD. It has been my experience that those with BPD endure significantly worse stigma then other mental disorders I have had personal experiences with, such as Bipolar disorder or MDD. Neglect towards those with BPD is unfortunately commonplace in emergency settings, and typically extends to outright refusal of service or admission, regardless of suicide risk or acute psychological distress. This is despite estimations that approximately 80% of individuals with BPD report a history of suicide attempts, and 8-10% of indervidicuals with BPD die due to suicide. This represents one of the highest suicide rates of all mental illnesses. Anecdotally, my past long term General Practitioner has told me that she rarely to never diagnoses individuals with BPD regardless of presentation or symptoms, as she believes this not to be in their best interest due to current stigma present in the medical community. This ultimately dissuades those with mental illness presenting to medical personal during critical crisis periods, resulting in denial of critical medical care for a highly vulnerable group in our community. Further education and awareness campaigns directed at frontline healthcare workers is therefore paramount. It would likely also be beneficial to seek the input of such workers to identify if they are currently facing professional hurdles impacting their capacity to manage mental illness cases.

Mental Health services and poor inpatient admission processes

While it is very important to involve patients in decisions regarding their own care, patients in contact with emergency services are typically in a very acute state, it is not always appropriate to expect them to advocate in their own interest or to the best of their capacity. This is especially true if they have presented primarily on the advice of their family or friend due to symptoms that typically occur with a lack of personal insight (e.g. a Manic episode). The burden to ensure immediate best care should therefore fall primarily on frontline workers (who possess significant training and asymmetrical knowledge of the healthcare system) and carers (who are best incentivised to ensure that best care takes place). While this currently occurs to a limited extent, carers are typically only engaged in a superficial fashion and lack any mechanisms for contesting questionable clinical decisions. This currently places crisis decisions between hands of the patient and frontline workers. This initially appears as a positive and inclusive policy, however emergency services possess significant inherent power over patients (e.g. the provision or withholding of physical and mental healthcare, the involuntary or voluntary status of the patient, ensuring safety from other patients, significant variation in societal legitimacy between the healthcare institution and the patient, and the capacity for patients to think clearly without concurrently managing an acute mental illness.) Carers currently lack any tools to counteract this power imbalance. This places patients in an extremely vulnerable position, and often results in services prioritising their institutional incentives over best care of the patient. For instance, I have found emergency department and psychiatric unit personal typically turn away mental health cases by default and promote patient discharge regardless of patient safety or severity of illness. I believe that such behaviour is unfortunately commonplace due to hospitals natural incentive to free resources and reduce overhead costs, which is often in direct conflict with the best interest of the patient. It is imperative that carers be provided with additional tools to counteract such incentives, such as the legal capacity to request a second opinion regarding if an admission or discharge is in the best interest of the patient.

- <u>One Personal Anecdote (non-exhaustive)</u>
  In late 2018 I presented to the [redacted] emergency department with who I cared for in severe distress. Who I cared for has long term suicidal ideation and a proven capacity to carry out planned and highly lethal suicide attempts. Upon arriving we were kept overnight in the emergency department, where sleep was impossible. No food was provided. Over the course of the evening (6pm-4am) we received approximately 6 consultations. In each consultation who I cared for, who has been clinically diagnosed with GAD and experiences severe disassociation (which directly hamper an individual's capacity to understand their immediate environment, communicate, and disagree with others), was placed under very large pressure from staff to agree that she was safe to go home. Staff attempted to sideline myself as much as possible, with my input only in the form of interjections. Only after the 6th consult, at approximately 4am, without food, water, sleep, and following a very large degree of advocacy from myself, was who I cared for allocated a bed in the hospital. Having the same statement repeated at you "You could be safe to go home though" (Paraphrased) over a 6-hour period while in a vulnerable mental state and without food, water, or sleep is not performing genuine consultation or risk assessment, but a deliberate coercive strategy to prevent admission regardless of need. I believe that similar cases would have been rapidly discharged without a carer present, resulting in very serious risk to life. 2 days following admission, who I cared for was discharged from the RMH despite expressing concerns for her safety, under the ultimatum that she be collected by myself or be discharged unaccompanied and asked to catch a tram home. She was readmitted to an emergency department within 1 week following a serious suicide attempt.

