Formal Submission to the Royal Commission into Victoria's Mental Health System

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In summary

In Victoria, thousands of people are forced to comply with Community Treatment Orders (CTOs) which is mostly about having to take medication against their will. CTOs were introduced in Victoria under the Mental Health Act 1986 and until recently Victoria was identified as having one of the highest rates of CTO use in the world, with 98.8 per 100,000 population compared, for example, to 30.2 per 100,000 population in Tasmania and 46.4 per 100,000 in NSW (Light, 2012). In her most recent analysis of the data available, Edwina Light has now found that rates of CTO use in Australia range from 40.0 per 100,000 population (in Western Australia) to 112.5 per 100,000 (in South Australia) and some apparent good news is that, since the last national survey in 2012, the rates of people subject to CTOs fell in Victoria to 76.4 per 100,000. However, this still remains one of the highest rates in Australia and the rate of use of CTOs in Australia overall remains at the highest in the world (Light, 2019).

There are doubts about the clinical efficacy of CTOs and the evidence about their effectiveness from both qualitative and quantitative research is consistently mixed and does not appear to be the main driver of practice or policy change (Brophy, Ryan and Weller, 2018). CTOs may be encouraging an increased reliance on coercion to achieve compliance with treatment, and sometimes appear to be being used to facilitate access to necessary care and treatment without due consideration being given to the potential harm associated with compulsory treatment and the human rights implications. The Convention on the Rights of Persons with Disabilities has raised the stakes on the human rights credentials of CTOs. Non-coercive alternatives such as decision-making supports and improvements in treatment and service provision must be explored (Brophy et al, 2019).

I have been concerned about this situation for many years. My PhD research focused on CTOs and my first publication regarding CTOs was in 2003 (Brophy & McDermott, 2003) and my most recent was in 2019 (Brophy, Kokanovic, Flore, McSherry & Herrman, 2019). representing a 16-year history of publishing research activity related to CTOs.

What drives my concern and interest in what is happening to people on CTOs? The answer lies in a number of important issues that I have observed. Initially it was through my own work experience – I commenced working as a social worker in mental health services in 1985 and I was working in services when CTOs started to become increasingly commonplace, especially during the mid-1990s when there was a surge in their use as Victoria's long stay psychiatric hospitals closed. I could see that this had significant human rights implications and also that, as CTOs were becoming more entrenched, there was increased reliance on

these orders and this was having an impact on individuals subjected to CTOs, and their families and others supporters. I also started to observe that CTOs were having an impact on the skills and practices of staff, and on the mental health system itself.

Subsequently my experience with CTOs has been located in what I have been learning through research and also my ongoing experience as a community member, initially of the Mental Health Review Board in Victoria, and subsequently on Victoria's Mental Health Tribunal. Thus my submission draws on this range of experience. While I do not claim to be totally opposed to CTOs (and that would be inauthentic considering the reality that on the Tribunal I am involved in making CTOs) I have no doubt that CTOs are overused in Victoria and that the detrimental impact of the overuse of CTOs is all too often minimised and underestimated. I believe we need to prioritise the needs of people on CTOs and ensure they receive the quality of care that is commensurate with the rights they are forced to sacrifice (otherwise known as reciprocity).

CTOs are controversial in several respects. They are often identified as being incompatible with the shift to recovery-oriented practice and the expectations of Article 12 of the UN Convention on the rights of persons with disabilities (CRPD). They lead to a restriction of human rights, including the rights to liberty and physical and mental integrity sometimes over many years (Brophy et al 2019 p.2). There is a poverty of evidence that CTOs are effective in relation to a range of measures (Brophy, Ryan and Weller, 2018; Rugkasa, 2016) and – even when some attempt has been made to establish that CTOs are working at perhaps keeping people out of hospital (the most common outcome measure) – there are doubts about whether results from studies undertaken in different jurisdictions are generalisable because of differences in legislation and how CTOs are implemented.

Something commonly observed about CTOs in a range of jurisdictions is that they are associated with a net widening effect. Once they're introduced, the use of CTOs expands beyond the classic high needs group of people with complex needs who are frequently requiring admission to hospital. It is now relatively common for people with, for example, first episode psychosis patients and women who do not have the clinical features typical of the stereotypical patient on a CTO, to be on CTOs and there is evidence that this is happening in Victoria (Morandi, 2016: Brophy, Reece and McDermott, 2006).

This relates to the evidence that there is a 'lobster pot' effect with CTOs – it's easy to get in but much harder to get out. So if you're doing well – it must be the CTO – if you aren't doing so well – you will be kept on the CTO regardless (Morandi, 2016). Thus the exit doors are hard to find unless there is a persistent commitment to moving people to less restrictive care. This might account for why there is a gradual build-up of the numbers of people on CTOs in jurisdictions over time. Furthermore, other studies, both in Victoria and elsewhere, suggest that CTOs are increasingly being used to facilitate continuity of care and fill other systemic gaps (Light et al, 2016; Brophy et al 2019). In Brophy et al (2019) this was identified by participants and the following quotes illustrate this situation:

> *The consultant [psychiatrist] had very strong, you know, views … everyone went out [of hospital] on a treatment order. Everyone … pretty much … who came in with a psychotic type illness. In, out on a treatment order because that way they'd get community follow up (*[redacted] *Psychiatrist).(p.5)*

> *They say, oh well if they weren't on an order, MST [the Mobile support and treatment team] probably wouldn't … keep them on their books because they only take the most severe people. But that's like totally putting the cart before the horse, you know … Like surely the whole point of MST is to get people to a point where they can be self-determining and autonomous and make their own decisions. It's really—you know,why, why, why should you need to be on an order to get a service, that doesn't make any sense ([redacted] Psychiatrist).(p. 5).*

Overall, CTOs have promised so much but delivered very little. Looking closely at the OCTET trial in the UK that tried to establish the effectiveness of CTOs - it is apparent that there were staff trying very hard to provide good care – hoping that this would be enhanced by adding a CTO, but it appears that mostly a CTO made little difference to the consumers care or outcomes. The clinicians are then left to decide whether a slight increase in contact with services (one of the only significant findings) justifies the extra coercion a CTO involves (Burns, Rugkasa et al 2013).

