Community treatment orders: the lived experience of consumers and carers in NSW
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Executive summary

i. There is limited research examining the lived experiences of consumers and carers subject to community treatment orders (CTOs).

ii. Between 2009 and 2012, the Centre for Values Ethics and the Law in Medicine (VELiM) at the University of Sydney conducted a research program examining this area, on behalf of the Mental Health, Drug and Alcohol Office (MHDAO) of NSW Health. (The research was part of a larger project examining CTO decision-making, in which clinicians and Mental Health Review Tribunal members were also interviewed.)

iii. Eleven participants – five consumers and six carers – participated in the research project by taking part in in-depth interviews about their experiences. This interview data set was analysed using qualitative methodologies.

iv. The lived experience of consumers and carers of CTOs in NSW had five themes: ‘access’, ‘isolation’, ‘loss and trauma’, ‘resistance and resignation’ and ‘vulnerability and distress’. These spoke to the experiential components of the losses and trauma associated with a severe mental illness, the compromises associated with the assumption of the sick role, and the challenges of managing the relationships and engagements necessitated by these processes.

v. According to the theory that emerges from our analysis of the data, the experience of living under a CTO in NSW is a mixture of distress and of acknowledgement of the value of the process. This generalised across both the consumer and the carer participant groups.

vi. In a number of the narratives provided, there were both direct and indirect experiences of sub-optimal care, usually the result of excessive demands on particular health services and the overall deprivation or social injustice faced by many suffering from severe mental illness.

vii. The distress, isolation, grief and loss experienced by those affected by CTOs appeared to be a part of the experience of a severe mental illness. Putting aside instances where CTOs were implemented poorly, the kind of illness and level of disability experienced by those who needed such treatment interventions was an intrinsic source of distress. The need for a CTO emerged from that illness and, by extension, that distress. In essence, the experience of distress around a CTO seemed to be indistinguishable from the distress of the severe illness that necessitated it.

viii. All of the consumer participants and many of the carer participants described the experience of CTOs as being characterised by problems with communication and understanding.

ix. The model of the lived experience of CTOs for consumer and career participants can be distilled as one of profound ambivalence. As a part of the tragic journey taken by consumers and their carers in the course of a severe mental illness, CTOs are associated with distress and a sense of loss, isolation and disempowerment.

x. From these data the study proposed a model of experience of being subject to a CTO in NSW is one of a core distress, emerging from the distress of the illness, communication gaps, difficultly accessing services, and the perceived benefits of CTOs.
xi. The findings of this research are in general agreement with other studies in that the loss of autonomy and constraints associated with a CTO are balanced with their clear benefits. These findings build on existing research in the field.

xii. From this research, it is evident that the distress arising from being subject to a CTO can be assuaged by those tasked with their implementation by focusing upon clearer communication about the order (including strategies to ensure consumers and their carers are aware of the specifics of the order), strategies to improve access to services for mental and physical services and other social institutions, and acknowledging that the CTO is a part of the overall distress of a severe mental illness.
Part 1 – Background

1.1 Community treatment orders

Laws for involuntary psychiatric treatment in the community setting
A community treatment order (CTO) is a legal order made by clinicians and tribunals, setting out the terms under which a person must accept treatment – including medication and therapy, counselling, management, rehabilitation and/or other services – while living in the community.

CTOs emerged in the 1980s in some North American and Australasian jurisdictions in response to the emergence of problems encountered in the community setting following deinstitutionalisation – such as the ‘revolving door’ syndrome (recurrent patient hospital admissions), homelessness and criminalisation of people with mental illness – as a less restrictive alternative to involuntary hospitalisation.\(^1\)\(^5\)

During the 1980s and 1990s, statutory provisions for CTOs were introduced in all Australian states and territories, Israel, New Zealand, Canada,\(^1\) and 44 states of the US.\(^6\) More recently, Scotland,\(^1\) England\(^7\) and Egypt\(^8\) have also introduced CTO laws.

The introduction of CTOs in NSW
In 1988, a NSW ministerial review of mental health legislation by the Steering Committee on Mental Health (the ‘Deveson Committee’) included in its recommendations for reform the introduction of ‘community treatment orders’, both as an alternative to compulsory hospitalisation and as a way of intervening to prevent deterioration to the point where compulsory hospitalisation is necessary.\(^9\) Following a further review of laws by the Ministerial Implementation Committee on Mental Health and Development Disability (the ‘Barclay Committee’) in 1988, the Mental Health Act 1990 was passed by the NSW Parliament, including its provisions for CTOs to authorise and regulate involuntary treatment in the community setting.