Mental Health Services and poor discharge planning

I have found that healthcare services possess extremely limited accountability regarding patient welfare in the immediate post discharge period. Patients readmitting to emergency departments due to suicide attempts within a few days of discharge appears to initiate no formal or informal review procedures regarding if discharge was appropriate. This results in little incentive for mental health units to act in the best interests of patients during discharge planning and promotes the prioritisation of other incentives, such as freeing up immediate resources. The implementation of additional key performance indicators for wards relating to post discharge outcomes (e.g. readmission within 2 weeks, attempted suicides) may prove beneficial in ensuring that discharge planning is in the best interest of the patient. Guidelines regarding such indicators could be set by leading professionals to allow appropriate latitude for clinically mandated risk. Failure to meet KPI standards could result in external review procedures against specific wards or healthcare providers, or be directly linked to public funding outcomes.

It is currently very common for nominated persons and carers to be completely excluded in discharge planning, as this typically viewed a clinical decision beyond the scope of family and friends. However, carers are currently responsible for ensuring that appropriate safety planning and supports are in place for the patient post discharge. Given that patient suicide risk is the greatest within 2 weeks post discharge, this is a critical function of the Victorian mental health carer. As such, it is inappropriate to conceptualise discharge as a solely clinical decision to be made by the treating team. Currently, discharge information is typically provided to carers within 24-48 hours of discharge occurring. This limited notice often creates major logistical problems that can result in recently discharged patients being inappropriately left alone in very high-risk states. As such, it is imperative that mental health services consult with carers to reasonably incorporate the logistical needs of the patient's social support system (e.g. work commitments) as a standard component of discharge planning. Given the incentives of health services to discharge patients as quickly as safely possible, I would suggest that recognised carers and nominated persons be provided a limited legal capacity to extend discharge by up to 24 hours, if proof can be provided that not doing so would negatively impact the support provided to the patient upon discharge.

Compulsory Treatment

The nature of Victorian compulsory treatment

Mental health services currently possess the capacity to legally detain patients immediately and without consent via issuing assessment orders, temporary treatment orders, and treatment orders. The existence of such processes an unfortunately necessary to maintain the welfare of patients at serious risk of harm and unlikely to act in their own interest. However, such practices are inherently dangerous and deepen the power differentials between healthcare services and patients. Under compulsory treatment, patients are entirely reliant on their service to provide them with basic necessities such as food, water, warmth, and safety from other patients. Compulsory patients are also typically kept in locked psychiatric units inaccessible to the public, some of which restrict mobile phone usage. This deeply isolates patients from their carer and social support network. Critically, patients under compulsory orders are also likely to be in a compromised mental state, and likely posses a reduced capacity for self advocation and limited social legitimacy relative healthcare providers. These conditions are ideal for human rights abuses to take place. I have found the tribunal system associated with long term compulsory treatment to be a ridged and effective mechanism to support patient rights. However, I have found short term compulsory treatment associated with assessment orders and temporary treatment orders to be highly arbitrary and frequently associated with patient right violations. Expecting mental health services to willingly address patient right violations (and therefore admit that they have occurred) is a direct expectation for the service to act against its own incentives to protect its reputation, and invites misbehaviour from healthcare staff. It is essential that the role of the nominated person is respected and that they are provided with the appropriate tools and legal capacities to counteract this power differential, ensure that the rights and wishes of compulsory patients are maintained, and act as a systemic safeguard against human rights abuses.

Current involvement of nominated persons in compulsory treatment.

As a nominated person I have found myself frequently and actively excluded from key clinical decisions regarding the compulsory treatment of who I provided care for. This has made it exceptionally difficult for me to effectively fulfil my role as their advocate while they were under a compulsory order.
Assessment orders and temporary treatment orders were frequently issued and revoked without any attempt to seek my input or inform me. Copies of the orders were frequently not provided to either myself or who I provided cared for, in violation of the mental health act. On one occasion, no statement of rights was provided to either myself of who I cared for upon the issue of an assessment order, in violation of the mental health act. On one occasion, neither myself or who I cared for were informed that an assessment order had been made, in violation of the mental health act. On one occasion, neither myself or who I cared for were informed that a temporary treatment order had been revoked, in violation of the mental health act. All of the above complaints took place approximately within the past 6 months.