However, despite problems in obtaining gold standard evidence for CTOs, many in Victoria's mental health system think CTOs are working and will guarantee ongoing community care and follow up. It appears that there are fears of take the risk of not implementing a CTO because the person will relapse –that's considered bad for them and their families and other supporters and places extra pressure on the mental health system due to the need for crisis intervention and inpatient beds. Indeed it appears that the pressures on the system partially account for why we have CTOs and why – even under the pressure of the weakness of the evidence regarding their effectiveness and the strengthening of evidence that they are doing harm - we, until now, have persisted with them.

Pat Bracken and 28 colleagues from around the world have all agreed that psychiatry needs to embrace the evidence that personally meaningful recovery from serious mental disorder is not necessarily related to the specific treatments that are prescribed (Bracken et al, 2012). Alternatively, research supports the importance of the therapeutic alliance and the importance of enhancing people's self-esteem and an 'internal locus of control' in determining outcomes. We need a therapeutic context that promotes empowerment and connectedness and that helps rebuild a positive self-identity. Dramatically scaling back the use of coercion, including CTOs, has to be part of these improvements in practice. Furthermore the CRPD requires countries that are signatories – including Australia - to reduce the use of coercion and substitute decision making.

Considering the lack of evidence, and the social justice and human rights issues raised by CTOs, it is now time to turn our attention in Victoria to innovation and developing approaches to care that are more attractive and engaging, with a more established evidence base. These supports and interventions also need to be compatible with supporting recovery and more consistent with human rights and the CRPD.

Rather than rotting with their rights on – scaling back CTOs may give people a chance to flourish though access to the best evidence regarding how to respond to the complex nature of mental health problems.

As Pat Bracken and his 28 co-authors suggest:

> *The evidence is becoming clear that to improve outcomes for our patients, we must focus more on contexts, relationships and the creation of services where the promotion of dignity, respect, meaning and engagement are prioritised. We must become more comfortable with cultural diversity, user empowerment and the importance of peer support. (Bracken et al, 2012 p.432)*

Thus, scaling back the use of CTOs is an inevitable consequence of evidence-based practice.

Below are some specific responses to the questions asked as part of the Formal Submission process relevant to CTOs:

4. 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.

While there is difficulty establishing evidence for Community Treatment Orders being effective - as judged by randomised control trials - qualitative findings about CTOs are mixed. Some people acknowledge that the CTO was or is helpful, but in a recent paper from Norway some consumers described feeling humiliated by being forced to take medication and used terms like abuse, war or Nazism to describe their experience of coercion in mental health care (Nyttingnes et al, 2016). In Victoria, people have also described their distress and humiliation in qualitative studies. For example, in Brophy and Ring (2004) consumers described CTOs as punitive, including like "being in jail without any walls" and in later studies similar comments have been made such as:

> *I read it (the order) and it was after when she left I read it and then I, and then I thought oh my goodness they've put me on something, I mean I felt like I was a criminal* ([redacted] (Brophy et al 2019 p.7)

Many participants have talked about their concerns about side effects and not feeling heard:

> *Because you know a few of the medications I'd had before that, I'd had you know really bad side effects from and I just was like no, I'm not taking this … the side effects are just making me miserable* ([redacted]
>
> *I feel I have no choice in the matter really. That's the way I feel. Like either it's going to be taking the—taking the depot or feeling sick. So that's the only two choices I have and even if I do try to tell the doctor, you know, can we change medications, I don't think the point's getting across to them. So I don't—I, I can only take the medication, that's it* ([redacted]
>
> *I just followed the psychiatrist until I started lactating. And that's when I realised that I needed to sort of stand up for myself a bit better. Because I was certainly well and I read the brochure they had in the waiting room about … being on a Community Treatment Order. And I read through the criteria and I thought I definitely—you know I'm definitely well so I don't belong on this CTO. So it's time that I, you know, stand up and just say to them, look you know you're keeping me on this treatment order and I'm well but I'm also compliant, I'd been compliant for—I think it was 10 months* ([redacted]
>
> (Brophy et al 2019 p. 7-8)

Also lack of continuity of care is a persistent and dreadful problem for people on CTOs. In the move to an agreement that relationships are central to mental health care then mental health services in Victoria need to reject the current extraordinary tolerance of all of the 'churn' in the system, created by changes in teams and changes of doctor and case manager that people accessing services experience. This results in distress, a lack of relationship building and also difficulties in making good decisions about the appropriateness of a CTO.

Owens and Brophy (2013)'s also found that:

> *Revoking [now varying] a patient's CTO and involuntary admission to hospital was regarded as a very significant and serious infringement of people's liberty, as well as their dignity, but there was a sense that the distress, shame or trauma resulting from this process was given minimal attention. This applied particularly to situations where police were in attendance and, to a lesser extent, when an ambulance attended the person's home.(p.49)*

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

While Community Treatment Orders have had a massive uptake other evidence based interventions have not had the uptake they deserve even though the evidence suggests they may be aligned with what many have always hoped CTOs would achieve. For example Assertive Community Treatment, Housing first models and advance statements have all been found to lead to improved engagement in treatment and reduce readmission to hospital – across different age groups, cultural differences and levels of complexity. Promoting safe, secure and affordable housing leads to people with serious mental illness doing better on a range of indicators.

Critical time intervention - especially when accompanied by practical and subsistence support - has assisted to engage people with complex needs in treatment. Providing advocacy, giving people greater choice and control and other strategies to empower people actually help to engage people in treatment and enhance personal recovery. By engaging people's families – from building family skills together to open dialogue, the evidence is very strong and might stand a better chance of keeping people out of hospital.

