Experiences of Community Treatment Orders (CTOs) in New South Wales

Perspectives of people with lived experience of CTOs, families/carers/kin, and public mental health staff



29 February 2024
inside out & associates australia

Acknowledgement of Country

This report was researched and written on Aboriginal Land within the borders of what is now referred to as New South Wales, Australia. We wish to pay our respects to the First Nations' Elders of these lands, past, present, and emerging, and all Aboriginal People who have exercised custodianship of this Country – the land, the seas, the rivers, and the sky. We affirm that sovereignty of Country was never ceded. And we express deep appreciation to the First Nations people who shared their lived experience in this exploration project.

Acknowledgements

Our heartfelt appreciation to the Co-design Team, for so generously contributing their knowledge and experiences to co-develop the CTO Project processes and protocols.

Our deepest gratitude to everyone who was interviewed for this project, for sharing their experiences so openly and thoughtfully, and for contributing in such a profound way to our understanding of the experiences of CTOs.

This project was coordinated by inside out & associates Australia and funded by the Mental Health Commission of NSW.

Artwork by Lucy Klippan, Good Point Design.

Submitted: 29 February 2024.

The views expressed in this report are those of the people who shared their lived experiences for this project and the authors of this report and should not be taken to reflect the views or any official stance of the funding organisation.

Table of Contents

ACKNOWLEDGEMENT OF COUNTRY **2**

ACKNOWLEDGEMENTS **3**

TABLE OF CONTENTS **4**

EXECUTIVE SUMMARY **5**

INTRODUCTION **7**

PURPOSE OF THIS PROJECT 7
WHO WAS INVOLVED 8
HOW THIS DOCUMENT IS INTENDED TO BE USED 8
WHAT WE KNOW ABOUT CTOS – AUSTRALIAN AND INTERNATIONAL RESEARCH 9

METHOD / APPROACH **12**

FINDINGS **17**

BIBLIOGRAPHY **47**

APPENDIX A – INTERVIEW QUESTIONS **52**

Executive Summary

This project, funded by the Mental Health Commission of NSW (the Commission), explored people's experiences with Community Treatment Orders (CTOs) in New South Wales. The purpose was to identify the key themes and issues that arise for people affected by CTOs. (A CTO authorises compulsory care for a person living in the community.)

This project sought to hear about the experiences of people who are subject to CTOs, their families, carers, friends and kinship groups, and service providers. The project was unique compared to other explorations of the experience of CTOs, in that

- The project was co-designed by people with lived experience of CTOs, family/carers/kin of people on CTOs, and workers with experience supporting people on CTOs,
- The Project Team represented people with lived experience of CTOs, family/carers/kin of people on CTOs, and workers with experience supporting people on CTOs, and
- The people interviewed included people with lived experience of CTOs, family/carers/kin of people on CTOs, and workers with experience supporting people on CTOs.

Four co-design sessions were held in August/September 2023 to determine how best to gather people's experiences of CTOs. This group co-designed the interview questions, interview processes and the supports that would be available. They also co-designed the brief for the project recruitment flyer.

The project interviewed 16 people with experience of CTOs:

- 7 people with lived experience of CTOs
- 4 people with experience as family/carer/kin/friends supporting someone on a CTO
- 5 service providers with experience supporting people on CTOs

As well as different experiences of CTOs, the interviewees came with other experiences of diversity including First Nations, culturally and linguistically diverse (CALD), LGBTQIA+, and regional/rural. Two interviewees identified as male (one person with lived experience and one service provider). Attempts to ensure the group of interviewees better reflected a gender balance were unsuccessful. Among the group, there were diverse experiences of being on (or supporting someone on) one CTO or multiple CTOs, being currently on a CTO or being on a CTO in the past. Families/carers/kin included parents and a partner of someone on a CTO. Service providers included 2 peer workers and 3 mental health clinicians.

While each group brought different experiences and concerns, there was also sufficient common ground that responses from each participant group were reflected in each of the

five major themes – **Hopes, High stakes, Harms, How it's done,** and **Health services and systems**. However, certain themes were more strongly represented for different participant groups. For example, Harms were raised significantly more often by people with lived experience of CTOs, while Hopes were more likely to be raised by families/carers/kin than other participant groups.

Overall, participants' experiences and perceptions of CTOs were negative, and this is reflected in these findings. It is possible this could reflect a limitation of this project, where people with negative experiences were more likely to be motivated to participate. However, these findings were recurring, both within this project and in the Australian and international research more broadly, suggesting that they are representative of the broader experience. The complete findings are outlined in this issues paper.

> *"Yeah, that's right. Being told that you had to take it to stay out of hospital, and you're better when you're on the drugs, which I'm not because I don't like the me that I am without the drugs – with the drugs I mean."*

> *"I thought, initially, good. I thought it had purpose, and it was a positive thing. More now I think it's working against him, and he may well do better without."*

> *"It set me back years. For years I couldn't do anything. Couldn't work, couldn't study, couldn't think, couldn't do anything. It literally took four years out of my life. Even now, I've got – there's such resentment and anger. Because you're so powerless."*

> *"...if this support [as a result of the CTO] wasn't there, my son wouldn't be able to recover."*

> *"…if you had really good systems to support people then perhaps we wouldn't need to do this."*

> *"I think that a better CTO would have been necessary, but not the kind that I was put on."*

> *"So I guess it's just harder to keep the rapport with the person because they don't want to be there, in essence. Usually, I can still maintain the relationship, but it is a lot more difficult."*

Introduction

This project sought to explore people's experiences with Community Treatment Orders (CTOs) in New South Wales in order to identify the key themes and issues that arise for people affected by CTOs. A CTO authorises compulsory care for a person living in the community.

Applications for CTOs are made by the Authorised Medical Officer of a public mental health facility for an inpatient, a medical practitioner who is familiar with the clinical history of the person, the person's Designated Carer or Principal Care Provider, or the Director or Deputy Director of a Community Mental Health Facility. The decision to grant a CTO is made by the Mental Health Review Tribunal of New South Wales, and the treatment is overseen by an employee of New South Wales Health called the Director of Community Treatment.

Many people are affected by these orders, including people who are subject to them, their families, carers, friends and kinship groups, the service providers who provide treatment under them, and others who may be providing services to a person who is subject to an order, even though the service they provide is not part of that order. This project sought to understand the experiences of these groups of people, with a particular emphasis on people who are or have been subject to CTOs.

Purpose of this project

The CTO Project was established to:

- Seek the views of the people of New South Wales on their experiences and perspectives of CTOs to identify the issues that matter to them (including people who are subject to CTOs, their carers, families, friends and kinship groups, and service providers),
- Consult existing relevant background information and literature,
- Consult with key stakeholders,
- Analyse the interview data, and
- Compile a report outlining the project findings.

Who was involved

There were three main groups of people involved in the CTO Project. These were:

- The Project Team – responsible for coordinating project activities, organising and facilitating co-design sessions and undertaking interviewing and analysis.
- The Co-design Team – responsible for co-developing project processes and protocols to explore people's experiences of CTOs sensitively and supportively.
- The CTO Project Advisory Group – responsible for providing advice to the Commission on the project approach, key stakeholders, and exploring people's experiences in a sensitive and inclusive fashion. Also responsible for ensuring the final content of the issues paper met the criteria outlined in the Project Terms of Reference.

Each of these groups represented people with lived experience of CTOs, experience as families/carers/kin/friends of people on CTOs, and experience as service providers. The Advisory Group also represented people involved in policy and research.

inside out & associates australia was funded by the Commission to coordinate the CTO Project, including the co-design process that informed the project processes and protocols.

How this document is intended to be used

This project aimed to understand the experiences of people who are subject to CTOs, their families, carers, friends and kinship groups, and service providers providers supporting people on CTOs. As reflected in this report, people's experiences of CTOs are diverse and complex, and the project findings will likely lead to further reflection and sharing of people's experiences and perspectives. Because this report is intended to encourage further sharing of perspectives and stimulate dialogue about the sorts of changes that are needed to improve people's experiences of CTOs, we've deliberately omitted recommendations or specific conclusions.

What we know about CTOs – Australian and international research

CTO rates in NSW

According to data presented in the Mental Health Review Tribunal Annual Reports from 2015 – 2022, the number of CTOs that have been approved/granted in NSW has been steadily increasing, with over 600 more CTOs granted in 2022/2023 compared to 2018/2019. CTO rates (the number of CTOs per 10,000 population) show that the number of CTOs granted each year varies between Local Health Districts (LHDs) and, to a lesser extent, within LHDs. Comparatively more CTOs are granted in regional/rural areas than metropolitan areas. However, some regional/rural LHDs have among the lowest CTO rates in the state while some metropolitan LHDs have among the highest CTO rates in the state. These figures suggest the need to determine those factors that influence CTO applications and approvals.

Australian research into CTOs

Australian research showed that, compared to other countries, Australia has high rates of CTOs. A recent meta-analysis of Australian and New Zealand studies identified better outcomes of CTOs in districts where use of CTOs was lower and more targeted, and when the process of coming off a CTO was planned, rather than abrupt (Kisely et al., 2023). Another NSW study suggested that CTOs were used often to increase or assure access to services, but that CTOs could not solve the problem of insufficient services (Light et al., 2016).

One study exploring the lived experience of CTOs found that people on CTOs experienced "lacking choice and control, an emphasis on medication, fear of the threat of hospitalisation, an absence of recovery-oriented practice, and staying supported" (Edan et al., 2019, p. 178). Another study found that the lived experience of CTOs was associated with feeling misunderstood, isolated and distressed, experiences of loss, grief and trauma, and disempowerment, and that CTOs did not always guarantee access to services (Light et al., 2014). In particular, people with lived experience of CTOs were concerned that medication was the main form of treatment, that they had no say in medication options and were expected to endure side effects that ranged from unpleasant to unbearable (Brophy et al., 2019).

Mental health staff have mixed feelings about CTOs, but concerns regarding risk are common (Brophy et al., 2019). Working from a recovery-orientation when someone is on a CTO is complex and challenging, especially where such practices are not supported by

services (Edan et al., 2019). One study identified the important, but poorly utilised, part that GPs can play in the care of people on CTOs (Light et al., 2015).

Trust is central to therapeutic relationships, but trust is often compromised when someone is on a CTO. McMillan and colleagues (2019) identified that people were more likely to find a CTO beneficial if they experienced trust in their relationship with mental health staff. This research acknowledged that establishing trusting relationships in the context of CTOs is difficult but possible if staff are sensitive to issues of power (McMillan et al., 2019). Other research identified the importance of supporting decision-making, respecting people's treatment preferences, and working to reduce the use of CTOs (Brophy et al., 2019).

The research strongly suggests that service system deficiencies are highly implicated in CTOs and points to an urgent need for system transformation if there are to be improvements in the use and outcomes of CTOs (Brophy et al., 2019; Edan et al., 2019)

International research into CTOs

International research over the past 15 years has similar findings to Australian research. Most of this research has been undertaken in Canada, the United Kingdom, and New Zealand. One study from Norway was also identified. Two international reviews concluded that the experience of CTOs was mixed, influenced by the local context and service provision in the study location (Churchill et al., 2007; Corring et al., 2017).

International studies support that the experience of being on a CTO is most likely to be negative. One study identified that almost two thirds of people interviewed said they felt harmed by the order (Newton-Howes & Banks, 2013), while another more recent study found that people experience CTOs as violence due to powerlessness, lack of legal and social recognition, and the overly biomedical orientation of treatment (Goulet et al., 2023).

Families/carers/kin have mixed feelings and experiences of CTOs, which may provide a sense of relief and some opportunities to contribute to care decisions related to their family member, but also involve challenging implementation processes, a narrow focus on medication and unreliable support from clinicians (Corring et al., 2018a). Another study identified that families/carers/kin can experience relief as the responsibility of services is formalised by the CTO but also excluded from involvement in care (Goulet et al., 2023). Clinicians believe that there is benefit with CTOs but acknowledge that there are struggles and tensions when practicing within the confines of a Community Treatment Order (Corring et al., 2018b).