- **Personal anecdote regarding poor compulsory treatment.**
  Following transfer of who I provided care for (under a temporary treatment order at the time), to the [redacted] we were immediately separated without warning upon arrival by approximately 6 armed guards. She was then surrounded by multiple healthcare staff and the 6 guards in a small room, causing serious and unnecessary distress. It is important to note that she did not have any violent history and was previously admitted and discharged from the unit without incident. It was suggested by staff that I leave the hospital, and upon who I cared for asking for me, she was told that I had voluntarily gone home and she 'should not contact me, give me a break for a while'(paraphrased). Who I cared for was then placed in the high dependency area of the unit and was not provided with sanitary products. Upon asking for sanitary products, she was informed in a highly unpleasant and demeaning manner that she would need to contact a male nurse for each individual product throughout the day, and change products via a bathroom door without a lock (with approximately 10 older, mentally unwell male patients in the adjacent room). Her following request for a staff member to stand outside the bathroom door while this occurs was denied. In the evening, she requested an extra blanket multiple times due to being very cold. This request was ignored. While in the High dependency area, she was directed to spend her the time sitting with a large group of older, unknown men, despite possessing a significant sexual and physical abuse history by older men. I believe the ward to have been aware of this significant trauma history. For the entirety of her stay within the high dependency area, she was significantly harassed by another patient (attempting to engage with her approximately every 10 minutes). Upon informing nursing staff, no action was taken, and harassment continued until she was removed from the High dependency area. She was not provided with her mobile phone within the high dependency area despite her requests, and despite most patients possessing mobile phones within the high dependency area. This prevented her from being able to contact me (her nominated person, which was also known to staff) and discuss her concerns as they were occurring. She did not feel comfortable requesting to contact me via a hospital phone, as a such requests were openly viewed very negatively by nursing staff and a staff member would stand over her during the entirety of the call. Under such circumstances, it is not reasonable to expect any acutely unwell patient with an anxiety disorder to express concerns regarding their care to their nominated person. Meaningful contact with myself only occurred in the high dependency area due to my quick return to the ward following our separation, where I frequently requested in-person visits due to the unwillingness of the ward to provide her with her mobile phone.

  Once moved from the high dependency to the low dependency area of the unit, she was sporadically unable to be receive PRN anxiety medication for up to an hour due to frequently misplaced pharmacy charts. She was openly blamed for this problem, with staff citing that medications would not be necessary if she 'tried better coping strategies'. Provided meals were frequently not vegetarian appropriate, despite this information being provided prior by myself once and herself twice. This also resulting in significant bullying from nursing staff, with the staff accusing her of not providing such information food had already arrived to seek attention. Due to a combination of her anxiety disorder and the bullish nature of the nursing staff, she become too frightened to ask for any medication or aid beyond this point. Any dialogue I attempted to initiate with nursing staff relating to her needs resulted in extreme frustration and anger directed towards myself and her. In one case, this resulted in her being ordered into a small room alone with 3 nursing staff. My understanding is that she was then verbally assaulted by the nurses, who emphases that it was highly inappropriate it was for me to express concerns regarding her care, convey requests on her behalf, or to be present on the ward any longer. This statement is a summery and is non-exhaustive.

  3 days following admission, we were told by a member of the nursing staff that her treatment order has been revoked (>24hours prior and without consultation or informing either the patient or myself). We were then then told a few hours later discharge planning would be for the next morning.

The (uncomfortable) role of carers in maintaining living memory

One of the most critical roles of carers is their capacity to bear witness to malpractice and human rights abuses, particularly in involuntary settings that sit beyond the public sphere and have the capacity to restrict patient communication. One critical and poorly acknowledged need for carers to pose a watchdog role against services is that exacerbation of many mental illnesses is significantly associated with the reduced capacity to process and store memories. Additionally, many medications frequently used in inpatient units significantly promote amnesia (such as diazepam, lorazepam, and many antipsychotics). This raises the highly uncomfortable and poorly acknowledged reality that some inpatients may not possess the capacity to self-advocate as they are unlikely to recall if abuse has taken place.

While acknowledging the substantial practical and ethical difficulties of carers advocating and pursuing violations that patients may not recall, processes for nominated persons to submit complaints against services confidentially and without involving patients may be warranted. Such complaints may assist the Mental Health Complaints Commission to identify specific areas of the mental health system where abuses are more likely to take place. The confidential nature of such processes is key to allow carers to maintain effective working relationships with healthcare staff and to preserve the caregiving relationship.