There may be concerns that funding alternatives to CTOs may not be possible or affordable. However, this needs to be considered in the context of CTOs creating an expensive bureaucracy and administrative burden that could be reduced. But most importantly any extra investment needs to be weighed up against people feeling like they are being robbed of hope and their human rights, and being forced into treatment that may be interfering with their recovery and social and economic inclusion. For example:

> *Well it's just draining and it saps me of energy – I just feel weak and sick all the time – like I've got a millstone like a big burden weighing down upon me – I just feel like it's total – but I've been through it before and I've been through worse so I feel like I can recover again but the community treatment order is not helping me at all. I would rather get a voluntary treatment order. (C1)* (Edan, Brophy et al, 2019 p.180)

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

According to Vine and Komiti (2015)'s study that was conducted in Victoria:

> *While empirical research has been ambivalent at best regarding the overall benefit of CTOs, this study suggests that, from the perspective of carers, while the person is on a CTO there is benefit, and that in many cases this benefit is lost once the CTO is removed. In particular, there appeared to be a high risk of relapse and readmission when the person was discharged from the CTO with all the impact of that for the person and their family.(p.157).*

Brophy et al (2019) also found that families tend to support people being on CTOs – often because they are worried services will abandon them or they may not gain access to services:

> *I think families feel safer that their loved ones are on orders … in the sense that they know it's going to access them to mental health services ([redacted] Social Worker).(p.5)*

The above suggests that families are in favour of CTOs because of concerns about being left with the responsibilities and impact of their relative or the person they care for becoming unwell and also fears about losing access to mental health services. However, in various studies, families have also been very worried about the poor quality of care, the over reliance on medication that gets emphasised when people are on CTOs, and concerns that CTOs are a substitute and interfere with building therapeutic relationships and more holistic treatment:

> *Like, I don't think that non-compliance should necessarily equate to, "You need to go on a Community Treatment Order". I think, you know, there are so many factors that go into an episode and, you know, people are just a lot more complex than drawing a straight line between those two things. So in my brother's case, when he's had, you know, 15 years of good compliance, became unwell and then it was suggested that he go on a Community Treatment Order. We had to fight really hard for that to not happen. ([redacted] Sister)* (Brophy et al 2019 p.9)

It is important that family members and other supporters and carers can access more consistent service providers or treatment teams who get to know them and communicate with them. There is always more potential, depending on the preferences of the consumer, for families and other supporters to be more involved in care and treatment and to be able to also face some of the ethical and human rights dilemmas associated with CTOs. Families may be much more supportive of the dignity of risk, and people being able to have greater autonomy, choice and control, if they believed that their family member or person they care for will get access to ongoing care that is consistent, of high quality and that they will not be abandoned.

9. 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?

I believe the implementation of Community Treatment Orders in Victoria requires its own inquiry. We need to do more to understand how and why we have had such high numbers of people on CTOs, why there has been an apparent reduction in numbers (although it remains high), and whether that reduction can be sustained and continued. We need to understand who is on CTOs and why, and consider whether there is still a net widening effect that means that people are on CTOs who don't need to be, other than because the system requires this to ensure continuity of care. How to build the skills and resources needed in the mental health

system to engage people who need treatment, but are reluctant to access it without coercion, needs to be considered.

We also need to explore why there is so much variation between rates of use of CTOs across states in Australia and how we compare to the rest of the world. We also need to understand, if we are to continue to use CTOs, who is most likely to benefit, and why, so that we can resist the net widening effect.

We also need to provide staff training and development and prepare mental health services staff properly for work that currently involves so much coercive practice. We have no equivalent to the approved mental health professionals (AMHP) training required in the UK and the rigour associated with being appointed as an AMHP - therefore we do not have staff well prepared for decision making regarding compulsory treatment.

All of the above would be enhanced through valuing lived experience and co production of research to investigate CTOs. Lived experience can also assist with the implementation of current evidence based strategies, as well as developing future new and innovative practice models that help to reduce reliance on CTOs

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

In relation to Community Treatment Orders in Victoria there are a number of changes that I recommend:

1. Non-coercive alternatives to CTOs such as decision-making supports and improvements in treatment and service provision must be explored (Brophy et al, 2019).
2. We need to continue to support improved uptake of advance statements. These and other ways of supporting a person's decision-making are favoured by many service users (Henderson et al., 2008). While the efficacy of these tools is only now beginning to be examined, de Jong et al. (2016) conclude that there is greater evidence for the effectiveness of advance directives in reducing compulsory admission than there is for CTOs.
3. People on CTOs need to be provided with support to self advocate to assist them to either avoid going on a CTO or to be discharged from a CTO (Brophy et al 2019). Thus all people on CTOs should have access to advocacy services and good information about their rights and treatment and care options.
4. It will be particularly important to negotiate with the RANZCP to reconsider the requirement that psychiatry registrars rotate around services every 6 months. This is currently meeting the needs of training- not the people being served and their families and supporters. I suggest that in continuing care teams in the community every effort should be made to enable a psychiatric registrar to work with consumers over a one year period.
5. All staff should receive training in working with people who are reluctant to engage and access services to build skills to prevent reliance on CTOs. Staff also need to have skills in working well with people on CTOs and there are practice models and guidance support this (Brophy and McDermott, 2012; Brophy et al, 2019). All staff training would be enhanced through co-production and co-facilitation by people with lived experience.
6. Immediately stop any requirement that people on CTO pay for their medication

scripts unless they chose to do this because of there own health provider or pharmacy preferences.

7. Other everyday injustices experienced by people on CTOs also need to be attended to - for example having to pay to use the hospital car park or pay for public transport to attend compulsory appointments - or not having access to out of hours appointments if they are employed. People on CTOs have not committed an offence and they should not be subjected to such burdens as a result of being on a compulsory order
8. While CTOs are a persistent feature of our services, people on CTOs should be prioritised. Services need to demonstrate reciprocity - that is – recognise that in taking away human rights in the persons 'best interests' is only justified by the level of care and treatment that is subsequently offered - from practical support, family work and access to preferred medication options. This requires services to reject defaulting to 'CTO plus depot'.
9. The families of people on CTOs, or coming off CTOs, need support - they need to not fear that if their relative or person they care for is not on a CTO then they will be abandoned.
10. CTOs should not be used to guarantee follow up by continuing care teams and a CTO should not be the gateway to gaining access to assertive community treatment.
11. Strategies need to be in place to avoid the trauma of having CTOs varied and sending people back to hospital - and if this does occur - more effort needs to be made to support people around the trauma of emergency services such as police being involved in their care.
12. There needs to be more investment in research.