Research conducted in England explored the experiences of people with lived experiences of CTOs, families/carers/kin, and psychiatrists (Canvin et al., 2014). People with lived experience generally felt restricted or 'trapped' by their CTO, with a very small minority finding the CTO to be a safeguard (Canvin et al., 2014). While families wanted CTOs to go beyond medication, psychiatrists were most likely to minimise CTO conditions to what could be enforced, which was usually medication and contact with mental health services (Canvin et al., 2014). All three groups identified significant shortcomings of CTOs and that only certain people benefit from them (Canvin et al., 2014).

The international research similarly points to the relationship between CTOs' use and systemic inadequacies and the need for service system transformation to improve approaches to support and care for people who are subject to compulsory treatment.

Commentary

Overall, the research suggests that there are significant concerns and complexities for everyone involved in CTOs, and particularly for those who are subject to CTOs. While it is expected that such differences would exist, there also appears to be some common ground across groups in relation to systemic shortfalls such as insufficient access to services and supports, and that their coercive nature means that the connection with services and treatment that CTOs aim to achieve is more likely to result in alienation. Based on the research to date, improving approaches to CTOs requires service system transformation at all levels.

Method / Approach

This project set out to interview people with lived experience of CTOs, families/carers/kin/ friends with experience supporting people on CTOs, and service providers with experience supporting people on CTOs.

Our Project Team represented people with lived experience of mental distress, experience of being on a CTO, experience of supporting family/kin/friends on CTOs, and experience as a service provider supporting people on CTOs.

The first step was to recruit a Co-design Team, representing people from all the above groups, to co-develop the project processes and protocols which would inform the development of accessible, ethical, and supportive approaches to exploring people's experiences of CTOs. The co-design process is described below.

This project was unique, compared to other explorations of the experience of CTOs, in that:

- The project was co-designed by people with lived experience of CTOs, family/carers/kin of people on CTOs, and workers with experience supporting people on CTOs,
- The Project Team represented people with lived experience of CTOs, family/carers/kin of people on CTOs, and workers with experience supporting people on CTOs, and
- The people interviewed included people with lived experience of CTOs, family/carers/kin of people on CTOs, and workers with experience supporting people on CTOs.

1. Co-design

An Expression of Interest (EOI) to join the Co-design Team was circulated in July 2023 via Being Mental Health Consumers NSW, Mental Health Carers NSW, the Mental Health Coordinating Council of NSW newsletters, and the Mental Health Commission of NSW. The EOI attracted a high degree of interest, and the 12 co-design places were easily filled. (People who submitted an EOI, but missed a place in the Co-design Team, were invited to participate in an interview if they wished to.) Efforts were made to recruit a diverse group of co-designers with the relevant experience of CTOs, including First Nations people, culturally and linguistically diverse people, younger persons, older persons, people from the LGBTQIA+ community, and people living in remote/rural/regional NSW. All co-designers were paid for their time, unless already being paid by another organisation (e.g., some service providers attended during work hours).

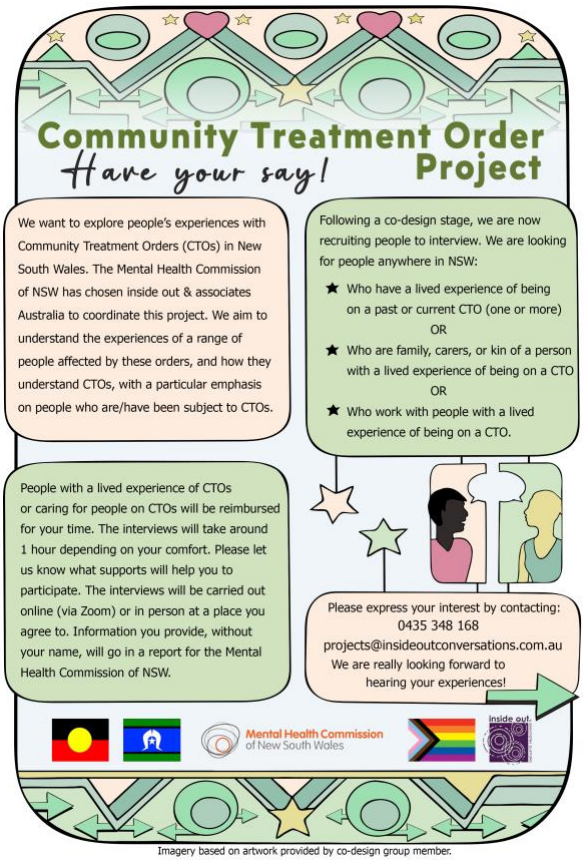
The Co-design Team comprised:

- 5 people with lived experience of CTOs
- 2 family members with experience supporting a loved one on a CTO
- 4 people with experience providing support to people on CTOs as service providers (2 peer workers and 2 health workers)
- 1 person with all of the above experiences.

The Co-design Team initially met over four two-hour online sessions, held weekly on Zoom, during August and September 2023. Together, they co-developed a design brief for the CTO Project recruitment flyer, the interview questions (one set for people with lived experience of CTOs and one set for families/carers/supporters and workers), and the project information sheet for anyone interested in being interviewed. The co-designers also determined the supports that should be available to people in the process of sharing their experiences of CTOs, and how the opportunity to be interviewed for the project would be promoted.

Once the CTO project processes and protocols had been developed and reviewed by the CTO Project Advisory Group, the Project Team commenced the interview stage.

Some members of the Co-design Team continued their involvement in the project, co-reviewing the analysis of findings at the very early stage, and again once the themes and subthemes had been identified. This process of bringing perspectives from outside the Project Team to the analysis aimed to check the Project Teams' understandings and interpretations and ensure the trustworthiness of the analysis.



Imagery based on artwork provided by co-design group member.

2. Interviews

People with lived experience of CTOs, families/carers/kin/friends of people on CTOs, and service providers with experience supporting people on CTOs were invited to share their experiences with the project via an interview. Recruitment occurred through a flyer that was distributed via a range of mental health lived experience and family experience organisations

(e.g., Being, Mental Health Carers NSW) and other community organisations (e.g., Mental Health Coordinating Council, Transcultural Mental Health Service). Rural community support services were contacted directly, in order to ensure representation of people in regional and rural NSW amongst the participants.

The project aimed to interview 12-16 people with experiences of CTOs, with 50% having experience of being on CTOs (currently or in the past). Due to some last-minute withdrawals, this intention was not quite achieved. However, people with lived experience of CTOs were the majority of people interviewed. The Project Team spoke to:

- 7 people with lived experience of CTOs
- 4 people with experience as family/carer/kin/friends supporting someone on a CTO
- 5 service providers with experience supporting people on CTOs

As well as different experiences of CTOs, the interviewees came with other experiences of diversity including First Nations, culturally and linguistically diverse (CALD), LGBTQIA+, and regional/rural. Two interviewees identified as male (one person with lived experience and one service provider). Attempts to ensure the group of interviewees better reflected a balance of genders were unsuccessful.

Among the group, there were diverse experiences of being on (or supporting someone on) one CTO or multiple CTOs, being currently on a CTO or being on a CTO in the past. Families/carers/kin included parents and a partner of someone on a CTO. Service providers included 2 peer workers and 3 mental health clinicians.

This project is based on a qualitative approach, which means it focussed on people's narratives and understanding the meaning of their experiences. Qualitative approaches are used to understand how things happened, and what people thought and felt about things that happened. This is different to a quantitative approach which is more interested in how many people had certain experiences, or how often they had them. It is common for qualitative approaches to involve smaller numbers of participants but to explore data in a greater depth.

Everyone was given the option to be interviewed in person (at a venue that was comfortable for them) or via videoconference (Zoom) or via telephone.

- 8 people chose to be interviewed in person
- 7 people chose to be interviewed via videoconference
- 1 person chose to be interviewed via telephone

Prior to being interviewed, everyone received detailed information about the project and the interview process verbally and/or in writing. Once the person confirmed their involvement, arrangements for their interview were made and a copy of the interview questions sent via email.

Once at the interview, and just prior to starting, the person was reminded that they did not have to answer every question, and that they could ask to pause or stop the interview and the recording at any time. They were advised they could withdraw from the project up to four weeks post interview. Recorded consent was obtained at the start of the interview.

Interviewees were also offered access to post-interview support. A member of the Project Team (who did not conduct the interview) was available by telephone during the interview timeframe and for up to two hours after the interview concluded. Interviewees could contact the project lead anytime during business hours, by telephone or email, to make any further arrangements for support. Support could be provided by someone outside the Project Team if preferred.

One interviewee required an interpreter for their interview, and the interview orientation conversation that preceded it. Written materials including the Interview Information Sheet and Interview questions were translated for them. (Short interactions, to confirm interview arrangements for example, did not require an interpreter, and occurred via SMS.)

All interviews were recorded, transcribed and de-identified. All participants were sent their transcription to review and make any changes or additions if they wished to. When the transcript was returned it was ready for coding and analysis. Everyone who participated in an interview was paid for their time.

One person withdrew from the project after their interview. Their transcript was deleted and not used for the analysis. Two people withdrew prior to interview.

3. Analysis

Thematic analysis was used to identify the main themes from the 16 interviews. The following process was employed to ensure that the analysis process was rigorous.

1. One transcript was selected and coded independently by each of the Project Team members. The team met to compare their understanding of what the interviewee was saying and how they had coded each point made by the interviewee.

2. Once the team had agreement about how to code different points or perspectives, at least one transcript from each of the participant groups was coded. Codes were then reviewed with the Co-design Team in affinity groups (people with lived experience of CTOs, family/carers/supporters of people on CTOs), who reviewed the codes for the relevant interview (e.g., people with lived experience of CTOs reviewed the codes from an interviewee with lived experience of CTOs). Any questions the Project Team had about the codes and what they were hearing or seeing in the transcript were also checked with the Co-design Team. The Co-design Team validated most codes and provided new perspectives for other codes.

Coding is a process that is used to summarise all the different things an interviewee says about a topic. First, the transcript is read very thoroughly, and then each different idea or perspective expressed by the interviewee is given a code, which is a short summary of the key message or concept. The same code may be used a number of times in the same transcript when that same point or perspective is being made again, or it may be used in different transcripts when that same point or perspective is being made by another person.

3. After the co-review with the Co-design Team, each transcript was coded by a member of the Project Team. Team members were able to discuss any questions that arose in the coding process at the weekly Project Team Meeting. They could also contact each other between meetings if necessary to check-in regarding any coding issues or queries.

4. The process of identifying themes commenced after all transcripts were coded (with the exception of one late interview, which was coded after theming had started). All the codes were grouped into similar categories, reviewed, and then regrouped as different themes were identified in the data. This happened until all codes were able to be grouped within the identified themes.

5. Throughout this process, the codes for each of the three participant groups were clearly marked so the Project Team was able to identify the extent to which different themes and sub-themes were relevant to the different participant groups.

6. Once this process was completed and the themes and sub-themes were agreed by the Project Team, a narrative describing each theme was compiled, with illustrative quotes, to form the project findings.

Findings

The following findings come from the perspectives of people with lived experience of CTOs, family/carers/kin of people with lived experience of CTOs, and health service providers with experience supporting people on CTOs. While each group brought different experiences and concerns, there was also sufficient common ground that responses from each participant group were reflected in each of the five major themes:

- Hopes
- High stakes
- Harms
- How it's done
- Health services and systems

However, certain themes were more strongly represented for different participant groups. For example, Harms were raised significantly more often by people with lived experience of CTOs, while Hopes were more likely to be raised by families/carers/kin than other participant groups.