Amendments to the CTO provisions of the Act since their introduction have included:

- Extending the maximum duration of CTOs from 3 months, to 6 months (1997 amendment) to 12 months (2007 amendment), and
- Enabling CTOs to be made for people living in the community, without the need for prior inpatient admission (2007 amendment).

The current CTO provisions are included in Sections 50-67 of the Mental Health Act 2007.

Under the Act, the criteria for involuntary community treatment focus on decisions about the necessity of care, treatment or control of a person with a mental illness:

- For the person’s own protection from serious harm, or
- For the protection of others from serious harm.

The continuing condition of the person, including any likely deterioration in the person’s condition and the likely effects of any such deterioration, are to be taken into account in considerations of whether a person is mentally ill.
Other criteria in the Act for making a CTO include determinations that:

- No other care of a less restrictive kind, that is consistent with safe and effective care, is appropriate and reasonably available to the person and that the affected person would benefit from the order as the least restrictive alternative consistent with safe and effective care, and
- A declared mental health facility has an appropriate treatment plan for the affected person and is capable of implementing it, and
- If the affected person has been previously diagnosed as suffering from a mental illness, the affected person has a previous history of refusing to accept appropriate treatment.

1.2 Previous research into the CTO lived experience

There have been only a limited number of well-conducted qualitative studies seeking to describe the lived experience of CTOs. Of those conducted, the findings tend to overlap. Consumers are generally dissatisfied with many aspects of the use of CTOs and view CTOs as 'stigmatising' and 'disempowering'. Many consumers harbour concerns about the loss of autonomy that follows the use of a CTO. In spite of this lamentable observation, many consumers and their carers are generally supportive of community treatment orders in lieu of inpatient care. Indeed many consumers attribute their clinical improvement to the improved quality of care they enjoyed under a CTO. There is general acceptance of the use of CTOs for beneficial purposes where there were psychiatric 'problems', lack of insight or risk. Many consumers prefer CTOs to hospital care, criminal justice settings or homelessness, although in contrast, they are aggrieved at loss of control over their circumstances.

One study identified a number of components of the experience of being on a CTO including 'Loss of credible identity', 'Playing the game', 'Medicalization', 'Therapeutic competence and incompetence' and 'Increased control'. In a New Zealand study, female consumers were observed to consider that the overall advantages of CTOs outweighed the disadvantages and conclude that CTOs allowed them to remain out of hospital long enough to rebuild their lives and maintain their close relationships. Similarly, consumers of Maori ethnicity considered CTOs as helpful in increasing their and their whānau (extended family) safety and in improved ability to access services.

Most consumers seem to believe the main purpose of CTOs was to ensure they took medication, although they further acknowledge that CTOs facilitate better access to other treatments, supported accommodation and improved clinical contact. Patients experienced some degree of coercion while on the orders, but many believed that CTOs provided necessary structure in their lives. Clinicians tended to be positive in their views and acknowledged the tension between the benefits of CTOs and the person's right to self-determination.

Carers consider that CTOs provide relief for them and a supportive structure for their relative's care. Indeed carers appear to be generally in favour of the use of CTOs, with positive influences on all parties. In the alternate, some carers regard the use of
the involuntary commitment as influenced greatly by the pressures experienced by the mental health services and many reported unsatisfactory interactions with health services, causing major problems in the therapeutic relationships.20

The existing scientific literature thus indicates that the observations of lived experience of CTOs from a consumer and carer perspective involves tension between the undesirable sense of coercion and loss of autonomy associated with such orders with the clear benefits in terms of improved clinical state and psychosocial function and improved access and engagement with treatment services.