    Despite the call for more research into the use of CTOs and efforts that have been undertaken in the USA and UK there has been minimal examples of national research in Australia. During a multi stakeholder symposium on CTOs, hosted by the Melbourne Social Equity Institute (MSEI) in 2017, we identified five potential projects for further research:

    - A scoping study on the use of CTOs across jurisdictions, which includes demographic data of those placed on CTOs and rationales for CTO use.
    - A RCT comparing the use of CTOs with voluntary assertive community treatment and/or other alternatives to CTOs.
    - A qualitative study exploring personal and cultural narratives from persons placed on CTOs.
    - A study of the effect of peer advocacy on the use of CTOs.
    - The impact of the national recovery framework and human rights principles in legislation on mental health tribunal members' decision-making concerning CTOs.

    (Brophy, Edan, Gooding et al 2018 p. 301)

In conclusion:

Support for research on CTOs is very important in Victoria. We need to explore what has driven such high rates of CTOs and explore what is currently happening. We also need to identify how we can improve the overall experience of service of people on CTOs and improve practice. Research may also support strategies for service systems to move away from reliance on CTOs and improve capacity to uptake other evidence-based services and

strategies and reduce risk aversion. Peer support and valuing the input of lived experience expertise are likely to be important resources in system change to become more recovery oriented and improve the focus on human rights. While the lower rate observed by Light (2019) might be seen as encouraging, this is also occurring in the context of Victoria's public mental health services falling behind other states in relation to funding (Vine and Judd, 2018). Thus there is the potential that lower rates of CTOs is not necessarily an indicator of service improvement and greater attention to human rights – it may actually be a signal that we are continuing to do less with less and that people who are being discharged from CTOs are at risk of benign neglect and being abandoned by our over stretched system (Vine and Judd, 2018; Davidson et al, 2016).

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these orders and this was having an impact on individuals subjected to CTOs, and their families and others supporters. I also started to observe that CTOs were having an impact on the skills and practices of staff, and on the mental health system itself.

Subsequently my experience with CTOs has been located in what I have been learning through research and also my ongoing experience as a community member, initially of the Mental Health Review Board in Victoria, and subsequently on Victoria's Mental Health Tribunal. Thus my submission draws on this range of experience. While I do not claim to be totally opposed to CTOs (and that would be inauthentic considering the reality that on the Tribunal I am involved in making CTOs) I have no doubt that CTOs are overused in Victoria and that the detrimental impact of the overuse of CTOs is all too often minimised and underestimated. I believe we need to prioritise the needs of people on CTOs and ensure they receive the quality of care that is commensurate with the rights they are forced to sacrifice (otherwise known as reciprocity).

CTOs are controversial in several respects. They are often identified as being incompatible with the shift to recovery-oriented practice and the expectations of Article 12 of the UN Convention on the rights of persons with disabilities (CRPD). They lead to a restriction of human rights, including the rights to liberty and physical and mental integrity sometimes over many years (Brophy et al 2019 p.2). There is a poverty of evidence that CTOs are effective in relation to a range of measures (Brophy, Ryan and Weller, 2018; Rugkasa, 2016) and – even when some attempt has been made to establish that CTOs are working at perhaps keeping people out of hospital (the most common outcome measure) – there are doubts about whether results from studies undertaken in different jurisdictions are generalisable because of differences in legislation and how CTOs are implemented.

Something commonly observed about CTOs in a range of jurisdictions is that they are associated with a net widening effect. Once they're introduced, the use of CTOs expands beyond the classic high needs group of people with complex needs who are frequently requiring admission to hospital. It is now relatively common for people with, for example, first episode psychosis patients and women who do not have the clinical features typical of the stereotypical patient on a CTO, to be on CTOs and there is evidence that this is happening in Victoria (Morandi, 2016: Brophy, Reece and McDermott, 2006).

This relates to the evidence that there is a 'lobster pot' effect with CTOs – it's easy to get in but much harder to get out. So if you're doing well – it must be the CTO – if you aren't doing so well – you will be kept on the CTO regardless (Morandi, 2016). Thus the exit doors are hard to find unless there is a persistent commitment to moving people to less restrictive care. This might account for why there is a gradual build-up of the numbers of people on CTOs in jurisdictions over time. Furthermore, other studies, both in Victoria and elsewhere, suggest that CTOs are increasingly being used to facilitate continuity of care and fill other systemic gaps (Light et al, 2016; Brophy et al 2019). In Brophy et al (2019) this was identified by participants and the following quotes illustrate this situation:

> *The consultant [psychiatrist] had very strong, you know, views … everyone went out [of hospital] on a treatment order. Everyone … pretty much … who came in with a psychotic type illness. In, out on a treatment order because that way they'd get community follow up (Joseph, Psychiatrist).(p.5)*

> *They say, oh well if they weren't on an order, MST [the Mobile support and treatment team] probably wouldn't … keep them on their books because they only take the most severe people. But that's like totally putting the cart before the horse, you know … Like surely the whole point of MST is to get people to a point where they can be self-determining and autonomous and make their own decisions. It's really—you know,why, why, why should you need to be on an order to get a service, that doesn't make any sense (Sam, Psychiatrist).(p. 5).*

Overall, CTOs have promised so much but delivered very little. Looking closely at the OCTET trial in the UK that tried to establish the effectiveness of CTOs - it is apparent that there were staff trying very hard to provide good care – hoping that this would be enhanced by adding a CTO, but it appears that mostly a CTO made little difference to the consumers care or outcomes. The clinicians are then left to decide whether a slight increase in contact with services (one of the only significant findings) justifies the extra coercion a CTO involves (Burns, Rugkasa et al 2013).

However, despite problems in obtaining gold standard evidence for CTOs, many in Victoria's mental health system think CTOs are working and will guarantee ongoing community care and follow up. It appears that there are fears of take the risk of not implementing a CTO because the person will relapse –that's considered bad for them and their families and other supporters and places extra pressure on the mental health system due to the need for crisis intervention and inpatient beds. Indeed it appears that the pressures on the system partially account for why we have CTOs and why – even under the pressure of the weakness of the evidence regarding their effectiveness and the strengthening of evidence that they are doing harm - we, until now, have persisted with them.