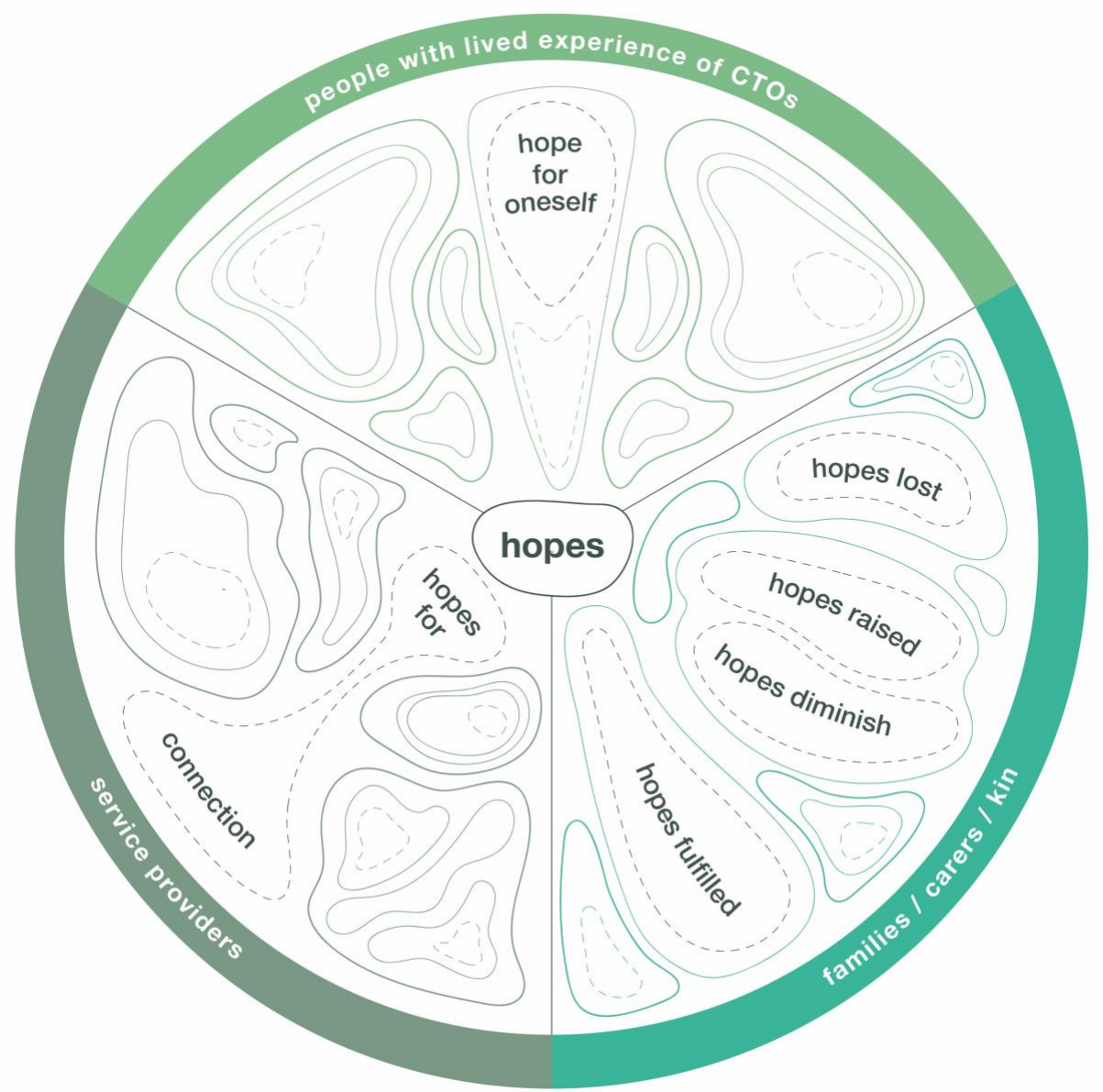
Overall, participants' experiences and perceptions of CTOs were negative, and this is reflected in these findings. It is possible this could reflect a limitation of this project, where people with negative experiences were more likely to be motivated to participate. However, these findings were recurring, both within this project and in the Australian and international research more broadly, suggesting that they are representative of the broader experience.

> My experience of CTOs is an up and down journey. Whilst it had its benefits, it also had a downside. I found it to be somewhat restrictive, especially when it came time to go to do cultural practices.
>
> Having to present, tick boxes and feeling unheard and under-supported can leave a person feeling alone and somewhat isolated as well as stigmatised and discriminated against. I have met peers who say it has saved their life. However, I was left wondering whether the benefits outweigh the risks associated with CTOs?
>
> I have experienced the wealth and knowledge of a mental health peer worker. I felt and experienced support for the first time. My mental health recovery journey started in the holistic healing way. Sharing of lived experience aided in my recovery.
>
> Person with lived experience of CTOs

Theme: Hopes

Hope was present in almost all narratives in some way. For people on CTOs, hope was something one held for oneself despite the CTO and what it represented. For families/carers/kin and service providers there were hopes that the CTO could lead to improvement in some way. For a minority of people these hopes were fulfilled, but for the majority they were not.

Figure 1: Hopes: summary of subthemes



People with lived experience of CTOs

Hopes for oneself despite the CTO

For people with lived experience of CTOs, hope was something they held for themselves, despite, not because of, the CTO. Hope for oneself and a sense of satisfaction in resisting low expectations could be a driving force.

> *"It was a lot of trying to reduce my hope" … "So, I went to university. That was great. They didn't say I wasn't going to go to university."*

Hope was also related to the possibility of better access to supports, such as a doctor or NDIS funding.

Families/carers/kin and informal supporters of people on CTOs

For most of the family members interviewed, this theme followed a trajectory from hope for how things could be, to a diminishing sense of hope, to hopes lost. However, there was also a counter-narrative of hopes fulfilled, which was less common, but clearly evident.

Hopes raised

Improvements (for the person and for the family) that family/carers/kin hoped the CTO would produce included 'stability', 'happiness as a family', a positive shift in family dynamics, guaranteed access to treatment and supports for the person on the CTO, including hospital admission when needed, and improvement in physical health and social connection.

> *"Initially it was a comforting feeling to know that there was one."*

> *"I was initially hopeful when the CTO was put in place, because I thought that at last my son would be guaranteed treatment."*

Hopes diminish

Families/carers/kin hoped the person would experience the benefits of the CTO and, as a result, engage with services and treatment. For some this sense of hope didn't last as it became evident that the person's sense of injustice, anger or opposition to the CTO was becoming an obstacle to trust and engagement with services. Even if the CTO appeared to have influenced treatment adherence, this was short term because the CTO disrupted access to treatment as people disengaged from the enforced nature of treatment. Hopes in

services also diminished because there was little offered to the person that families/carers/kin perceived to be of value, except for monitoring of medication.

> *"I thought, initially, good. I thought it had purpose, and it was a positive thing. More now I think it's working against him, and he may well do better without."*

> *"It was just different expectations and hopes and dreams for him, but unfortunately, the CTOs didn't even support him with that."*

> *"So, I was hoping he'd get some opportunities for some education and social interactions... relationship support... trauma counselling... dietary and nutrition support... a therapeutic relationship…But none of those things actually came to pass."*

Hopes lost

Family/carer/kin experiences varied from a one-off CTO that lasted six months, to repeated CTOs over many years and ongoing. The duration of the CTO did not correlate to the degree of impact on family relationships, which in most instances were detrimental. Impacts ranged from distrust to relationship breakdown to power struggles to estrangement. Family/carers/kin found themselves in the role of monitoring the person, trying to 'encourage' the person to adhere to the CTO requirements (including paying for the medication) while services did not follow through. Families/carers/kin expressed a sense of being abandoned by the system, with no support to safeguard and foster their relationship with the person on the CTO.

> *"The CTO was of no real help. It just added to the problems. I believe it was destructive of my relationship with my son."*

> *"So, there were times where the CTO worked, right at the beginning stages... Initially it was very good, but moving forward it wasn't... It's an absolute failure the whole way."*

At times the family/carer/kin might step back from the monitoring role in order to reduce the negative power dynamic that being 'involved' in the CTO created with the person on the CTO. However, in the stories shared, support from services lacked continuity, and the family/carer/kin was not contacted, even as things were going badly for their loved one. For one family this had terrible consequences.

Hopes fulfilled – a less common story

One family/carer/kin, a parent, was very satisfied with the CTO, having seen great improvement in their family member who responded well to medication, and was connected with support services. The family member felt the CTO was integral to their family member's recovery and that without it the supports they had access to would not have been available to them.

> *"And sometimes he was sick and tired of taking medication and he was throwing them away ... And this was going on for nine years, and if this support wasn't there my son wouldn't be able to recover."*

Service providers working with people on CTOs

Hopes for connection with services

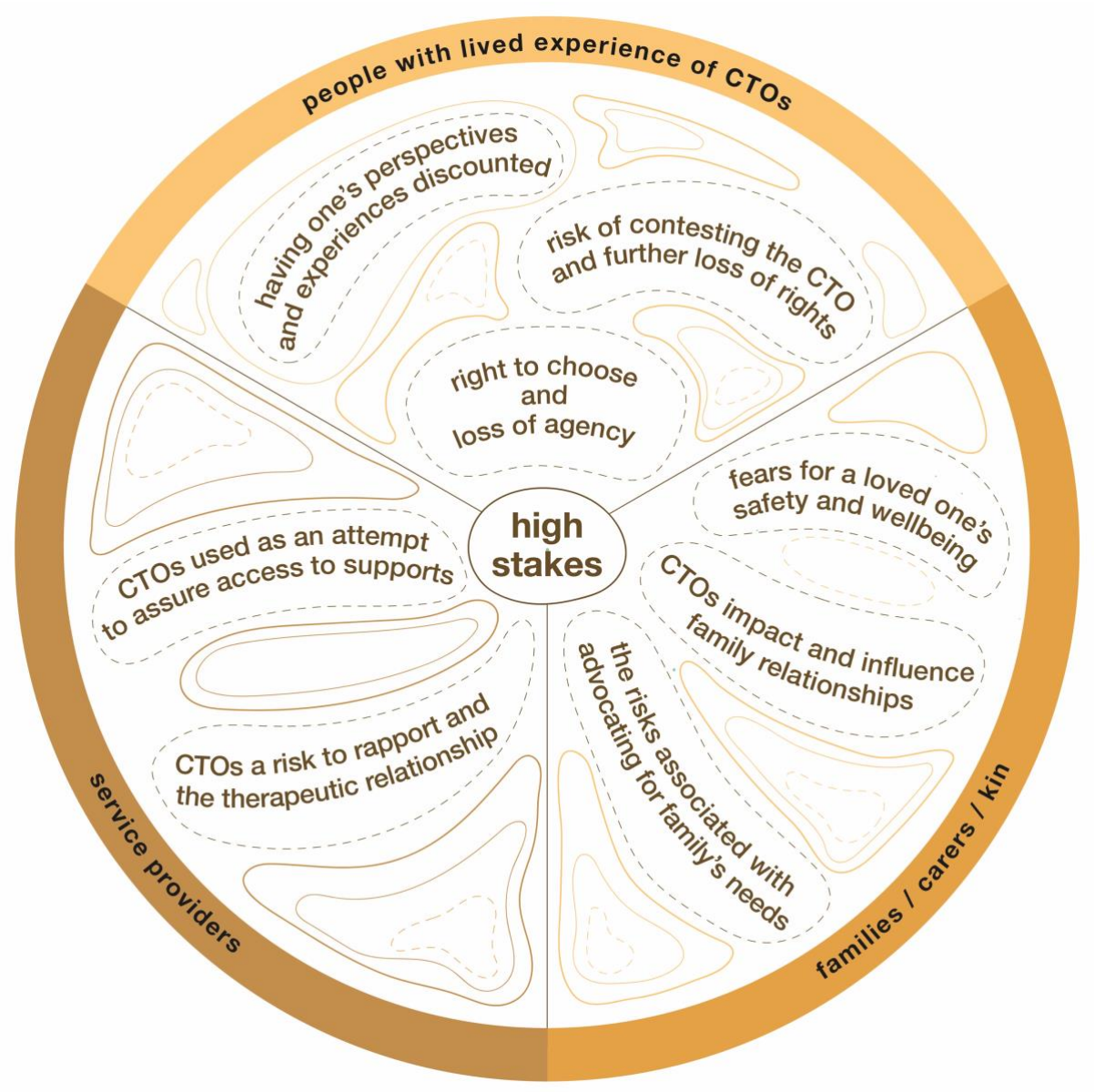
Service providers generally hoped that any opposition to the CTO could be a starting point from which a therapeutic alignment, focussed on supporting the person to do what they needed to do to get off the CTO, would develop. The peer workers and mental health workers interviewed hoped the CTO would be a chance to engage with the person and develop a positive working relationship, even though it was also acknowledged that a CTO could reinforce disengagement and make it hard to build relationships.