1.3 Definitions

‘Community treatment orders’
For the purposes of consistency, this study uses the term ‘community treatment order’ (or ‘CTO’) throughout to refer to the legal orders that authorise and govern involuntary psychiatric treatment in the community setting. This is consistent with the terminology used in the relevant sections of the NSW Mental Health Act 2007 and in the clinical and legal processes that administer involuntary treatment in NSW, as well as other Australian and international jurisdictions. In some Australian jurisdictions, they may also be called ‘community management orders’ or ‘involuntary treatment orders (community category)’. Internationally, CTOs may also be known as ‘mandatory outpatient treatment’, ‘assisted outpatient treatment’, or ‘involuntary outpatient treatment’.1

‘Consumer’
This report uses the term ‘consumer’ to refer to someone who is using, or has used, or may use mental health services. In Australia, ‘consumer’ is the most common term for a mental health service user and can be aligned with the wider consumer rights movement and accompanying expectations around rights and protection, being treated with respect and dignity, having regulations and standards and having an entitlement to redress for misrepresentation and poor quality services.

‘Carer’
The term ‘carer’ in this report refers to an unpaid person who cares for a consumer, as distinguished from a ‘care worker’ who is a paid worker providing services to a consumer. The term ‘carer’ can also describe a person whose life is affected through a close relationship with a consumer, or who has a chosen caring role with a consumer. Under the Mental Health Act 2007 in NSW, a consumer can nominate a ‘primary carer’, who is the person a mental health facility will notify and share information with in relation to the consumer’s treatment and care planning. Section 71 of the Act states that if a ‘primary carer’ is not already a guardian, a parent of a patient who is a child, or someone nominated by the patient, then they may be a spouse, a close relative or friend, or ‘any person who is primarily responsible for providing support or care to the patient (other than wholly or substantially on a commercial basis)’. ‘Close friend or relative’ is defined as a friend or relative of the patient who maintains both a close personal relationship with the patient through frequent personal contact and a
personal interest in the patient’s welfare and who does not provide support to the patient wholly or substantially on a commercial basis.

1.4 The ‘CTO project’
This study was commissioned by the Mental Health, Drug and Alcohol Office (MHDAO) of NSW Health to provide a qualitative analysis of the lived experience of consumers subject to CTOs and carers of people subject to CTOs in NSW. This study was linked to another inquiry conducted on behalf of MHDAO by the same research group examining how the concepts of ‘risk’ and ‘capacity’ could be constructed in the context of decisions around the use of CTOs. (The results of the ‘risk and capacity’ arm of the study are reported elsewhere.)

The study was funded over two years by a discretionary grant from NSW Health of $115,624 (AUD) from July 2009 to August 2012.

The study was conducted by the Centre for Values, Ethics and the Law in Medicine (VELiM) at the University of Sydney in cooperation with the Discipline of Psychiatry and the Faculty of Law at the University of Sydney.

**Investigators**
The research team comprised:

- Clinical Associate Professor Michael Robertson – Chief Investigator (VELiM and Discipline of Psychiatry)
- Clinical Professor Allan Rosen (Brain and Mind Research Institute)
- Professor Terry Carney (Faculty of Law)
- Professor Philip Boyce (Discipline of Psychiatry)
- Dr Chris Ryan (VELiM and Discipline of Psychiatry)
- Associate Professor Glenn Hunt (Discipline of Psychiatry)
- Dr Nick O’Connor (Discipline of Psychiatry)
- Associate Professor Michelle Cleary (School of Nursing)
- Ms Edwina Light (VELiM)
- Ms Pippa Markham (VELiM)

**Stakeholder reference group**
In addition to the investigation team, the project also sought the ongoing involvement of representatives from different stakeholder groups:

- Mr Peter Bazzana (NSW Institute of Psychiatry)
- Mr Rodney Brabin (Mental Health Review Tribunal)
- Ms Corinne Henderson (Mental Health Coordinating Council)
- Dr Peri O’Shea / Ms Lauren Whibley (NSW Consumer Advisory Group - Mental Health Inc)
• Mr Patrick Parker (Community Mental Health Services Liverpool/ Fairfield & NSW Health Mental Health, Drug and Alcohol Office representative)
• Dr Grant Sara (InforMH)
• Ms Laraine Toms (Carers NSW)

Funding/Costs
A report of the project’s expenditures is included in Appendix 5.1.

Conduct of study
The study was conducted between July 2009 and August 2012. Administrative and academic activities were based at VELiM at the University of Sydney.

The research involving consumers and carers was conducted with the approval of the University of Sydney Human Research Ethics Committee (approved 6 April 2010) reference number 12583.