Pat Bracken and 28 colleagues from around the world have all agreed that psychiatry needs to embrace the evidence that personally meaningful recovery from serious mental disorder is not necessarily related to the specific treatments that are prescribed (Bracken et al, 2012). Alternatively, research supports the importance of the therapeutic alliance and the importance of enhancing people's self-esteem and an 'internal locus of control' in determining outcomes. We need a therapeutic context that promotes empowerment and connectedness and that helps rebuild a positive self-identity. Dramatically scaling back the use of coercion, including CTOs, has to be part of these improvements in practice. Furthermore the CRPD requires countries that are signatories – including Australia - to reduce the use of coercion and substitute decision making.

Considering the lack of evidence, and the social justice and human rights issues raised by CTOs, it is now time to turn our attention in Victoria to innovation and developing approaches to care that are more attractive and engaging, with a more established evidence base. These supports and interventions also need to be compatible with supporting recovery and more consistent with human rights and the CRPD.

Rather than rotting with their rights on – scaling back CTOs may give people a chance to flourish though access to the best evidence regarding how to respond to the complex nature of mental health problems.

As Pat Bracken and his 28 co-authors suggest:

> *The evidence is becoming clear that to improve outcomes for our patients, we must focus more on contexts, relationships and the creation of services where the promotion of dignity, respect, meaning and engagement are prioritised. We must become more comfortable with cultural diversity, user empowerment and the importance of peer support. (Bracken et al, 2012 p.432)*

Thus, scaling back the use of CTOs is an inevitable consequence of evidence-based practice.

Below are some specific responses to the questions asked as part of the Formal Submission process relevant to CTOs:

4. 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.

While there is difficulty establishing evidence for Community Treatment Orders being effective - as judged by randomised control trials - qualitative findings about CTOs are mixed. Some people acknowledge that the CTO was or is helpful, but in a recent paper from Norway some consumers described feeling humiliated by being forced to take medication and used terms like abuse, war or Nazism to describe their experience of coercion in mental health care (Nyttingnes et al, 2016). In Victoria, people have also described their distress and humiliation in qualitative studies. For example, in Brophy and Ring (2004) consumers described CTOs as punitive, including like "being in jail without any walls" and in later studies similar comments have been made such as:

> *I read it (the order) and it was after when she left I read it and then I, and then I thought oh my goodness they've put me on something, I mean I felt like I was a criminal (Yolanda).*(Brophy et al 2019 p.7)

Many participants have talked about their concerns about side effects and not feeling heard:

> *Because you know a few of the medications I'd had before that, I'd had you know really bad side effects from and I just was like no, I'm not taking this … the side effects are just making me miserable (Cheryl).*
>
> *I feel I have no choice in the matter really. That's the way I feel. Like either it's going to be taking the—taking the depot or feeling sick. So that's the only two choices I have and even if I do try to tell the doctor, you know, can we change medications, I don't think the point's getting across to them. So I don't—I, I can only take the medication, that's it (Amrick).*
>
> *I just followed the psychiatrist until I started lactating. And that's when I realised that I needed to sort of stand up for myself a bit better. Because I was certainly well and I read the brochure they had in the waiting room about … being on a Community Treatment Order. And I read through the criteria and I thought I definitely—you know I'm definitely well so I don't belong on this CTO. So it's time that I, you know, stand up and just say to them, look you know you're keeping me on this treatment order and I'm well but I'm also compliant, I'd been compliant for—I think it was 10 months (Alejandra).*
>
> (Brophy et al 2019 p. 7-8)

Also lack of continuity of care is a persistent and dreadful problem for people on CTOs. In the move to an agreement that relationships are central to mental health care then mental health services in Victoria need to reject the current extraordinary tolerance of all of the 'churn' in the system, created by changes in teams and changes of doctor and case manager that people accessing services experience. This results in distress, a lack of relationship building and also difficulties in making good decisions about the appropriateness of a CTO.

Owens and Brophy (2013)'s also found that:

> *Revoking [now varying] a patient's CTO and involuntary admission to hospital was regarded as a very significant and serious infringement of people's liberty, as well as their dignity, but there was a sense that the distress, shame or trauma resulting from this process was given minimal attention. This applied particularly to situations where police were in attendance and, to a lesser extent, when an ambulance attended the person's home.(p.49)*

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

While Community Treatment Orders have had a massive uptake other evidence based interventions have not had the uptake they deserve even though the evidence suggests they may be aligned with what many have always hoped CTOs would achieve. For example Assertive Community Treatment, Housing first models and advance statements have all been found to lead to improved engagement in treatment and reduce readmission to hospital – across different age groups, cultural differences and levels of complexity. Promoting safe, secure and affordable housing leads to people with serious mental illness doing better on a range of indicators.

Critical time intervention - especially when accompanied by practical and subsistence support - has assisted to engage people with complex needs in treatment. Providing advocacy, giving people greater choice and control and other strategies to empower people actually help to engage people in treatment and enhance personal recovery. By engaging people's families – from building family skills together to open dialogue, the evidence is very strong and might stand a better chance of keeping people out of hospital.