> *"I hear it all the time that 'the person ... just won't engage with the service'. And I just go 'of course they don't have to engage with us. We have to engage with them. We have to actually show that we've got something to offer them and work with them'... But that idea of a CTO will keep someone engaged, no, I think it actually drives a wedge between ... a mental health worker and a person."*

Theme: High Stakes

CTOs and related care and treatment (or its absence) have major impacts on the lives of people who are on CTOs, on their family/carers/kin, supporters, and on service providers. CTOs are contentious and emotionally laden. The fears, hopes, wants, and needs of people and groups are often experienced as conflicting in the CTO 'landscape' (the assembly of events, relations, and responses that surround and interact with CTOs). This combination of impacts and conflicts and experiences 'raise the stakes' for people and health systems when CTOs are in the mix.

Figure 2. High stakes: summary of subthemes



Hopes	High Stakes	Harms	How it's done	Health services

People with lived experience of CTOs

Right to choose and loss of agency

People with lived experience expressed the human right to make one's own decisions about one's life. They felt that others' interpretations of risk did not align with their own. For one person, being on a CTO and the consequent loss of personal control was incompatible with having a life.

> *"And all I'm asking is, "Please listen to the facts that I can't live a life. I have no life to live."*

> My experience being under a CTO is a negative and a positive experience depending on your understanding of taking medication and staying as well as you can be, whilst learning through being unwell and many hospitalisations and family and friends and while you wait for the Mental Health Review Tribunal to state that they don't need you under a CTO.
>
> And all you want is to be in control instead of a Mental Health Review Tribunal and doctors. Eventually you take control after many years of being under a CTO and you realise it's not much different, because you really do need medication to stay as well as you can be, it's needed to keep people well.
>
> Some say negative things about CTO like, 'I don't like medication', 'I don't like hospitals', 'I don't like doctors' and 'I'm not unwell'.
>
> Some say positive things about CTO like, 'sometimes I get unwell' and 'without it I wouldn't be here today and as well as I am'.
>
> Person with lived experience of CTOs

Risk of contesting the CTO and further loss of rights

Formally contesting the CTO felt dangerous and difficult. There were a range of barriers including social (resisting the CTO would be interpreted as 'lacking insight' and be used as a reason *for* the CTO), procedural (the complex process of challenging the CTO and having little access to legal supports), and economic (e.g., the cost of legal representation). People with lived experience felt there was potentially a lot to lose if they tried to challenge the CTO. They described having no independent options, whether the person wanted to challenge the CTO, or complain about how it was implemented.

> *"So, I've reported it in all different directions. I've reported to the patient liaison officer, and all they want to do is go back to the team, which is what the HCCC*

[Health Care Complaints Commission] would do as well, so then there's repercussions for you because you're complaining about somebody doing their job."

Having one's perspective and experiences discounted

People described their experiences of not being seen, believed, or heard. Having a psychiatric diagnosis and being on a CTO meant that their perspective was discounted or devalued. This is a kind of 'epistemic devaluing' where a person's credibility to know is undermined because of the assumptions associated with having a psychiatric diagnosis *and* being on a CTO.

"They absolutely refused to listen. They never asked one single question. After four years. I was diagnosed as schizophrenic by one doctor. Because I was going through a trauma at the time. When I first got out [of hospital], it triggered this post-traumatic stress disorder. So, I was in this very agonised state, but I was getting kicked out of my house where I lived. My car broke down, I had these psychos that were after me. All this… all this stuff was happening at the same time. It was overwhelming."

Family, carers, and informal supporters of people on CTOs

Fears for a loved one's safety and wellbeing

For family/carers/kin, CTOs (and health care systems and services) are 'high stakes' because they fear for their loved one's safety and future, and hope that the care provided through the CTO will improve the lives of the people they care for.

"The expectations, oh, when you have a baby, you have these expectations that they'll grow up, they'll be a productive member of society, they'll have children, they'll have a partner, they'll work, and I had to mourn that and let go of that. But I was hoping that there was a new [Person], right?... There was my new [Person], right, and I learned to love my new [Person]. It was just different expectations and hopes and dreams for him, but unfortunately, the CTOs didn't even support him with that."

CTOs impact and influence family relationships

CTOs impact and influence the relationships between family members and the people they support. Families/carers/kin had hopes of improving relationships and relieving existing

conflicts. However, the CTO often exacerbated conflict and distrust as families/carers/kin were enlisted into monitoring and adherence processes.

> *"It changed the dynamic a lot, to be just monitoring. It doesn't feel nice to monitor someone. I do that with our child ... because you are a parent, but not – you shouldn't have to parent your husband ... he didn't like that, and nor did I."*

> *"The CTO was of no real help. It just added to the problems. I believe it was destructive of my relationship with my son... From his point of view, it gave me a lot of power over him that he didn't want me to have and took away his autonomy. It exacerbated his negative beliefs about me, increased his distrust in the mental health system, and helped to increase his paranoia."*

The risks associated with advocating for the family's needs

CTOs and tribunal processes are experienced as high stakes for families/carers/kin. During tribunal hearings, family/carers/kin experience tension between how they might like to advocate for their needs and their perspective on the needs of their loved one, and not feeling able to do so freely in order to maintain a relationship with their loved one.

> *"The only thing I have to say there is that… after those tribunal hearings, because the judge would ask me personally what I thought, if I told the 100% truth in those, that would have caused massive, massive problems between [Person] and I, and so I would come up with wording to the effect of, 'Well, I'm not a doctor, so I'm here to support [Person] in every way I possibly can, but we're here to listen to people who know what they're talking about.' He would still get angry with me about it, but it didn't sever our relationship, and that was what that was about."*

Service Providers working with people on CTOs

CTOs used as an attempt to assure access to supports

CTOs were used where there was concern that people may not have access to mental health care after an acute admission. CTOs were seen as a way to ensure that people had access to support from mental health services and community managed organisations (CMOs) that are insufficiently resourced to provide required care in their communities.

> *"The only way – … there was a belief that the only way to get a person case management if they were in the intensive unit, was to put them on a CTO."*

"… the other problem was that for most of the NGOs, in fact, all of them at the time, and I don't know if it's culturally changed, I really hope it has, there was a belief that somebody had to be case managed to access the NGO."

CTOs a risk to developing rapport and the therapeutic relationship

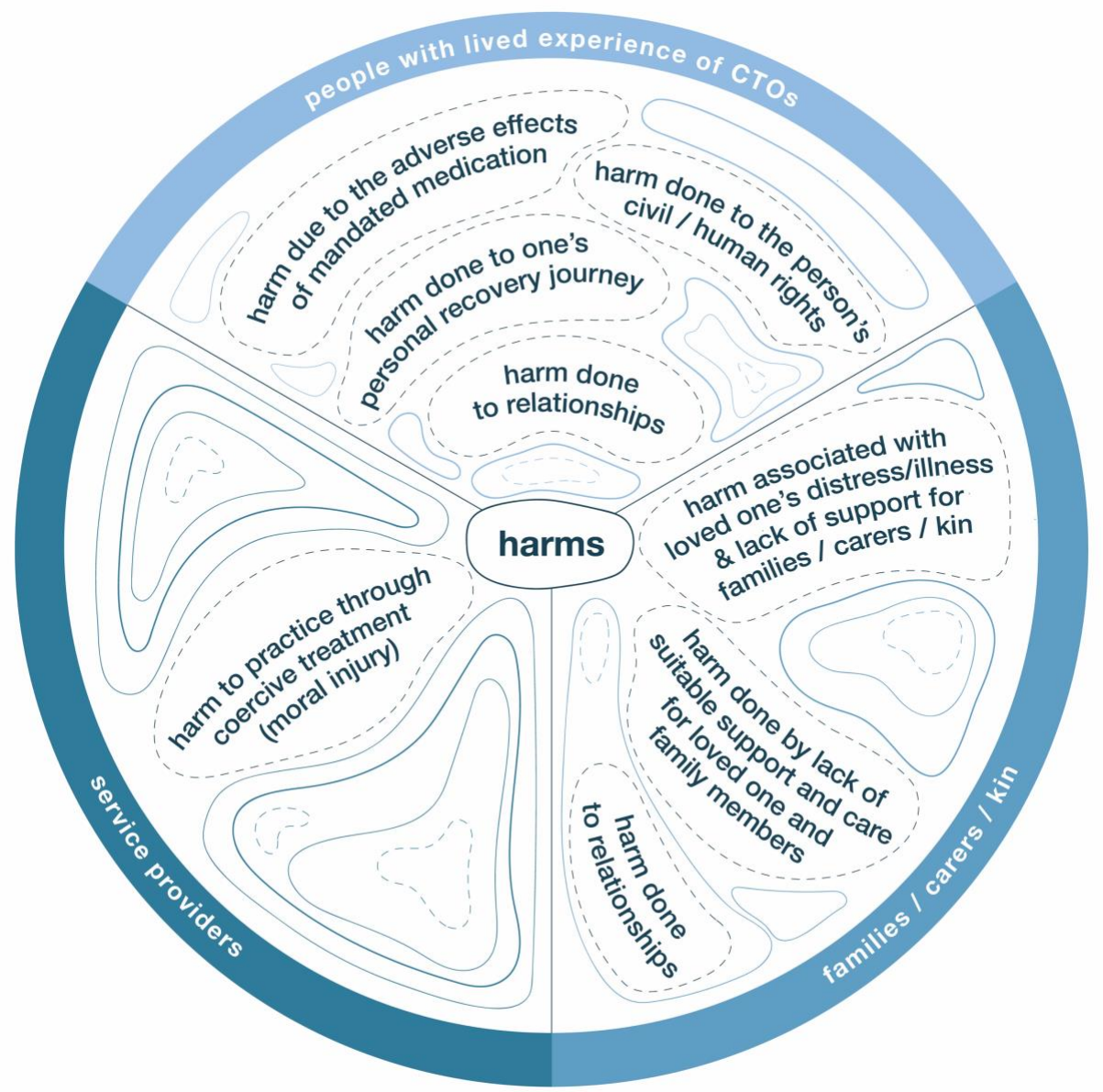
CTOs presented a risk to establishing connection and a therapeutic relationship that may be effective in the longer term. CTOs were seen to often damage rapport and increase disengagement with mental health services.

"But that idea of a CTO will keep someone engaged, no, I think it actually drives a wedge between a mental health case manager, a mental health worker, and a person. As far as the benefits go, look, yeah, sure. I can see some benefits too, for some people sometimes. But for the vast majority of times, it's actually - I don't think it's really that helpful at all. And if the person wants to avoid us, they'll avoid us. And we put so many strings and attachments onto their relationship [with health services] on that basis. "If you want this, then you have to do this."

Theme: Harms

CTOs are justified as an attempt to reduce risk of harm. However, the perspectives of different people on what constitutes 'harm' and which 'harms' should take priority, or are considered most important, will be influenced by each person's experiences, position, and underlying beliefs about the phenomena of mental/emotional distress/illness.

Figure 3. Harms: summary of subthemes



Hopes	High Stakes	Harms	How it's done	Health services

People with lived experience of CTOs

Harm due to the adverse effects of mandated medication

The most commonly cited harms were associated with the adverse effects of medications that were mandated under the CTO. People felt that their experience of side effects were ignored or invalidated. For some people, side effects were debilitating, with significant short and/or long-term consequences.