Copies of the relevant ethics committee approval and associated documents are included in Appendix 5.2.
Part 2 – Methods

3.1 Research questions
The investigators sought to derive an idiographic model of the lived experience of consumers and carers of CTOs in NSW. An idiographic approach aims to understand the meaning of specific and subjective phenomena, in this case the unique, dynamic and often multi-faceted experience of involuntary psychiatric treatment in the community setting.

The research questions were formulated as:

1. How do mental health consumers describe their experiences of being subject to CTOs?
2. How do mental health consumers and carers describe clinical decision-making about CTOs and their participation in those processes?

2.2. Sample acquisition

Recruitment
The participants were recruited using a theoretical purposive model of sampling. Recruitment and data collection methods were framed around answering the above research questions and informing the development of the lived experience model. The researchers therefore sought to recruit people with a range of CTO experiences, including but not limited to current or past CTOs, those ordered in different geographic locations, or those relating to people with different diagnoses of mental illness. This involved an iterative process of data acquisition and analysis in which the analysis of one interview informed the conduct of the subsequent interviews. The value of this approach was that as new themes emerged from the existing analysis, subsequent interviews were modified to focus on clarification or exploration of emergent themes. As new themes, or expanded concepts of other themes emerged, the existing data was re-coded in the light of this information.

Initial contact between researchers and participants was at ‘arm’s length’, with the circulation of an invitation to participate to Carers NSW, the Mental Health Coordinating Council, and NSW Consumer Advisory Group – Mental Health Inc. This was further circulated through their relevant networks and by individual recommendations of the study. People interested in participating then contacted the researchers for more information and/or to arrange an interview. Participants received $40 at interview to go toward any public transport, taxi fares or parking fees associated with their attendance.

Sample strategy
The investigators sought to build a sample of maximum variation, rather than a representative sample. Maximum variation sampling involves developing a sample in which as many different subgroups of different participants are included. This did not allow justification of claims to generalisability of the findings of the study, but rather it
enabled the investigators to describe and understand a range of experience and build a comprehensive model of the lived experience of consumers and carers of CTOs in NSW.

**Data saturation**
The investigators concluded that the data had reached saturation at the time of the analysis of the interview of the 10th participant. A further interview was conducted to confirm the inference of theoretical saturation. The investigators sought to confirm saturation by triangulation of the data coded separately by two members of the team (MR/EL) and through discussion of the data among the investigators and stakeholder reference group members at regular research meetings. Triangulation is an intrinsic component to methodologically sound qualitative research. Triangulation usually involves comparisons from the data source, investigator, theory, and method.

**2.3. Interviews**
The investigators opted to conduct the study using in-depth semi-structured interviews conducted in a variety of sites. The interview structure is included in Appendix 5.2. Consumer and carer participants were not interviewed in clinical settings, as the investigators sought to maintain a clear distinction between their voluntary participation in the study and their involuntary treatment status. Interviews were conducted at the offices of Carers NSW, Mental Health Coordinating Council, and the NSW Consumer Advisory Group.

In the conduct of the interviews, the investigators sought to prompt the participants to speak from their unique experience by providing narrative accounts of their experience of CTOs and related processes.

The interviews were recorded digitally and transcribed. The interview transcripts were de-identified, removing any details that might identify individual participants and compromise participant confidentiality.

**2.4 Analysis**
The investigators analysed the data using the NVIVO9 computer program which enables different coding strategies and cross checking of different concepts across the sample. The investigators utilised Grounded Theory methods as described by Charmaz and Corbin and Strauss.

As the data was coded, new themes were identified and a coding structure then developed. This involved a process of ‘sorting’ the different fragments of the coded data and ‘memo writing’ in which theoretical ideas about the nature of the codes and their relationship with other codes emerged. After this process of ‘open’ coding of the data, the codes were collapsed into different categories using the ‘tree nodes’ function of NVIVO9. This process included an intermediate step of generating visual models of the coded categories and their clustering around a central theme. This facilitated the emergence of ‘concepts’, which were then brought together to create ‘categories’.
As the model of lived experience emerged, the researchers then linked the different categories to theorise explanations of the model that emerged from the data.

2.5. Reflexive processes

Given the deep engagement with the data required by qualitative data analysis, researchers need to acknowledge the situation of the analysis and identify sources of bias in the analysis of the data. Biased analysis of qualitative data inhibits the emergence of new ideas and forces the data into existing models, thus privileging a particular perspective. In order to avoid the data being ‘forced’, the open coding process was performed by a research officer who had no direct experience of the use of CTOs prior to the project (EL).