There may be concerns that funding alternatives to CTOs may not be possible or affordable. However, this needs to be considered in the context of CTOs creating an expensive bureaucracy and administrative burden that could be reduced. But most importantly any extra investment needs to be weighed up against people feeling like they are being robbed of hope and their human rights, and being forced into treatment that may be interfering with their recovery and social and economic inclusion. For example:

> *Well it's just draining and it saps me of energy – I just feel weak and sick all the time – like I've got a millstone like a big burden weighing down upon me – I just feel like it's total – but I've been through it before and I've been through worse so I feel like I can recover again but the community treatment order is not helping me at all. I would rather get a voluntary treatment order. (C1)* (Edan, Brophy et al, 2019 p.180)

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

According to Vine and Komiti (2015)'s study that was conducted in Victoria:

> *While empirical research has been ambivalent at best regarding the overall benefit of CTOs, this study suggests that, from the perspective of carers, while the person is on a CTO there is benefit, and that in many cases this benefit is lost once the CTO is removed. In particular, there appeared to be a high risk of relapse and readmission when the person was discharged from the CTO with all the impact of that for the person and their family.(p.157).*

Brophy et al (2019) also found that families tend to support people being on CTOs – often because they are worried services will abandon them or they may not gain access to services:

> *I think families feel safer that their loved ones are on orders … in the sense that they know it's going to access them to mental health services (Sophia, Social Worker).(p.5)*

The above suggests that families are in favour of CTOs because of concerns about being left with the responsibilities and impact of their relative or the person they care for becoming unwell and also fears about losing access to mental health services. However, in various studies, families have also been very worried about the poor quality of care, the over reliance on medication that gets emphasised when people are on CTOs, and concerns that CTOs are a substitute and interfere with building therapeutic relationships and more holistic treatment:

> *Like, I don't think that non-compliance should necessarily equate to, "You need to go on a Community Treatment Order". I think, you know, there are so many factors that go into an episode and, you know, people are just a lot more complex than drawing a straight line between those two things. So in my brother's case, when he's had, you know, 15 years of good compliance, became unwell and then it was suggested that he go on a Community Treatment Order. We had to fight really hard for that to not happen. (Nicole, Sister)* (Brophy et al 2019 p.9)

It is important that family members and other supporters and carers can access more consistent service providers or treatment teams who get to know them and communicate with them. There is always more potential, depending on the preferences of the consumer, for families and other supporters to be more involved in care and treatment and to be able to also face some of the ethical and human rights dilemmas associated with CTOs. Families may be much more supportive of the dignity of risk, and people being able to have greater autonomy, choice and control, if they believed that their family member or person they care for will get access to ongoing care that is consistent, of high quality and that they will not be abandoned.

9. 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?

I believe the implementation of Community Treatment Orders in Victoria requires its own inquiry. We need to do more to understand how and why we have had such high numbers of people on CTOs, why there has been an apparent reduction in numbers (although it remains high), and whether that reduction can be sustained and continued. We need to understand who is on CTOs and why, and consider whether there is still a net widening effect that means that people are on CTOs who don't need to be, other than because the system requires this to ensure continuity of care. How to build the skills and resources needed in the mental health

system to engage people who need treatment, but are reluctant to access it without coercion, needs to be considered.

We also need to explore why there is so much variation between rates of use of CTOs across states in Australia and how we compare to the rest of the world. We also need to understand, if we are to continue to use CTOs, who is most likely to benefit, and why, so that we can resist the net widening effect.

We also need to provide staff training and development and prepare mental health services staff properly for work that currently involves so much coercive practice. We have no equivalent to the approved mental health professionals (AMHP) training required in the UK and the rigour associated with being appointed as an AMHP - therefore we do not have staff well prepared for decision making regarding compulsory treatment.

All of the above would be enhanced through valuing lived experience and co production of research to investigate CTOs. Lived experience can also assist with the implementation of current evidence based strategies, as well as developing future new and innovative practice models that help to reduce reliance on CTOs

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

In relation to Community Treatment Orders in Victoria there are a number of changes that I recommend:

1. Non-coercive alternatives to CTOs such as decision-making supports and improvements in treatment and service provision must be explored (Brophy et al, 2019).
2. We need to continue to support improved uptake of advance statements. These and other ways of supporting a person's decision-making are favoured by many service users (Henderson et al., 2008). While the efficacy of these tools is only now beginning to be examined, de Jong et al. (2016) conclude that there is greater evidence for the effectiveness of advance directives in reducing compulsory admission than there is for CTOs.
3. People on CTOs need to be provided with support to self advocate to assist them to either avoid going on a CTO or to be discharged from a CTO (Brophy et al 2019). Thus all people on CTOs should have access to advocacy services and good information about their rights and treatment and care options.
4. It will be particularly important to negotiate with the RANZCP to reconsider the requirement that psychiatry registrars rotate around services every 6 months. This is currently meeting the needs of training- not the people being served and their families and supporters. I suggest that in continuing care teams in the community every effort should be made to enable a psychiatric registrar to work with consumers over a one year period.
5. All staff should receive training in working with people who are reluctant to engage and access services to build skills to prevent reliance on CTOs. Staff also need to have skills in working well with people on CTOs and there are practice models and guidance support this (Brophy and McDermott, 2012; Brophy et al, 2019). All staff training would be enhanced through co-production and co-facilitation by people with lived experience.
6. Immediately stop any requirement that people on CTO pay for their medication

scripts unless they chose to do this because of there own health provider or pharmacy preferences.

7. Other everyday injustices experienced by people on CTOs also need to be attended to - for example having to pay to use the hospital car park or pay for public transport to attend compulsory appointments - or not having access to out of hours appointments if they are employed. People on CTOs have not committed an offence and they should not be subjected to such burdens as a result of being on a compulsory order
8. While CTOs are a persistent feature of our services, people on CTOs should be prioritised. Services need to demonstrate reciprocity - that is – recognise that in taking away human rights in the persons 'best interests' is only justified by the level of care and treatment that is subsequently offered - from practical support, family work and access to preferred medication options. This requires services to reject defaulting to 'CTO plus depot'.
9. The families of people on CTOs, or coming off CTOs, need support - they need to not fear that if their relative or person they care for is not on a CTO then they will be abandoned.
10. CTOs should not be used to guarantee follow up by continuing care teams and a CTO should not be the gateway to gaining access to assertive community treatment.
11. Strategies need to be in place to avoid the trauma of having CTOs varied and sending people back to hospital - and if this does occur - more effort needs to be made to support people around the trauma of emergency services such as police being involved in their care.
12. There needs to be more investment in research.