> *"And my life just revolved around the side effects of this medication I was on – they repeated the CTO every six months for five years... And the doctor's like, "Yeah, it's normal for you."*

People spoke directly to a range of harms from medication including harm to:

- physical health:

  "Which was wrong. Which was negligent… Because I've got all these terrible problems now. I've got osteoporosis. My right eye keeps closing. I've got ... tardive dyskinesia, it's called, which is this long-term symptom, maybe permanent symptom of being on [medication]."

- sense of self:

  "What changed while I was on the CTO was…my departure from society and reality. My social skills changed…. changed for the worst. Very isolating. Very isolating. My pride and dignity changed in the fact that I did not stick up for myself in times where I was threatened, and I was bullied. I was very submissive – very submissive."

  "Yeah, that's right. Being told that you had to take it to stay out of hospital, and you're better when you're on the drugs, which I'm not because I don't like the me that I am ... with the drugs."

- ability to maintain social roles and relationships:

  "I thought that it really needs to have a doctor's scope on the side effects because the side effects are so dangerous. I wasn't allowed to visit my daughter unless I was okay. Because I was passed out anywhere, at swimming lessons, I was dribbling, I was standing up. My mum's like, "Sit down!" And I'm standing up real quick, and my body shakes. I was 300 milligrams for five years. And then I had no life."

Harm done to the person's civil/human rights

People experienced Tribunal processes and being placed on a CTO as a violation of their civil/human rights and personal autonomy.

> *"Well, I just don't believe we really have rights."*
>
> *"There was no such thing as my rights. All I had to do was I had the right to take my medication…"*

People have a human right to have faith without it being used against them.

The doctors say they are helping but when information is shared it is recorded and used against them in Tribunal, the system is unfairly weighted against the person suffering to take their rights away. There are very bad people working in the system... I am never safe.

An example was a male clinician who should not of been in my hospital room without a female present, he caused me so much fear and they just used an order on me without good reason to try and control my medical decisions about having an operation when I knew I was not safe to do so. They only show the good things on that show about that but inside I saw and heard and experienced evil operations.

I was so happy to get a breakthrough and be out of the system but now I have been forced to go back into it.

I'm not sure that the government really wants to improve the lives of people with lived experience…

Doctors are given too much authority over people's lives and the government covers up what they want to. The government really needs to be sued in a class action by all the people they have abused but I doubt that would be possible...

I really think anyone involved in the mental health system should be locked up and see how horrible it is to have your freedom taken away.

Person with lived experience of CTOs

Harm done to relationships

CTOs were seen by people to damage their relationships through the recruitment of family, friends, and supporters into the monitoring and administration of CTOs by health services and tribunals.

> *"I do have a relationship with my family, I do see them. I walk on eggshells… I try and maintain the peace. … But basically, I don't want my family to have any involvement in whether I'm on a CTO or not, or to speak to the team because anything gets misconstrued."*

Harm done to one's personal recovery journey

People described the physical, social, and personal impact of being on CTOs as impeding (or even destroying) their recovery and attempts to live a personally meaningful life.

> *"It set me back years. Four years I couldn't do anything. Couldn't work, couldn't study, couldn't think, couldn't do anything. It literally took four years out of my life. Even now, I've got – there's such resentment and anger. Because you're so powerless."*

Families/carers/kin and informal supporters of people on CTOs

For families/carers/kin, harms were experienced as relating to their loved one's mental distress, health service responses or lack of response, and the impact of CTO processes and treatments on relationships.

Harm associated with loved one's distress/illness and lack of support for families/carers/kin

Family/carers/kin experienced a great deal of distress in the face of their loved one's suffering from a range of mental distress experiences as well as the personal and social repercussions of these. Families often didn't have support to work through their own distress responses.

> *"I went through a lot of hard time and trauma... I suffer a lot when [my son is not on medication]."*

Harm done by lack of suitable support and care for loved one and family members

For most of the families/carers/kin interviewed, the CTO did not result in the sort of supports that they hoped their family member would have access to. In certain situations, families/carers/kin felt a deep sense of desperation when they could see the potential for disaster, but their concerns were not responded to by services. In other situations, families described feeling helpless and disappointed that the CTO didn't result in the types of therapeutic or practical supports that their family member might benefit from.

> *"I begged them, 'please put him in hospital, if he wants to change [medication], these are the repercussions of ... having to change your medication…"*

"Well, it was a compliance treatment order really. It wasn't community treatment. It was just compliance basically. He had to show up. He had to be injected ... His quality of life was given little if any attention."

Harm done to relationships

CTOs can cause additional pressures on what may already be a fractured or tense relationship due to the complexities of distress experiences, the social consequences and the lack of support. Families/carers/kin could find themselves responsible for monitoring medication, even becoming a main point of contact for mental health staff if the person did not engage with services, which would further impact the relationship with their family member. Families/carers/kin wanted support to manage the impacts on their family relationships, to protect relationships in the longer term.

"It did create an extra stress in the relationship, for me to have to watch or remind him to take it... it changed the dynamic a lot, to be just monitoring."

"[The CTO] was destructive of my relationship with my son ...There was no support for my son's relationship with me ... I had hoped that clinicians would recognise and be able to respond to the complexities and stresses of relationships when there is mental ill health, this was not the case."

Service providers working with people on CTOs

Harm to practice through coercive treatment (moral injury)

Service providers felt that the requirements of CTOs and their involvement in coercive treatment had significant negative impacts on their practice and their ability to work according to their personal ethics. Clinicians and peer workers were often expected to uphold the conditions of CTOs they did not agree with, and which negatively impacted their relationships with the person on the CTO. This was experienced by some as a moral injury.

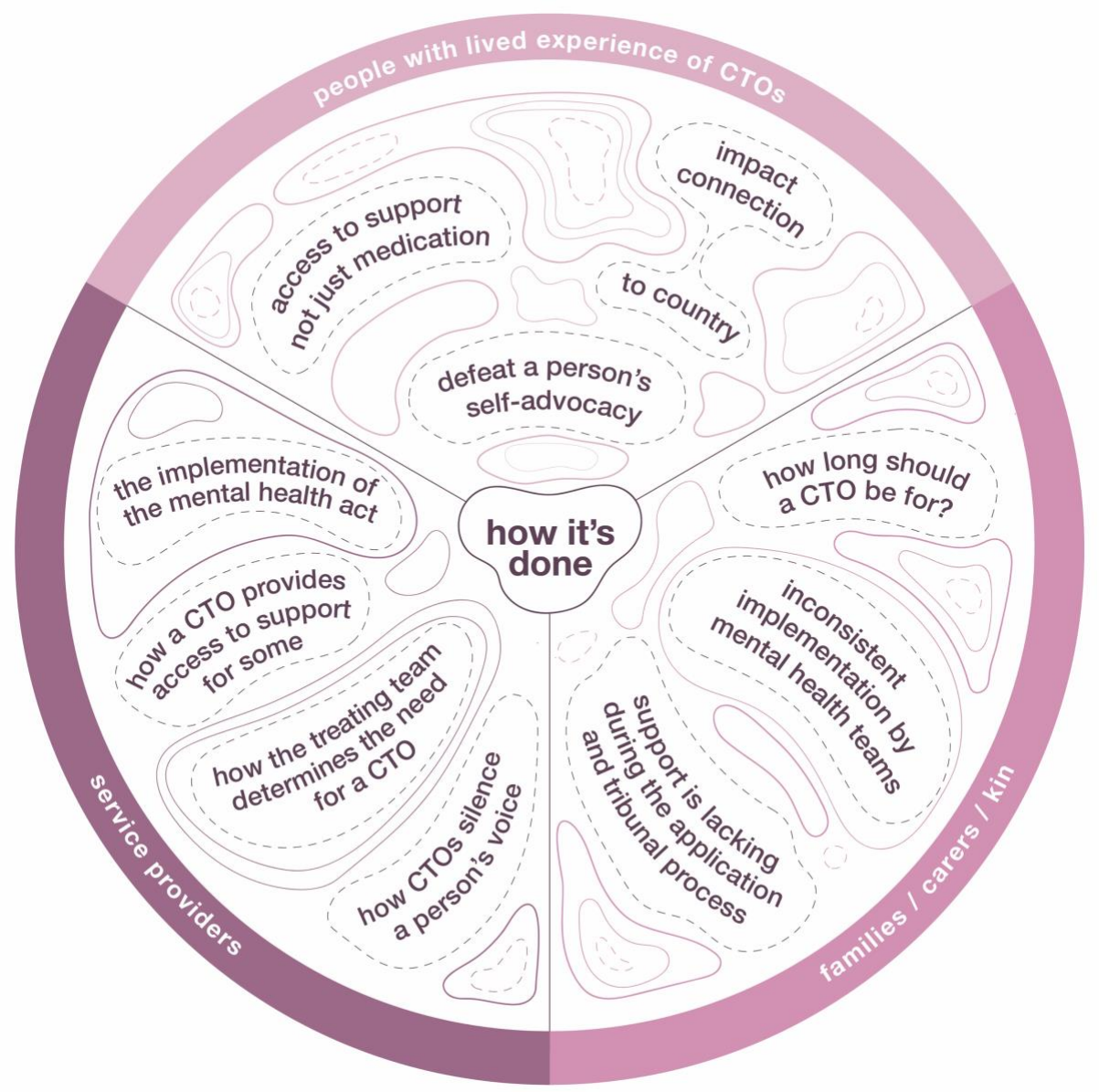
"And that's been a theme right through over the years I've noticed with CTOs as a way of ensuring follow-up, which is good and bad. It's bad in the sense that some community teams will only take people on a CTO as a mental health team, which is really tragic because ... it means overuse of that coercive power at the expense of that engagement and working with people."

“I don't think it's ever done in a malevolent way ... I don't think it's ever done to harm people or ... to make it easy for the services to treat people. I think sometimes ... there's a lot of pressure to use them ... And that pressure comes from the team, comes from family members sometimes, community, police, the hospital, that if this person wasn't on a CTO, they would become dangerous and do a lot of bad things. And so they need to be on a CTO. I don't always know whether that's necessarily true or not. But it's the way it is.”

Theme: How it's done & how it could be done

This theme relates to the CTO process, including the Tribunal Hearing, legal mechanisms and treatment plans. The theme is divided into two main sections: How it is done (current situation) and How it could be done (recommended improvements).

Figure 4. How it's done: summary of subthemes



Hopes	High Stakes	Harms	How it's done	Health services

People with lived experience of CTOs

How people need access to support, not just medication

Being on a CTO links people with a community mental health team. While resource constraints were acknowledged, connection to holistic support is necessary and treating teams have a role in connecting people to relevant supports beyond medication. Support needs to extend beyond the duration of a CTO.

> *"I started to have these weekly meetings with somebody from Drug and Alcohol…It was very nice to go visit this person every week… They said we're going to put you through to support workers…They didn't think I was crazy… Because I had been on the CTO for four years I got given the NDIS. Cleaners and two beautiful coffee dates each week…Why would I say no to that?"*

How CTO processes defeat a person's self-advocacy

Mental health services and the Tribunal frame a person's informed decision to fight against the adverse effects of mandatory medication as non-compliance. Further self-advocacy becomes pointless within an inevitable, unfightable CTO and tribunal process, leaving people feeling helpless despite their strengths and determinations to speak for themselves. Not receiving information about CTOs in an accessible format, or having adequate legal representation are other impediments to self-advocacy.

The lived experience of systemic harm, coercion and being "done to" while subject to a CTO creates a sense of solidarity with others. Even so, as one person said, "no one should ever have to experience that".

> *"The process is such that you don't feel like you have rights in a Tribunal hearing."*
>
> "*You can fight it. But you have very little chance of anything happening."*
>
> *"I took the medication, and I got community housing…but the price I had to pay, and the future? – well the future looks bleaker and bleaker."*

How CTO's impact connection with Country for First Nations people

A First Nations person described how the restrictions of CTOs impact on their cultural practices, connection with spirituality, community, and Country. Culturally safe community mental health services could help restore connection.