Law enforcement and use of force.

Who I cared for has reported being handled with unnecessary force by police following her absconsion from a psychiatric unit on multiple occasions. Force has been to the degree of causing physical pain. Concerningly, she reports that this has only occurred after handcuffs have been used and resistance has ceased. It is interesting to note that this is not the typical behaviour of sergeants, who consistently have demonstrated understanding attitudes and intervene to control the behaviour of lower ranked police members. Additional mental health training to low ranking members of the police force may prove beneficial.

Law enforcement not currently linked to health services

Please see ‘Confidential- Law enforcement and health services’ attachment regarding this topic. Please note that this attachment is to be regarded as **private and confidential** for the purposes of the royal commission.

4. <u>What are the needs of family members and carers and what can be done better to support them?</u>

Who are carers?

A carer is typically conceptualised as any member of the public providing support to someone experiencing mental illness. The emergence of carers are a natural product of the social support structure of an unwell individual mobilising to the perceived need to support of that individual in a community setting, and often draws upon the close friends and families of the individual. It is critically important to note that modern mental health carers are often not the traditional carers of unwell individuals, as mental illnesses are often associated with and promote the degradation of traditional family structures. As such, it is critical that services do not assume that the carers are or should be a biological parent, as this is only true is approximately 50% of cases and may delay or prevent effective coordination between carers and the service. This has been a chronic problem for myself and who I provided care for, despite my role as carer being actively endorsed by the patient via my establishment as their nominated person.

The unique, inherent strengths of mental health carers

The fact that carers are directly drawn from a patient’s social support structure results in both the greatest strengths and weaknesses of the carer community. These strengths and weaknesses must be actively acknowledged when determining which roles carers may reasonably fulfil in the current and future Victorian mental health systems. Carers have typically known patients for an extended period and possess extensive knowledge regarding the patient's habits and personality. This context often provides carers with the capacity to asses a patient's mental state as (or more) effectively then mental health personal, especially if the consumer enters a novel clinical environment. Further integration of clinical assessments incorporating the views of carers is likely to positively impact the accuracy of assessments and improve patient outcomes.

Additionally, the social proximity of carers with patients in the community allow for much more frequent monitoring then what can reasonably be expected of outpatient mental health services. This is especially relevant for high risk and recently discharged patients. Open dialogue between mental health services and carers provides an indirect mechanism for clinical teams to maintain close monitoring of high-risk cases in the community that otherwise may necessitate hospitalisation. The close personal relationship between patient and carer is also often associated with in a great degree of trust, which may at times supersede those of healthcare services. This trust can be used to promote engagement with services or treatment methods if required. Additionally, this trust is often the result of the patient perceiving the carer to act in the patients interests and understanding that they hold a genuine emotional investment in the patient's wellbeing. As previously discussed, this emotional investment strongly aligns the incentives of carers and patients, allowing carers to fill an advocacy and watchdog role on behalf of patients in the Victorian mental health system should the patient's judgement or capacity become compromised. As the inherent strengths and defacto role of carers typically arise as an intrinsic component of their social relation to the patients, such strengths are inherently unable to be transferred to services via policy changes, and the existence of carers is unlikely to change. Therefore, recognising the current role of carers in the mental health system and supporting their effective integration is essential to allow their unique strengths to be more effectively utilised and for their weaknesses to be supported.

Inherent flaws in the Community care model- Impacts on carers and patient care

The community care model is central to the modern Victorian mental health system, and primarily posits that it is preferential for mental illness to be managed outside hospital settings (i.e. in the community) if possible. This model has arisen primarily out of increased awareness of problems associated with long term inpatient admissions, such as institutionalisation and the degradation of the patients social support network. Unfortunately, the medical community is yet to acknowledge that the simple consequence of discharging patients from clinical settings is to effectively promote their admission into alternative settings, and to consequently expect care to arise in such settings regardless of capacity or consent. If mental health professionals continue to discharge medium and high-risk patients into 'community care', then they are discharging the day to day management and care of that individual to that community. Additionally, the decision for dedicated health services to discharge to 'the community' is also the decision to discharge all risk and responsibility for the patient to 'the community', who lack any funding or expertise. This contradiction of the community care model, where 'the community' is considered to be the preferred medical environment for patients, without considering 'the community' or its component carers to be a legitimate and active component of the mental health system is what I believe to be the single most fundamental flaw of the current mental healthcare system. This contradiction leads to extremely limited provision of outpatient services for patients and simultaneously robs carers of essential support required to manage patients on behalf of services in medium to high risk settings, resulting in a major lapse in care. Given the well documented disadvantages of extended inpatient admissions and natural advantages of carers to provide support to patients within community settings, I would recommend further measures to empower and equip carers to carry out their essential defacto role in the current mental health system. While this may not always be in the best interests of carer wellbeing, I believe this to be typically in the best interest of long-term patient outcomes.