The necessary reflexive process utilised a two-phased triangulation strategy where the chief investigator (MR – a psychiatrist) coded selected transcripts independent of the initial coding process. The two coding structures were compared for disparities and then, utilising a quasi-dialectic process, the divergent coding structures were synthesised into an integrated structure.

The models were further triangulated through discussion at research meetings with the investigation team and stakeholder reference group. The investigators then presented preliminary analysis of the data at several research seminars and scientific meetings, where audience responses were noted.
Part 3 – Results

3.1 Population
Five consumers and six carers participated in interviews. Six were men and five women from metropolitan or regional/ rural areas. Among either the consumers or the relative of the carer were diagnoses of schizophrenia, depression, bipolar disorder, and anxiety.

Figure 1: Consumer and carer participants

All of the CTOs under discussion were initiated from hospital, although renewals of CTOs in a community setting were also discussed at interview. Six of the interviews related to CTOs currently in place, whereas other CTOs had either lapsed or the status of the CTO was unknown.

Figure 2: Diagnoses of people subject to CTOs discussed at interviews

One issue of note was the difficulties in recruiting consumers subject to CTOs through non-clinical pathways. In opting to not recruit through treating clinicians, the yield of
suitable participants was lower than anticipated. Moreover, several suitable participants agreed, and either later withdrew or were unable to participate. This is in line with the experiences of other researchers in this area.\textsuperscript{17} Also noteworthy that it is possible, as with other research about CTOs,\textsuperscript{17} there may be systematic bias in the consumer participant sample in that those who agreed to take part were more likely to have some level of positive regard for CTOs and insight. At least one potential participant, who did not proceed to interview in our study, had indicated he or she wished to raise at interview a number of negative views about CTOs and a current challenge he or she was making to an order. Several other potential participants did not proceed to interview due to deterioration in their health. Regardless of the problems of achieving a maximum variation sample, we were confident in our claims of thematic saturation.

**Figure 3: Status of CTOs discussed at interviews**

<table>
<thead>
<tr>
<th>CTO status at interview</th>
<th>Current (n=6)</th>
<th>Lapsed</th>
<th>Unknown (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>55%</td>
<td>27%</td>
<td>18%</td>
<td></td>
</tr>
</tbody>
</table>

### 3.2 Data analysis

Through the Grounded Theory analysis of the data, the lived experience of consumers and carers of CTOs in NSW had five themes (Figure 4): ‘Access’, ‘Isolation’, ‘Loss and trauma’, ‘Resistance and resignation’ and ‘vulnerability and distress’. These spoke to the experiential components of the losses and trauma associated with a severe mental illness, the compromises associated with the assumption of the sick role, and the challenges of managing the relationships and engagements necessitated by these processes.
3.2.1 Access
The theme of ‘access’ is shown in Figure 5. ‘Access’ referred to the experiences and challenges of carers and consumers in accessing to mental health services.

One carer reported of the difficulties in ensuring ongoing access to care when his or her relative considered relocating:

‘But, you know I was in a state about a month ago when no one was applying for it, trying to push, push, push the psychiatrist and his case manager. And I finished up having a big argument with his psychiatrist, because it was three weeks before the CTO was finished, and my son was packing up to go the country again. And if he had of gone, they wouldn’t apply for it because he’s not there, the team in [RURAL AREA] wouldn’t apply for it, because there’s no one to administer it, and we would have gone through exactly the same process as we did the year before, where you just have to wait six to nine months until he’s so bad or does so much damage to something, that the Police pick him up.’

In some instances, the participants referred to their difficulties accessing services and maintaining care and in particular ‘having to push for help’ or ‘being ignored or pushed out of system’. For many, this problem with access led to treatment gains being lost. One carer spoke of his or her experience trying to prevent a relative being given leave or discharge over a weekend:

‘He may be not here now, because he was really, really saying, “I am sick”. And when I explained it to the doctor at the hospital, he was talking about sending him home on the weekend. And I questioned the doctor, said “are you sure he’s coming home, isn’t he a risk to hurt himself?” He didn’t answer that question. But he never sent him home on the weekend.’
Figure 5: The theme of access

A number of participants expressed the view that the care they received from busy mental health services would only be enhanced if a CTO was in place. As one carer observed of his or her spouse:

‘When she was on the CTO, yes I think she was much more, there was much more treatment involved. ... I felt they were giving her more attention because she was on a CTO. Maybe that wasn’t the case, but I really felt it was.’