Hopes	High Stakes	Harms	How it's done	Health services

"…Because you spiritually cannot feel anything. There's times where I got invited out to Country, and I said I can't because I'm on a CTO. And then I found out later on that, "Oh well, if you call the pharmacist that's in the area at that time, you can get the medication delivered to you at the chemist out there" But there's no chemist out there. That's Country."

Families/carers/kin and informal supporters of people on CTOs

How long should the CTO be for?

There are varying views of how long a CTO should be for and when a new application should be made if a person is already on one. Families/carers/kin suggested that CTO duration be tailored to the person's unique situation. Families/carers/kin also identified that the timing of the CTO review and the Tribunal process means the person on the CTO is continually working towards the review. Less frequent reviews may allow a person to 'be' - working towards personal recovery rather than working towards the review. One family member/carer/kin advocated for consideration of longer CTOs when a person experiences a "long term mental illness".

"For people who have a better chance of recovery with their own insight, and knowing they need to take medication, perhaps less time is better, because it is restrictive."

How mental health teams implement the CTO inconsistently

Families experienced disrupted and inconsistent care by health services responsible for administering the CTO. They said that health services did not address the barriers experienced by people on CTO's that were impacting their ability to access and engage with services. The requirement of the person on a CTO and their family needing to pay for mandatory medication impact on family members financially and emotionally.

How support during the application and tribunal process is lacking

Families/carers/kin described limited access to legal support if the CTO is applied for via an inpatient service, but little access to legal support if the CTO is applied for in the community. Families/carers/kin experienced poor explanation of the CTO process. Even with legal support and an understanding of their rights, families/carers/kin found the Tribunal process difficult, especially when tribunal hearings were held via telehealth.

"The process itself, it felt very formal. So, it was a little bit nerve wracking the first time I'd gone in."

"I think in the hospital it was just [an information] sheet given to him and I would read it."

Service providers working with people on CTOs

The implementation of the Mental Health Act is the problem, not the Act itself

Some service providers thought that CTOs were needed at times, and were even effective sometimes, albeit rarely, but that they were relied on too much, and at times misused. There was agreement that a CTO should be a last resort. One service provider who had experience working overseas was shocked at how frequently CTOs were used in Australia. Service providers were concerned that people were not given the opportunity to demonstrate the CTO is no longer needed.

"I think they have a place. I think they can be misused."

"I still believe there's a need for them, unfortunately, but maybe not to the extent that they're used."

"...and it means overuse of that coercive power at the expense of that engagement and working with people."

Peer Workers in particular talked about having 'mixed feelings' about the CTO: that they understood why a CTO was being considered but that the general approach to CTOs was 'barbaric'. Peer Workers also talked about being excluded by their clinical colleagues when it came to decisions about the care of people on CTOs.

"I have very mixed feelings around it. I understand that some people should be on it, but I really think that it needs a big review. I think that it is quite barbaric, especially when people are trying to get through their mental illness just in general and then they have to feel they're doing something wrong."

"They wouldn't just take my word for it because it's the treating team that are making the decision anyway."

How a CTO provides access to support for some

Service providers identified that having a CTO in place provides access to treatment and support and, when implemented well, CTO's can initiate a positive mental health journey. Due to service system resource constraints, people seeking help early in their recovery journey may not receive supports unless a CTO is in place.

> *"…it made sure that the person got follow-up."*

> *"…he actually got quite stable and was working. We got him off his injection, he was on oral [medication], and he was quite stable…all the stuff that goes with someone recovering and doing well."*

How the treating team determines the need for a CTO

Service providers identified that CTO decisions are often made unilaterally by the medical team rather than collaboratively with the person and their supports, including mental health staff. These practices do not align with person-centred and trauma informed care principles.

> *"…there was a belief they wouldn't accept treatment…"*

> *"A lot of people are on CTOs for years without even having any kind of advocacy …or opportunities to get off it."*

How mental health workers perceive the tribunal process

Service providers said that legal representation does not meet the needs of the person. Lawyers and legal advocates turn up on the day, often just ten minutes before the hearing, with little knowledge of the person they are representing.

> *"I don't know they have a lot of understanding about mental health conditions."*

How CTOs silence a person's voice

Peer workers see themselves as natural advocates and responsible for providing the person with information about the CTO that they may not receive otherwise. Peer workers do not replace clinicians in relation to informed choice about medication, however they may often be the information provider. Due to time constraints and the tendency for decisions to be made in clinical meetings "about the person without them", peer workers endeavour to advocate for the person to come off the CTO and affirm the right of the person to self-advocate.

> *"…whether they understand the purpose of it…making sure people are completely aware of what their rights and responsibilities are…"*

How it could be done (suggested improvements)

'How it could be done' is part of the theme, 'How it's done'

Figure 5. How it could be done: summary of subthemes



People with Lived Experience of CTOs

How health services can listen

People with lived experience have the capacity to ask for help when they need it. Mental health services need to listen to the person and respond when they ask for help, and not just focus on the distress experience which led to involuntary treatment.

Hopes	High Stakes	Harms	How it's done	Health services

"I think that if anybody rings the …one of the 1800 numbers and says, "I'm getting sick, I need to see someone urgently", they need to let them see somebody."

Treatment and support need to work around a person's life to enable full participation in the community of their choice. This requires treating teams to ask questions, dig deeper, listen, and take on board the person's preferences in relation to their personal recovery, especially to minimise and mitigate adverse effects of medications. Attitudinal and systemic barriers often prevent a person's right to medication review.

"I would just like to say that there isn't enough training with these doctors about how to actually communicate with – actually how to listen…then look at you and ask deeper questions. … how life's going and actually listen and go, 'Oh you missed your daughter's birthday party. Okay let's look at reducing the medication so you can actually go to your daughter's birthday party'."

Families/carers/kin and informal supporters of people on CTO's

How mental health teams can deliver support

Families/carers/kin suggested improvements to the levels of support and care which mental health services provide, regardless of whether a person is on a CTO or not. Good support can prevent the need for involuntary treatment.

"…we weren't followed up with anyone. …You're doing well. And then he relapsed. And then they realised, okay, you need it."

"A step-up step-down structure would be better so that there'd be a ... period of time of more intense support".

Families/carers/kin want holistic care and psychosocial support for the family and the person on the CTO, rather than only medication compliance. The requirements and responsibilities of a treatment plan is often a standardised pro forma, not individualised, and this is not helpful. The non-medication side of CTO implementation was more important to families/carers/kin.

"…It seemed that the conditions were just a tick box thing that were, as he thinks, a bit of a waste of time…"

Families/carers/kin had different experiences of mental health teams, and their approach to interaction and engagement. Families/carers/kin recommend that mental health teams seek to actively engage people and build relationships. Families need to trust that service providers will follow through with the CTO and check in on the person regularly, especially when families/carers/kin need to step out of that role temporarily to improve family relationships for the longer term.

> *"There were ongoing complex power struggles between the mental health service, my son and myself"*

Some mental health teams took a family-inclusive approach to care and support, while others did not. Families/carers/kin sought an equal partnership approach.

Several years ago, my teenage daughter was involuntarily hospitalised with psychosis. The day after discharge, she stopped taking her anti-psychotic medication and the psychosis returned within days. A few months later, she was involuntarily hospitalised a second time and discharged on a CTO.

Over the next two years, my daughter had three out-patient case managers, one after the other. The first two, young and inexperienced, failed to gain her trust and make any progress with her recovery. The third case manager, older and more experienced, was much more flexible in her approach and prioritised developing a personal connection with my daughter. Trust soon emerged. Real, genuine, enabling trust. Still on a CTO, and with the third case manager's continued support, my daughter's recovery steadily progressed and a reduction in her medication was trialled.

Two-and-a-half years after being discharged from hospital, her medication was reduced to the lowest dose, and she was taken off a CTO on the condition she continue to stay connected with the out-patient service and take her medication.

Three years after being discharged from hospital, her medication was discontinued on the condition she continue to be clinically reviewed for signs of relapse. She continues to meet this condition and remain well.

Can I imagine my daughter being as well as she is today without CTOs? No, I can't. Can I imagine her being taken off a CTO (and medication altogether) without the experience and skills of the third case manager? No, I can't.

Person with family/carer/kin experience of CTOs

How people can have access to legal supports

Consistent access to person-centred legal representation across inpatient and community mental health settings will enable more effective and equitable Tribunal hearings.

Service Providers working with people on CTOs

How moving beyond CTOs requires planning and adequate support

Service providers wanted to assist people to come off their CTOs, with enough supports in place to increase the likelihood of success. Service providers frequently suggested that availability of meaningful supports and having the time to build relationships with people could reduce the reliance on CTOs.

> *"…a lot of people should have the opportunity to not be on it for a bit. And there should be a lot of preparation around helping the client be able to do that as well."*

> *"…if you had really good systems to support people then perhaps, we wouldn't need to do this."*

> *"Why aren't we focusing more on awareness raising, and educating, and psychotherapy and setting up good support systems…"*

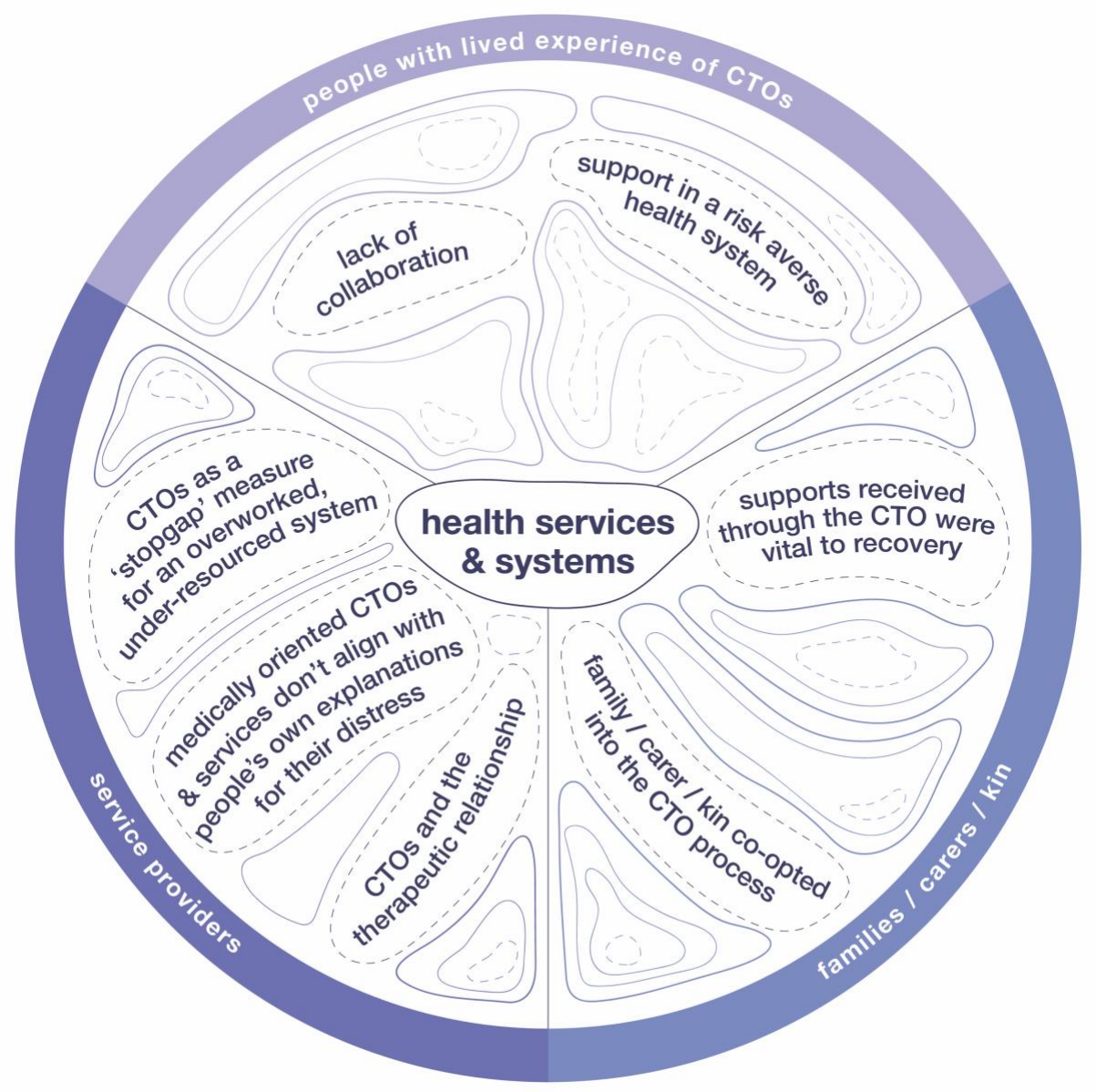
How perceived bias impacts a person's journey

Peer workers have experienced being 'side-lined' when advocating for people to come off CTO's due to assumptions that their own mental health experiences mean their judgments are biased in favour of the consumer. Peer workers suggest that the person/consumer is more involved in the CTO decision making process.