Carers as community care coordinators

Currently, one major function of carers is to act as community case managers. The natural capacity for carers to be in relatively frequent contact with patients naturally allows for frequent, informal risk assessments to take place at much shorter intervals then what could be reasonably be expected of outpatient services. This allows carers to quickly respond to patients exhibiting rapidly changing or high risk, and to convey pertinent information to healthcare services. Additionally, primary carers may act to coordinate the efforts of a patient's broader social support network, which may not be in direct contact with the patients' health service and periodically experience lapses in communication from the patient as a natural component of the patient's illness. Depending on illness severity, it may also fall on carers to manage day to day activities on behalf of the patient, such as scheduling and tracking appointments or ensuring medication compliance.

The social proximity of carers to patients also places them at high risk of becoming the first interval present for suicide attempts, self harm injuries and other mental health crisis. This results a defacto burden for carers to coordinate frontline services such as paramedics or emergency departments, and to provide basic first aid prior to emergency department or paramedical arrival. As such, I believe that it is fair to consider mental health carers as typically the true 'first responders' for a significant proportion of critical crisis events. As this intrinsically arises due to the social interconnectedness between carer and patient, this is unlikely to be affected by policy changes. To facilitate carers responding effectively to such scenarios, I would strongly recommend the dedication of public funds to run free short courses for mental health carers, focusing on first aid, mental health literacy and conflict resolution skills. Additionally, I would suggest that subsidised counselling become available for carers if required if such a crisis event takes place.

Carers in admissions and discharges

In addition to the directly supporting patients, carers play a major role in patient advocacy within the broader mental health system. As previously discussed in question 1, carers must be provided with greater tools to advocate for the best interests of patients in areas relating to hospital admission, discharge, and during periods of involuntary treatment to ensure that the best interests of the patient are met. Relating inpatient admissions with the community care model, the presentation of patients and carers presenting to emergency departments must seen as an implicit declaration by 'the community' that safe or effective care can no longer be maintained in a community setting.

Carers maintaining Continuity of care between inpatient and outpatient services

Personally, I have found handover between mental health services to be inaccurate, incomplete, or not to take place. This has frequently led to major lapses in care following transfer inpatient units (inaccurate medications, allergies and intolerances becoming unknown, Suicide and self-harm risk becoming unknown). To counteract this, I have found it vital to collate my own medical records and aggressively engage the staff of new units to ensure clinically relevant information remains present and correct. In public inpatient units, patients are typically offered minimal group programs and lack processes to keep patients in contact with their regular outpatient team. This is especially true for high risk patients, who may lack unescorted leave privileges. To counteract this, I have found it necessary to visit who I cared for (who frequently lacked unescorted leave privileges) multiple times a week, to minimise their social isolation and allow them any time off the inpatient unit. Additionally, I have found it necessary to visit inpatient units to shuttle who I cared for to appointments with their outpatient team, despite both the unit and outpatient team operating under the same the mental health service (OYH). This is typical, as public outpatient and inpatient teams are usually geographically isolated, and minimal processes are in place to ensure contact with a patient's outpatient team after an inpatient admission takes place, breaking continuity of care. In planning future mental health services, I would strongly recommend housing outpatient and inpatient services within the same facility in order to minimise logistical difficulties maintaining contact with the patient's outpatient team, who typically know the patient better then inpatient staff. This will also act to reducing the current carer burden to provide services with support to shuttle patients between sites under supervision.