Participants noted that under an involuntary treatment order, they still had to advocate, be assertive and proactive in accessing care for themselves or their relative. One carer participant discussed his or her frustration and concern about iatrogenic harm from medication and the need to argue for a review of treatment:

‘I disagreed, and I said “no, I think the equation has changed now, I think the risk is greater than the benefit”. And so I really encouraged them strongly, would they review her medication with a view of stopping it. Anyway, so they’ve entertained that thought, she’s now been off antipsychotic medication. Well it’s been 12 months or more off antipsychotic medication.’

Another carer participant spoke of the need for family members to be more assertive in their interaction with the mental health system and his or her advocacy among other carers:

‘It’s changing, but I think they want the family members to be more proactive themselves. And that’s what I’ve been training my people, or the ladies who come to the group, to start speaking up, because if you don’t say anything, then the system won’t change.’

When there was good access and agency in care, consumers were able to manage symptoms, recognise signs of deterioration and improvement in health. The person’s
health would then stabilise, enabling the consumer and his or her family to learn to live with the illness. One consumer noted of his or her CTO:

‘It made me think that hey I really need to take my medication daily, you know because what happened was I started feeling well and I thought yeah this is the medication, so yeah it was taking the medication.’

When asked about his or her feelings about the longer term management of their health, this participant stated:

‘No, I’m not worried, I think I’m going to learn to live with it, and live with it well...’

Another consumer participant reflected on the benefits of a CTO, observing that:

‘...in the event that a person really is a problematic person, I think that it’s a good thing that those things are in place, I think some people actually need those sort of implementations.’

The complexities of medico-legal procedures and the nature of debate over the complexities of the Mental Health Act was a particular challenge in accessing care. This required the consumer and his or her family to both identify and engage in the specialised processes around CTOs. One carer observed that, regardless of the interaction with case managers, psychiatrists or other mental health professions:

‘...a CTO is a legal matter, it’s a legal medical matter isn’t it when you think about it?’

Another carer acknowledged that, while imperfect, he or she had to engage as best they could and manage each contingency as it presented itself:

‘You know, I can’t change the system, I can just exist within it. [Laughs] You fight the battles as they come.’

The actual engagement with both the health system and the legal processes surrounding CTOs, by necessity, involved the development of a nuanced understanding and knowledge of the processes involved in the administration and implementation of CTOs. One carer recalled of their initial encounter with the processes of CTOs:

‘...definitely at that time I didn’t have the knowledge that I have now. I know now to be more assertive, and I know now that I have more resources available to me.’
One carer participant noted that his or her knowledge of the imperfections of the system was critical in his or her understanding of the operation of involuntary treatment:

‘I liken it to a paling fence, all I can see is between the gaps, and when you link that together, I’ve come up with my sense of my perspective of what’s going on.’

The impairment of the capacity for insight or judgement meant that many of the participants valued the compulsion to adhere and engage in treatment. One consumer participant reflected that:

‘I think it was really helpful for me in my situation, I think it was really helpful for me, I was really happy that I was on it for say three months and then taken off it once you could see that I was taking my medics and correctly, but actually going on the community treatment order was the best thing that happened to me.’

The process of engagement through a CTO engendered and helped maintain a sense of optimism in the face of the challenges of insightlessness, impaired judgement or disorganisation when caring for a relative with mental illness. A carer participant noted that the CTO applied to his or her son:

‘proved to be the most effective way of treating my son, so I’m very happy with them doing that. I think that for people like my son who is uncompliant, it is a way of keeping him out of hospital. I know that the general trend in mental health is towards making it more for the rights of the individual, and my argument against this is he’s also got a right to be well.’

While CTOs fostered engagement, the intrinsic coercion and the at times impenetrable processes around CTOs had the effect of excluding consumers or their families from the process. One consumer described his or her wrangling with the balance between the affront of coercion and the benefits of forced engagement with treatment under a CTO:

‘In a way it may seem like one’s incarcerated or something as such, to go to hospital and do all these things, but I think you can still be happy. I have a certain freedom now that I’m out of the hospital, but I suppose it could be likened to a bit of a wrestling with governments and institutions. But there are a few injustices in the world, so maybe we could view myself as a victim or someone unfortunate, but I’m trying to keep it positive.’