> *"…the clinicians may think that [peer workers] have more of a bias around it."*

Theme: Health Services & Systems

Figure 6. Health services & systems: summary of subthemes



People with lived experience of CTOs

Support in a risk averse health system

People with lived experience of CTO's experienced the consequences of risk averse services. People had been placed on CTO's following their first hospitalisation to mitigate risks forecasted by services independent of the person's capabilities. At other times, CTO's

were in place to filter historical risk. People with lived experience of CTOs viewed requirements for a CTO to be in place to enable discharge from hospital as punitive and manipulative.

> *"So, it wasn't really discussed. It was just they assumed that I wasn't going to take medication and I wasn't going to be compliant with medication, so they just did it. It wasn't like tried that I stopped taking medication. It was just immediately I was on CTO. That was the first time, after my first admission."*

I am a former recipient of two six-month CTOs in the 2000's. My personal experience is that CTOs are a breach of human rights. Nobody should be forced to take anti-psychotic medication. The side effects of these forced medications outweigh the benefits. The whole process is a form of social control [which] treats the symptoms of mental distress and not the cause, which is often trauma. These tranquilising medications bomb you out, so nothing matters. Robbed of motivation, one is exposed to decreased risk, simply through the 'non-living' of using anti-psychotics. This is a form of chemical restraint.

Forcing people to take medication against their will further adds to society's stigma. If people can be supported in their own time to willingly use these medications, it will go a long way to destigmatising the experience.

When people experience trauma, it is essential that they are welcomed, safe, heard, collaborated with, maintain choice and control so as not to further traumatise. This is where CTO's fail grossly in their application. Over 90% of public mental health patients have experienced trauma. I claim that because of due procedure it is more like 100%. The process of a CTO fails to be trauma informed.

Whilst I acknowledge the benefit of anti-psychotic medication when it is used voluntarily, my two CTOs did more harm than good and placed me in opposition to my community of supports. CTOs speak only of forced compliance and trauma. What we need is a trauma informed therapeutic alliance.

The author of this account has used anti-psychotic medication for 25 years and is a psychiatric survivor.

Person with lived experience of CTOs

Within a resource constrained health system, the CTO becomes a gateway to adequate mental health and disability support. This support is necessary for personal recovery and should be available whether a person is on a CTO or not. Some people said that health services neglected to provide necessary support. Mandatory interactions were often experienced as unhelpful, especially when workers misused their power. People highlighted

the need for positive interactions, helpful relationships, connection, and referrals to enable recovery. Some people agree that CTO's are needed, but not in the current approach.

> *"I became in contact with this NGO [Non-Government Organisation, for housing and support], which was helpful."*

> *"I think as long as people have the ability to abuse power, there will always be a negativity towards CTOs… I understand the necessity of them, but until there is a perfect world where people don't abuse power, then I don't think that they're a positive experience."*

> *"I think that a better CTO would have been necessary, but not the kind that I was put on."*

Lack of collaboration

People on CTOs may have experiences that impact their ability to engage with services, such as distressing cognitive processes, difficulties in self-management or prior trauma from services. Health services need to take a caring, non-threatening approach to the relationship, encouraging the person to engage with needed supports.

One young person who experienced eating distress was on a CTO that their family disagreed with. This was experienced as incompatible with the notion of family focussed practice and the benefits of family therapy over individual approaches.

> *"The people in my life at the time highly disagreed with the CTO but didn't have any involvement. But they highly disagreed with it."*

The forced nature of CTOs means there is often mutual antipathy between the person on the CTO and the mental health service, which makes collaboration difficult. Further, CTO requirements may be prioritised over personal recovery activities making it difficult for people to recover.

> *"I don't think they had any desire to work with me on it. But that goes the other way around, I don't think I had much of a desire to work with them."*

CTOs are experienced as "treating the symptoms not the cause, so relapse becomes inevitable until the cause is addressed".

> *"It's the easiest thing to treat because they just treat the physical side of it… if they just fatten you up and kick you out, it's the easiest thing to do. Stick a tube up there, drug you up… They don't actually do the hard work and get someone therapy."*

Families/carers/kin and informal supporters of people on CTOs

Family/carer/kin co-opted into the CTO process

The accumulation of health system failures to provide meaningful support can fall on families/carers/kin, consequently disrupting family ties, hopes, and someone's life trajectory. The person and their family/carer/kin may have different perspectives on the role and usefulness of health services and approach their interactions differently.

> *"It was fine initially, but then due to a lack of insight, he didn't – obviously didn't want to take the medication…"*

> *"…but that's where the CTO should be ... not just the medication, but the whole person. Let's look after these people. They didn't ask to have this illness."*

Supports received through the CTO were vital to recovery

A less common experience among the families/carers/kin interviewed was that CTO provided access to needed supports and played a vital part in the person's clinical and personal recovery. There was a great sense of relief for families/carers/kin who had this experience.

> *"If this support wasn't there my son wouldn't be able to recover."*

> *"But being on [a] CTO and having his medication, he started going and learning language. He started going to music classes. He started to have driver's licence and now he sits behind the wheel next to me and is very calm and relaxed and drives."*

Experiences of Service Providers

CTOs as a 'stop-gap' measure for an overworked, under-resourced system

In some areas, CTOs are seen as the only way to ensure someone being discharged from hospital has access to mental health care coordination, so they are imposed to ensure access to treatment. In addition, some medical officers will only provide psychosocial support if a person has a case manager, which means a CTO also becomes a point of access to psychosocial supports.

> *"This is another issue with the whole community treatment order scenario and community mental health as well, is everybody's so overworked and they have so*

many clients that sometimes people get caught in a CTO just so they're, 'They'll be okay because they have to take the medication."

"[The CTO] made sure that the person got follow-up. So if they were referred on a CTO, then they had to be followed up by the community team."

"I ... know that the evidence for CTOs is pretty abysmal, and I think you've got to have a really, really good reason to pursue treating somebody against their will."

Medically-oriented CTOs and services don't align with people's own explanations of their distress

There are many social and cultural explanations and understandings of distress and extreme states that may differ from medically oriented frames. Service providers expressed a desire for more nuanced understandings to inform responses, care, and treatment.

"I mean, it's also about how we more broadly view mental health, and mental distress, and mental illness, and so one person's unwell might not actually be unwell. Like, what does it mean to be unwell?"

"It doesn't really consider beyond that medical model take what the actual impact on that person would be, and I dare say it's more convenient for the service in many ways to just enforce what they think, rather than have any kind of conversation where the person potentially will disagree."

CTOs and the therapeutic relationship

Peer workers identified 'being in the system but not of it' and noted that CTOs impacted the peer-to-peer relationship in a way that felt antithetical to the 'peer ethos'. However, peer workers were also able to offer a non-judgmental space for a person to talk about what was going on for them, and in this way became somewhat of a buffer for the less humanistic CTO.

"In terms of how that impacted the relationship, I guess it also meant that I felt a bit like I was, I don't know if complicit is the right word, but just that then I was also having to enforce the CTO in my capacity as supporting them. And it felt, to me, it felt yucky, it felt like this isn't how I want to be conducting myself as a peer worker."

"I feel like just being able to have those conversations with her, where she wasn't seen as someone who was being difficult or bucking up against the system."

"It's very, very rare that I've actually seen a CTO enhance the [therapeutic] relationship."

Bibliography

Australian Institute of Health and Welfare (AIHW). (2024). *Involuntary treatment in mental health care.* AIHW. https://www.aihw.gov.au/mental-health/topic-areas/involuntary-treatment.

Bardell-Williams, M., Eaton, S., Downey, L., Bowtell, M., Thien, K., Ratheesh, A., Killackey, E., McGorry, P., & O'Donoghue, B. (2019). Rates, determinants and outcomes associated with the use of community treatment orders in young people experiencing first episode psychosis. *International Journal of Law and Psychiatry, 62,* 85-89. https://doi.org/10.1016/j.ijlp.2018.11.007.

Barkhuizen, W., Cullen, A. E., Shetty, H., Pritchard, M., Stewart, R., McGuire, P., & Patel, R. (2020). Community treatment orders and associations with readmission rates and duration of psychiatric hospital admission: A controlled electronic case register study. *BMJ Open, 10,* 1-9. https://doi.org/10.1136/bmjopen2019035121.

Beaglehole, B., Newton-Howes, G., & Frampton, C. (2021). Compulsory community treatment orders in New Zealand and the provision of care: An examination of national databases and predictors of outcome. *The Lancet Regional Health – Western Pacific, 17,* 1-9. https://doi.org/10.1016/j.lanwpc.2021.100275.

Brophy, L., Kokanovic, R., Flore, J., McSherry, B., & Herrman, H. (2019). Community treatment orders and supported decision-making. *Frontiers in Psychiatry, 10,* 1-12. https://doi.org/10.3389/fpsyt.2019.00414.

Canvin, K., Rugkåsa, J., Sinclair, J., & Burns, T. (2014). Patient, psychiatrist, and family carer experiences of community treatment orders: qualitative study. *Social Psychiatry and Psychiatric Epidemiology, 49,* 1873-1882. https://doi.org/10.1007/s00127-014-0906-0.

Churchill, R., Owen, G., Singh, S., & Hotopf, M. (2007). *International experiences of using community treatment orders.* Institute of Psychiatry: UK. https://www.researchgate.net/publication/228452019_International_Experience_of_Using_Community_Treatment_Orders.

Corring, D., O'Reilly, R., & Sommerdyk, C. (2017). A systematic review of the views and experiences of subjects of community treatment orders. *International Journal of Law and Psychiatry, 52,* 74-80. http://dx.doi.org/10.1016/j.ijlp.2017.03.002.

Corring, D., O'Reilly, R., Sommerdyk, C., & Russell, E. (2018a). What families have to say about community Treatment orders. *Canadian Journal of Community Mental Health, 37*(2), 1-12. https://doi.org/10.7870/cjcmh-2018-008.

Corring, D., O'Reilly, R. L., Sommerdyk, C., & Russell, E. (2018b). What clinicians say about the experience of working with individuals on community treatment orders. *Psychiatric Services, 69*(7), 791-796. https://doi.org/10.1176/appi.ps.201700492.

Corring, D., O'Reilly, R., Sommerdyk, C., & Russell, E. (2019). The lived experience of community treatment orders (CTOs) from three perspectives: A constant comparative analysis of the results of three systematic reviews of published qualitative research. *International Journal of Law and Psychiatry, 66,* 1-5. https://doi.org/10.1016/j.ijlp.2019.101453.

Department of Health and Social Care. (2018). The independent review of the Mental Health Act: Interim report. Department of Health and Social Care: UK. https://www.gov.uk/government/publications/independent-review-of-the-mental-health-act-interim-report.