    Despite the call for more research into the use of CTOs and efforts that have been undertaken in the USA and UK there has been minimal examples of national research in Australia. During a multi stakeholder symposium on CTOs, hosted by the Melbourne Social Equity Institute (MSEI) in 2017, we identified five potential projects for further research:

    - A scoping study on the use of CTOs across jurisdictions, which includes demographic data of those placed on CTOs and rationales for CTO use.
    - A RCT comparing the use of CTOs with voluntary assertive community treatment and/or other alternatives to CTOs.
    - A qualitative study exploring personal and cultural narratives from persons placed on CTOs.
    - A study of the effect of peer advocacy on the use of CTOs.
    - The impact of the national recovery framework and human rights principles in legislation on mental health tribunal members' decision-making concerning CTOs.

    (Brophy, Edan, Gooding et al 2018 p. 301)

In conclusion:

Support for research on CTOs is very important in Victoria. We need to explore what has driven such high rates of CTOs and explore what is currently happening. We also need to identify how we can improve the overall experience of service of people on CTOs and improve practice. Research may also support strategies for service systems to move away from reliance on CTOs and improve capacity to uptake other evidence-based services and

strategies and reduce risk aversion. Peer support and valuing the input of lived experience expertise are likely to be important resources in system change to become more recovery oriented and improve the focus on human rights. While the lower rate observed by Light (2019) might be seen as encouraging, this is also occurring in the context of Victoria's public mental health services falling behind other states in relation to funding (Vine and Judd, 2018). Thus there is the potential that lower rates of CTOs is not necessarily an indicator of service improvement and greater attention to human rights – it may actually be a signal that we are continuing to do less with less and that people who are being discharged from CTOs are at risk of benign neglect and being abandoned by our over stretched system (Vine and Judd, 2018; Davidson et al, 2016).

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

Organisation Name
N/A

Name
Professor Lisa Brophy

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
N/A

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?
N/A

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

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.
"While there is difficulty establishing evidence for Community Treatment Orders being effective - as judged by randomised control trials - qualitative findings about CTOs are mixed. Some people acknowledge that the CTO was or is helpful, but in a recent paper from Norway some consumers described feeling humiliated by being forced to take medication and used terms like abuse, war or Nazism to describe their experience of coercion in mental health care (Nyttingnes et al, 2016). In Victoria, people have also described their distress and humiliation in qualitative studies. For example, in Brophy and Ring (2004) consumers described CTOs as punitive, including like being in jail without any walls and in later studies similar comments have been made such as: I read it (the order) and it was after when she left I read it and then I, and then I thought oh my goodness they've put me on something, I mean I felt like I was a criminal ([redacted] (Brophy et al 2019 p.7) Many participants have talked about their concerns about side effects and not feeling heard: Because you know a few of the medications I'd had before that, I'd had you know really bad side effects from and I just was like no, I'm not taking this the side effects are just making me miserable ([redacted] I feel I have no choice in the matter really. That's the way I feel. Like either it's going to be taking thetaking the depot or feeling sick. So that's the only two choices I have and even if I do try to tell the doctor, you know, can we change medications, I don't think the point's getting across to them. So I don'tI, I can only take the medication, that's it ([redacted] I just followed the psychiatrist until I started lactating. And that's when I realised that I needed to sort of stand up for myself a bit better. Because I was certainly well and I read the brochure they had in the waiting room about being on a Community Treatment Order. And I read through the criteria and I thought I definitelyyou know I'm definitely well so I don't belong on this CTO. So it's time that I, you know, stand up and just say to them, look you know you're keeping me on this treatment order and I'm well but I'm also compliant, I'd been compliant forI think it was 10 months ([redacted] (Brophy et al 2019 p. 7-8) Also lack of continuity of care is a persistent and dreadful problem for people on CTOs. In the move to an agreement that relationships are central to mental health care then

mental health services in Victoria need to reject the current extraordinary tolerance of all of the churn' in the system, created by changes in teams and changes of doctor and case manager that people accessing services experience. This results in distress, a lack of relationship building and also difficulties in making good decisions about the appropriateness of a CTO. Owens and Brophy (2013)'s also found that: Revoking [now varying] a patient's CTO and involuntary admission to hospital was regarded as a very significant and serious infringement of people's liberty, as well as their dignity, but there was a sense that the distress, shame or trauma resulting from this process was given minimal attention. This applied particularly to situations where police were in attendance and, to a lesser extent, when an ambulance attended the person's home.(p.49) "

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

"While Community Treatment Orders have had a massive uptake other evidence based interventions have not had the uptake they deserve even though the evidence suggests they may be aligned with what many have always hoped CTOs would achieve. For example Assertive Community Treatment, Housing first models and advance statements have all been found to lead to improved engagement in treatment and reduce readmission to hospital across different age groups, cultural differences and levels of complexity. Promoting safe, secure and affordable housing leads to people with serious mental illness doing better on a range of indicators. Critical time intervention - especially when accompanied by practical and subsistence support - has assisted to engage people with complex needs in treatment. Providing advocacy, giving people greater choice and control and other strategies to empower people actually help to engage people in treatment and enhance personal recovery. By engaging people's families from building family skills together to open dialogue, the evidence is very strong and might stand a better chance of keeping people out of hospital. There may be concerns that funding alternatives to CTOs may not be possible or affordable. However, this needs to be considered in the context of CTOs creating an expensive bureaucracy and administrative burden that could be reduced. But most importantly any extra investment needs to be weighed up against people feeling like they are being robbed of hope and their human rights, and being forced into treatment that may be interfering with their recovery and social and economic inclusion. For example: Well it's just draining and it saps me of energy I just feel weak and sick all the time like I've got a millstone like a big burden weighing down upon me I just feel like it's total but I've been through it before and I've been through worse so I feel like I can recover again but the community treatment order is not helping me at all. I would rather get a voluntary treatment order. ([redacted] (Edan, Brophy et al, 2019 p.180) "