The process of access to treatment through CTOs saw consumer and carer participants valuing communication, personalised approaches, and partnerships with mental health professionals.

One consumer noted that this was a problem in his or her care:
‘I talk about it with friends and mentors and stuff, but not with doctors and stuff, they really don’t have time to talk about it.’

Another consumer noted that his or her patient journey through a CTO was made much worse by their perceived lack of communication with mental health professionals at the outset of the process:

‘Yeah, I wish people like the psychiatrist or somebody would have actually taken you to a room and told you, “this is what we do for the next six months, this is how we look after you”, so you know what to expect. But when nobody’s told you anything, you don’t know what to expect. So I wish somebody would have said more at the time, rather than just given you medication. It’s a matter of talking to you.’

The process of access involved consumers and careers building relationships with professionals and having a care history with services. In doing so, this allowed them to acquire information about their treatment and build confidence in processes involved in the implementation of care under a CTO. In an ideal world, one consumer participant saw that long-term, collaborative engagement with a case manager enabled a therapeutic relationship that could be almost collegiate:

‘But to assign someone to a case manager is a good idea I think, as long as you don’t feel like you’re being threatened or constricted in your movements. I tend to view the people just as friendly associates and there’s something to do each fortnight or each three months or whatever the cycle is in terms of seeing people, and just try and get along with them.’

Another consumer participant described the value of being listened to and developing a rapport to enable good communication between the health system and the consumer. Such a level of communicative understanding enabled the consumer to engage productively with care:

‘I think that it could be a good idea, because it could get the person back on track, and once again I think it’s very important for the person who’s explaining the CTO, to explain it to the person in a way that it’s not a huge issue, it’s an issue to get your life back on track. And I think that verbal talk at the start is important, I think that’s where you can make it or break it with someone.’

Both consumer and carer participants noted that problems with access frequently seemed related to the system in terms of inadequacies in structure and resources, and excessive workloads. One carer participant recalled a conversation with a psychiatrist who, presumably in an unguarded moment, was unaware of the inadequacies of the system:

‘I was talking to this doctor who is a psychiatrist there, he said “oh they’re all meant to have case managers”, and I said “they’re meant to have, but we don’t have them”.”
Another carer expressed frustration that little other than the administration of depot medication had been recorded in his or her relative’s case notes. This had led to very little continuity of care between the hospital and the community mental health service:

‘Okay, where [X] came into hospital and she did go to the mental health unit, the doctor pulled me inside and said “[Y], I was wondering if you could tell me how [X] was when she was well, as there’s nothing written in her notes”. And I said “what do you mean there’s nothing written in her notes?” “Oh there’s nothing in her notes that lets me know actually how she’s going.” So she’s been maintained in a community mental health service, on a fortnightly depot injection, and the only thing that’s recorded is the fact that she’s been given an IMI injection.’

Many of the participants expressed their concern about clinical care and responsibilities associated with it. One consumer participant recalled a troubling encounter with a psychiatrist who he or she felt was not up to the task of his or her care:

‘It’s being responsible. Like I said with the psychiatrist at [Hospital X], I knew, I just had such a feeling he’s going to get it wrong, and I was right. I remember thinking he’s going to do something wrong, and I just knew by his manner, his walk, up and down the hospital, that I just knew he wouldn’t get that piece of paperwork right, and he hadn’t done it. And the magistrate said “why haven’t you done it?” And he didn’t have an answer for her.’

Regardless of the imperfections in the system, many of the consumers or carers who participated in the interviews held the view that, ultimately, CTOs were a means of keeping a person with a severe mental illness safe, and hopefully, well. One consumer participant reflected that:

‘It’s [a CTO] to make sure that you’re given the best recovery, to make sure that you’re taking medication, because obviously it keeps you well, and it helps you get on top of your life again, and you’re seeing the psychiatrist and you’re getting to tell him how you’re feeling. So yeah, just making sure that you’re recovering from what you’ve been through.’