Edan, V., Brophy, L., Weller, P. J., Fossey, E., & Meadows, G. (2019). The experience of the use of community treatment orders following recovery-oriented practice training. *International Journal of Law and Psychiatry, 64,* 178-183. https://doi.org/10.1016/j.ijlp.2019.04.001.

Glaw, X., Inder, K., Kable, A., & Hazelton, M. (2017). Visual methodologies in qualitative research: Autophotography and photo elicitation applied to mental health research. *International Journal of Qualitative Methods, 16,* 1-8. https://doi.org/10.1177/1609406917748215.

Goulet, M-H., Lessard-Deschênes, C., Pariseau-Legault, P., Breton, R., & Crocker, A. G. (2023). Community treatment orders: A qualitative study of stakeholder perspectives. *International Journal of Law and Psychiatry, 89,* 1-7. https://doi.org/10.1016/j.ijlp.2023.101901.

Gupta, S., Akyuz, E. U., Baldwin, T., & Curtis, D. (2018). Community treatment orders in England: Review of usage from national data. *BJPsych Bulletin, 42,* 119-122. https://doi.org/10.1192/bjb.2017.33.

Harris, A., Chen, W., Jones, S., Hulme, M., Burgess, P., & Sara, G. (2019). Community treatment orders increase community care and delay readmission while in force: Results from a large population-based study. *Australian & New Zealand Journal of*

Psychiatry, 53(3), 228-235. https://doi-org.ezproxy.scu.edu.au/10.1177/0004867418758.

Kisely, S., McMahon, L., & Siskind, D. (2023). Benefits following community treatment orders have an inverse relationship with rates of use: Meta-analysis and meta-regression. *BJPsych Open, 9*(68), 1-12. https://doi.org/10.1192/bjo.2023.28.

Kisely, S., Moss, K., Boyd, M., & Siskind, D. (2020). Efficacy of compulsory community treatment and use in minority ethnic populations: A statewide cohort study. *Australian & New Zealand Journal of Psychiatry, 54*(1), 76-88. https://doi-org.ezproxy.scu.edu.au/10.1177/0004867419877690.

Kisely, S., Yu, D., Maehshi, S., & Siskind, D. (2021). A systematic review and meta-analysis of predictors and outcomes of community treatment orders in Australia and New Zealand. *Australian & New Zealand Journal of Psychiatry, 55*(7), 650-665. https://doi-org.ezproxy.scu.edu.au/10.1177/000486742095428.

Lawton-Smith, S., Dawson, J., & Burns, T. (2008). Community treatment orders are not a good thing. *The British Journal of Psychiatry, 193,* 96-100. https://doi.org/10.1192/bjp.bp.107.049072.

Light, E. (2014). The epistemic challenges of CTOs. *Psychiatric Bulletin, 38,* 6-8. https://doi.org/10.1192/pb.bp.113.045732.

Light, E., Kerridge, I. Robertson, M., Boyce, P., Carney, T., Rosen, A., Cleary, M., Hunt, G., O'Connor, N., & Ryan, C. (2015). Involuntary psychiatric treatment in the community: General practitioners and the implementation of community treatment orders. *The Royal Australian College of General Practitioners, 44*(7), 485-489. https://search-informit-org.ezproxy.scu.edu.au/doi/10.3316/informit.299640941218845.

Light, E., Kerridge, I., Ryan, C., & Robertson, M. (2012). Community treatment orders in Australia: Rates and patterns of use. *Australasian Psychiatry, 20*(6), 478-482. https://doi.org/10.1177/1039856212466159.

Light, E., Robertson, M., Boyce, P., Carney, T., Rosen, A., Cleary, M., Hunt, G. E., O'Connor, N., Ryan, C., & Kerridge, I. (2014). The lived experience of involuntary community treatment: A qualitative study of mental health consumers and carers. *Australasian Psychiatry, 22*(4), 345-351. https://doi.org/10.1177/1039856214540759.

Light, E. M., Robertson, M. D., Boyce, P., Carney, T., Rosen, A., Cleary, M., Hunt, G. E., O'Connor, N., Ryan, C. J., & Kerridge, I. H. (2017). How shortcomings in the mental health system affect the use of involuntary community treatment orders. *Australian Health Review, 41,* 351-356. https://doi.org/10.1071/AH16074.

McMillan, J., Lawn, S., & Delany-Crowe, T. (2019). Trust and community treatment orders. *Frontiers in Psychiatry, 10,* 1-10. https://doi.org/10.3389/fpsyt.2019.00349.

Mfoafo-M'Carthy, M., & Williams, C. C. (2015). Coercion and community treatment orders (CTOs): One step forward, two steps back? *Canadian Journal of Community Mental Health, 29*(1), 69-80. https://doi.org/10.7870/cjcmh-2010-0006.

Nakhost, A., Simpson, A. I. F., & Sirotich, F. (2019). Service users' knowledge and views on outpatients' compulsory community treatment orders: A cross-sectional matched comparison study. *The Canadian Journal of Psychiatry, 64*(10), 726-735. https://doi.org/10.1177/0706743719828961.

Nakhost, A., Sirotich, F., Francombe Pridham, K. M., Stergiopoulos, V., & Simpson, A. I. F. (2018). Coercion in outpatients under community treatment orders: A matched comparison study. *The Canadian Journal of Psychiatry, 63*(11), 757-765. https://doi.org/10.1177/0706743718766053.

Newton-Howes, G., & Banks, D. (2014). The subjective experience of community treatment orders: Patients' views and clinical correlations. *International Journal of Social Psychiatry, 60*(5), 474-481. https://doi.org/10.1177/0020764013498870.

O'Brien, A-M. A., & Farrell, S. J. (2005). Community treatment orders: Profile of a Canadian experience. *Canadian Journal of Psychiatry, 50*(1), 27-30. https://doi.org/10.1177/070674370505000106.

Owens, N., & Brophy, L. (2013). Revocation of community treatment orders in a mental health service network. *Australasian Psychiatry, 21*(1), 46-50. https://doi.org/10.1177/1039856212470504.

Riley, H., Lorem, G. F., & Høyer, G. (2018). Community treatment orders – what are the views of decision makers? *Journal of Mental Health, 27*(2), 97-102. https://doi.org/10.1080/09638237.2016.1207230.

Robertson, M., Light, E., Boyce, P., Carney, T., Rosen, A., Cleary, M., Hunt, G., O'Connor, N., & Ryan, C. (2013). *Community treatment orders: The lived experience of consumers and carers in NSW.* Centre for Values, Ethics and the Law in Medicine, University of Sydney. http://hdl.handle.net/2123/14913.

Rugkåsa, J., & Burns, T. (2017). Community treatment orders: Are they useful? *BJPsych Advances, 23,* 222-230. https://doi.org/10.1192/apt.bp.115.015743.

Ryan, C. J. (2019). Community treatment orders are (somewhat) effective: Their future in the context of rights-based mental health law. *Australian & New Zealand Journal of*

Psychiatry, 53(1), 11-12. https://doi-org.ezproxy.scu.edu.au/10.1177/00048674187913.

Segal, S. P., Rimes, L., & Badran, L. (2023). Crime and victimization outcomes following civil rights limits to the use of compulsory treatment. *Psychiatry Research, 327,* 1-11. https://doi.org/10.1016/j.psychres.2023.115377.

Simon, J., Mayer, S., Laszewska, A., Rugkåsa, J., Yeeles, K., Burns, T.A. (2021). Cost and quality-of-life impacts of community treatment orders (CTOs) for patients with psychosis: Economic evaluation of the OCTET trial. *Social Psychiatry and Psychiatric Epidemiology, 56,* 85-95. https://doi.org/10.1007/s00127-020-01919-4.

Stroud, J., Banks, L., & Doughty, K. (2015). Community treatment orders: Learning from experiences of service users, practitioners, and nearest relatives. *Journal of Mental Health, 24*(2), 88-92. https://doi.org/10.3109/09638237.2014.998809.

Taylor, M., Macpherson, M., Macleod, C., & Lyons, D. (2016). Community treatment orders and reduced time in hospital: A nationwide study, 2007-2012. *BJPsych Bulletin, 40,* 124-126. https://doi.org/10.1192/pb.bp.115.051045.

Weller, P., Alvarez-Vasquez, S., Dale, M., Hill, N., Johnson, B., Martin, J., Maylea, C., & Thomas, S. (2019). The need for independent advocacy for people subject to mental health community treatment orders. *International Journal of Law and Psychiatry, 66,* 1-9. https://doi.org/10.1016/j.ijlp.2019.101452.

World Health Organization (WHO). (2023). *Mental health, human rights, and legislation: Guidance and practice.* WHO & United Nations: Geneva. https://www.who.int/publications/i/item/9789240080737.

Appendix A – Interview Questions

Interview Questions (and prompts) for People with Lived Experience of Community Treatment Orders (CTOs)

Do/did you think you should be on a CTO? How do/did you feel about the CTO?

- What do you understand about being on a CTO?
- Do/did you agree about the need for it? What do/did you think about the treatment/medication it required/mandated?
- How do your beliefs/experiences compare with those of the professionals implementing your CTO?

Did you understand the process of being put on a CTO and the reason for it?

- Was it explained to you (in a way you could understand e.g., interpreters, written explanation)? How were language barriers addressed?
- Do you have any suggestions for how CTOs could be explained to people?

Do you believe your perspective was heard and your rights upheld?

- Were you listened to? Were your rights explained? Did you have access to legal representation?
- How do you feel you were treated in the process of being on a CTO?
- Were your beliefs about your experiences and needs understood and respected through the process of being on a CTO? If so, how? If not, how?
- Were your spiritual or religious beliefs understood and respected through the process of being on a CTO? If so, how? If not, how?

What is your perspective on (your) CTO/s? (positive, negative, mixed, has this changed?)

- How has your experience of the CTO changed over time?
- Has your wellbeing changed over time?

What changed when you were on a CTO?

- Did you get the support you needed while you were on the CTO? Did your supports change during the CTO?

How did the CTO impact in relation to your 'recovery' and life plans?

- Do you feel like the people supporting you understand the concept of mental health recovery and citizenship?
- What happened when your CTO finished? How did you feel about this? Was anything else needed?

How do you understand your distress/mental health experiences?

- What caused/s your mental distress? (or not?)
- Does your perspective align with that of doctors and other health workers involved in your CTO/s? What is your experience of doctors and health workers involved in your CTO/s? How does this impact you/your mental wellbeing? (Or not?)

Did you have any agreements with the mental health service about working together in relation to the CTO? e.g., alternative approaches to the CTO process or implementation

- Was there any sort of planning around how you would work together?

What sort of involvement did your family/kin/carers have with the CTO? How would you have liked them to be involved, if at all?

- How would people like their carers/families/friends to be involved in the implementation of the CTO and towards the end of it?

For First Nations people on CTOs:

- Does the CTO impact when you need to go back on Country or attend to sorry business? If so, could you describe how it impacts?

Final question:

- Is there anything else you'd like to tell us about your experience of CTOs?

Interview Questions for Supporters (Family Members, Service Providers)

1. What did the CTO mean to you, and what did it mean to have to uphold the conditions? Did that affect the relationship?
    a. What challenges, if any, arose from the CTO for you as the person's supporter?
    b. Does the CTO impact rapport with the person?

2. Do you believe the CTO played a role in the person's recovery?

3. What level of involvement did you have in the CTO decision-making process? How did you feel about this?

4. How confident did you feel about the purpose of the CTO?

5. What are your intentions when treating/supporting a person/loved one on a CTO (Prompts: Time? Goals? What do you want to achieve?)

6. Have you noticed any changes in the person, positive or negative, while on the CTO?

7. Were there any positive or negative impacts on the person's physical wellbeing? What were they?

8. Advocacy aspect - What is your experience advocating for the person on the CTO?

9. What is your experience of the process of the CTO? (The procedural aspects, involvement of the tribunal etc) (Also right to information and legal representation)

10. The timeframe of review for CTOs is usually 6 months. How long do you think that should be? (Prompts: Shorter? Longer? The same? Are supporters aware they can ask for an earlier review?)