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

"According to Vine and Komiti (2015)'s study that was conducted in Victoria: While empirical research has been ambivalent at best regarding the overall benefit of CTOs, this study suggests that, from the perspective of carers, while the person is on a CTO there is benefit, and that in many cases this benefit is lost once the CTO is removed. In particular, there appeared to be a high risk of relapse and readmission when the person was discharged from the CTO with all the impact of that for the person and their family.(p.157). Brophy et al (2019) also found that families tend to support people being on CTOs often because they are worried services will abandon them or they may not gain access to services: I think families feel safer that their loved ones are on orders in the sense that they know it's going to access them to mental health services ([redacted] Social Worker).(p.5) The above suggests that families are in favour of CTOs because of concerns about

being left with the responsibilities and impact of their relative or the person they care for becoming unwell and also fears about losing access to mental health services. However, in various studies, families have also been very worried about the poor quality of care, the over reliance on medication that gets emphasised when people are on CTOs, and concerns that CTOs are a substitute and interfere with building therapeutic relationships and more holistic treatment: Like, I don't think that non-compliance should necessarily equate to, You need to go on a Community Treatment Order. I think, you know, there are so many factors that go into an episode and, you know, people are just a lot more complex than drawing a straight line between those two things. So in my brother's case, when he's had, you know, 15 years of good compliance, became unwell and then it was suggested that he go on a Community Treatment Order. We had to fight really hard for that to not happen. ([redacted] (Brophy et al 2019 p.9) It is important that family members and other supporters and carers can access more consistent service providers or treatment teams who get to know them and communicate with them. There is always more potential, depending on the preferences of the consumer, for families and other supporters to be more involved in care and treatment and to be able to also face some of the ethical and human rights dilemmas associated with CTOs. Families may be much more supportive of the dignity of risk, and people being able to have greater autonomy, choice and control, if they believed that their family member or person they care for will get access to ongoing care that is consistent, of high quality and that they will not be abandoned. "

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

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?
N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
"I believe the implementation of Community Treatment Orders in Victoria requires its own inquiry. We need to do more to understand how and why we have had such high numbers of people on CTOs, why there has been an apparent reduction in numbers (although it remains high), and whether that reduction can be sustained and continued. We need to understand who is on CTOs and why, and consider whether there is still a net widening effect that means that people are on CTOs who don't need to be, other than because the system requires this to ensure continuity of care. How to build the skills and resources needed in the mental health system to engage people who need treatment, but are reluctant to access it without coercion, needs to be considered. We also need to explore why there is so much variation between rates of use of CTOs across states in Australia and how we compare to the rest of the world. We also need to understand, if we are to continue to use CTOs, who is most likely to benefit, and why, so that we can resist the net widening effect. We also need to provide staff training and development and prepare mental health services staff properly for work that currently involves so much coercive practice. We have no equivalent to the approved mental health professionals (AMHP) training required in the UK and the rigour associated with being appointed as an AMHP - therefore we do not have staff well prepared for decision making regarding compulsory treatment. All of the above would be

enhanced through valuing lived experience and co production of research to investigate CTOs. Lived experience can also assist with the implementation of current evidence based strategies, as well as developing future new and innovative practice models that help to reduce reliance on CTOs "

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

"In relation to Community Treatment Orders in Victoria there are a number of changes that I recommend: 1.Non-coercive alternatives to CTOs such as decision-making supports and improvements in treatment and service provision must be explored (Brophy et al, 2019). 2.We need to continue to support improved uptake of advance statements. These and other ways of supporting a person's decision-making are favoured by many service users (Henderson et al., 2008). While the efficacy of these tools is only now beginning to be examined, de Jong et al. (2016) conclude that there is greater evidence for the effectiveness of advance directives in reducing compulsory admission than there is for CTOs. 3.People on CTOs need to be provided with support to self advocate to assist them to either avoid going on a CTO or to be discharged from a CTO (Brophy et al 2019). Thus all people on CTOs should have access to advocacy services and good information about their rights and treatment and care options. 4.It will be particularly important to negotiate with the RANZCP to reconsider the requirement that psychiatry registrars rotate around services every 6 months. This is currently meeting the needs of training-not the people being served and their families and supporters. I suggest that in continuing care teams in the community every effort should be made to enable a psychiatric registrar to work with consumers over a one year period. 5.All staff should receive training in working with people who are reluctant to engage and access services to build skills to prevent reliance on CTOs. Staff also need to have skills in working well with people on CTOs and there are practice models and guidance support this (Brophy and McDermott, 2012; Brophy et al, 2019). All staff training would be enhanced through co-production and co-facilitation by people with lived experience. 6.Immediately stop any requirement that people on CTO pay for their medication scripts unless they chose to do this because of there own health provider or pharmacy preferences. 7.Other everyday injustices experienced by people on CTOs also need to be attended to - for example having to pay to use the hospital car park or pay for public transport to attend compulsory appointments - or not having access to out of hours appointments if they are employed. People on CTOs have not committed an offence and they should not be subjected to such burdens as a result of being on a compulsory order 8.While CTOs are a persistent feature of our services, people on CTOs should be prioritised. Services need to demonstrate reciprocity - that is recognise that in taking away human rights in the persons best interests' is only justified by the level of care and treatment that is subsequently offered - from practical support, family work and access to preferred medication options. This requires services to reject defaulting to CTO plus depot'. 9.The families of people on CTOs, or coming off CTOs, need support - they need to not fear that if their relative or person they care for is not on a CTO then they will be abandoned. 10.CTOs should not be used to guarantee follow up by continuing care teams and a CTO should not be the gateway to gaining access to assertive community treatment. 11.Strategies need to be in place to avoid the trauma of having CTOs varied and sending people back to hospital - and if this does occur - more effort needs to be made to support people around the trauma of emergency services such as police being involved in their care. 12.There needs to be more investment in research. Despite the call for more research into the use of CTOs and efforts that have been undertaken in the USA and UK there has been minimal examples of national research in Australia. During a multi stakeholder symposium on CTOs, hosted by the Melbourne Social Equity Institute

(MSEI) in 2017, we identified five potential projects for further research: ?A scoping study on the use of CTOs across jurisdictions, which includes demographic data of those placed on CTOs and rationales for CTO use. ?A RCT comparing the use of CTOs with voluntary assertive community treatment and/or other alternatives to CTOs. ?A qualitative study exploring personal and cultural narratives from persons placed on CTOs. ?A study of the effect of peer advocacy on the use of CTOs. ?The impact of the national recovery framework and human rights principles in legislation on mental health tribunal members' decision-making concerning CTOs. (Brophy, Edan, Gooding et al 2018 p. 301) "

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