The cost of mental health caregiving

The current burden for carers in the modern mental health system is extreme and often poorly acknowledged by broader society. Currently, labour associated with caregiving is not traditionally considered a legitimate form of work but as a natural extension of an individual's personal relationship with the patient during a period of crisis. However, carer relationships are often long term and lead to serious degradation of the carer's personal life and wellbeing. In my case, providing care has often required a time commitment in excess of 20 hours per week. This was in addition to working full time, which has significantly impacted my physical wellbeing. In many cases, I am aware of carers that have been forced to reduce their professional commitments to provide additional caregiving support, resulting in significant financial hardship and stunted Career progression. A fortnightly $100 government allowance is currently offered to carers; however, this is often insufficient to offset the direct costs of caregiving (e.g. medications and fuel) and does not address lost professional income. The demands of caregiving places carers at risk of long-term unemployment and unable to undertake higher education, placing this group at risk of significant social disadvantage. Additionally, there are currently no frameworks to test or recognise the clinical skills obtained by carers in the course of their role, preventing them from applying their lived experience in future professional roles.

The heavy time commitment of caregiving also often results in carers becoming isolated from their own support networks. Compounded by serious psychological stress, this places carers at risk of developing their own mental illnesses. For example, a study at Deakin University found that 65% of carers exibit some form of clinical depression, with 40 per cent of carers were estimated to fall in the "severe" to "extremely severe" range. This study also found carers to have the lowest level of wellbeing of any demographic the group has investigated (R. Cummin, A. Tomyn 2017). It is imperative that further carer relief services are developed in order to maintain the wellbeing of carers and support their capacity to provide care long term.

5. 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?

Current attitudes of Job providers

Job providers associated with Newstart allowance widely possess dismissive, belittling, and bullying attitudes towards clients. This is supported through my past personal experience, my experience as a mental health caregiver, and via my experience working for [redacted] (where I supervise work for the doll participants on a daily basis). It is important to note that those accessing Newstart payments are at an increased likelihood of possessing a mental illness, and that this attitude is likely to compound feelings of shame, guilt and helplessness. This culture often causes maintained contact with such services to be very difficult and distressing, promoting clients to fail meeting their mutual obligations and attend obligatory appointments. This results in cessation of payments, compounding mental distress and creating a vicious cycle of disengagement that places clients at risk of severe financial difficulty and homelessness. Targeted mental illness training for job providers may aid in reducing sigma and shame felt by clients, who have a legitimate right to request Newstart payments under current legislation and may lack capacity to clearly express their needs and self-advocate due to their ongoing medical conditions. A more rigorous complaints system should also be integrated to ensure that job providers are incentivised to provide adequate support and accessibility in line with their own mutual obligations to clients. Such a system should also be accessible by carers, in the case that the client is unable to adequately self-advocate in a timely manner.

Advantages of dedicated employment services

Additionally, I would recommend the provision of dedicated employment services for those managing long term mental illness, with an emphasis on case management. Such services should have the capacity to communicate directly to employers regarding their clients changing needs and in response to recovery or exacerbation of their condition. This is important as many clients often find secure employment only to experience an exacerbation in their mental illness, where they subsequently lose the capacity to communicate effectively with their employer (due to anxiety, psychosis, mania, ext) and subsequently return to unemployment. This has proved a major problem for who I personally care for. Currently this niche filled by disability employment services. However, accessing such services is very difficult, requires a range of varying appointments and assessments, and in our case, took approximately 2 months to obtain. Their also appears to be a major disconnect between Centerlink and disability employment services, which has resulted in many wasted appointments due to miscommunications between departments (the wrong appointment type being booked by one service or the other, specialist staff for assessments not being available despite bookings weeks in advance). Without carer intervention, I would judge such services to be a practical impossibility for those with a serious mental illness given the current range of hurdles. It is imperative that access such services be streamlined for accessibility, and if possible, directly linked to acute and outpatient mental health services as a natural progression of continuity of care.

6. 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?

- Further education for healthcare staff regarding Cluster B personality disorders to reduce the current bullying, exclusionary, and highly counterproductive culture, and to limit unintentional miscommunication perceived as noncompliance.

- Major improvements in outpatient services available for those with severe and complex mental illnesses (addressing 'the missing middle').

- Increased integration between mental health services and other public services, such as police and social services (housing, employment services).

- Increased recognition for the role of carers in mediating effective community care and an increased carer involvement in admission and discharge planning.

- Increased involvement of Nominated persons and carers regarding involuntary patients, especially in areas regarding duty of care and maintenance of human rights.