A carer participant noted that a CTO, by ensuring adherence to medication, enabled a person with a severe mental illness to be both safer and have a greater degree of autonomous function:

‘I think to keep the patients safe, to keep them safe and to keep them functioning at a level that’s reasonable, and that they can care for themselves, better than they can care for themselves if they’re not on; it’s basically to keep them on the medication.’
### 3.2.2 Isolation

Suffering a severe mental illness and being placed on a CTO is an isolating experience. The experience of isolation takes the form of marginalisation, stigma and feeling alone (Figure 6).

Many consumer and carer participants noted that they felt excluded and marginalised in both the clinical and legal decision-making involved in their care.

**Figure 6: The theme of isolation**

- **Stigma**
- **Feeling alone**
- **On the outer - social disadvantage**

One consumer participant recalled the experience of the hearing over the matter of the application for a CTO prior to their discharge from hospital and in particular the lack of any perceived communication of information over the whole process:

‘I just remember being taken to the magistrate, and the next thing was being placed on a CTO, and I didn’t know what that was, and I would be on it for six months, and then when I realised afterwards that somebody would be coming around to check up on me, to make sure that I was taking my medication, and to see that I was getting better in myself, which luckily I did. And nobody ever really sat down and explained anything to me. So it was all a matter of intuition to find out what was actually going on. ... As I say, it was really more intuition that taught me. Nobody actually took me aside and said “this is what we’re going to do”. So yeah, so I think it’s lacking in the system that you’re not told what’s going on.’

A carer participant noted that the process of mental health care, in particular the implementation of CTOs was not inclusive of the carer and that there seemed little discernible improvements in carer participation in the process:
‘I think the whole system generally is not inclusive, like I’ve said it a couple of times there, it’s not inclusive of the carer. And I think that that could be improved. Maybe it is improving, but everything is slow.’

Another carer participant noted that in the process of implementing a CTO, he or she had minimal information communicated in regards to the care of their relative:

‘We might know that the CTOs in place, we know that she’s going to get medication, we know she’s going to go to the community team, we don’t know who the case manager is except that [X]might know them by first name as to who that case manager is...’

The same carer noted that the nature of his or her relative’s diagnosis and medical history overshadowed other components of his or her identity in the system and how this shaped responses to her needs:

‘She’s at high risk of exacerbating comorbid conditions. She’s had open heart surgery and a mitral valve repair, because of her drug use. She’s had septicaemia endocarditis because of her drug use. She’s had all these major things because of drug use, and they have still persisted over 20 years of saying that her major health problem is schizophrenia. The rest of the health system don’t see anything else but schizophrenia. And despite the myriad and complexity of her health conditions, the sum total of her health-care treatment is a fortnightly depot injection. Which is bizarre.’

Adding:

‘...you look at a health system that’s actually treating her more like a prisoner and a criminal than a patient.’

A number of consumer and carer participants noted that involuntary treatment itself was stigmatising and marginalising. One consumer participant observed that:

‘Because you don’t want people to think that you’re watched all the time, and you have to take your medication, and they come around daily and give it to you, and it’s just an embarrassing, a whole embarrassing thing.’

This sense of stigma also extended to family members. A carer participant shared that:

‘I basically didn’t talk to anyone who didn’t know about mental health, like anybody at work very much didn’t understand, so I didn’t talk to them about it.’

A feeling of ‘embarrassment’ was the predominant experience of being placed on a CTO and suffering a mental illness. This sense of embarrassment or discomfort inhibited communication with others and contributed to the isolation many consumers felt. One consumer participant described his or her feelings of embarrassment and sense of isolation in the face of it:
‘No, I don’t really know of too many people on CTOs, I know that they’re probably on CTOs, people that I know, but they don’t tell me about it. ...Because you don’t want people to think that the government run your life, and it’s embarrassing. ...Yeah, I’m embarrassed I think for myself that I’ve got schizophrenia, and it’s because I’ve got it later on in life I think I’m not used to saying to people “look, I’ve got schizophrenia”.’

Another consumer participant compared with a physical illness the experience of stigma tied to suffering a mental illness:

‘Well a lot of people know about cancer, not about this, this is different. Or a lot of people know that if you’re schizophrenic, you’re going to kill somebody, that’s the image people have isn’t it?’

Some consumer participants spoke of feeling alone with no access to confiding relationships. One consumer participant noted:

‘It’s nice just to be in touch with someone, a lot of people are lonely and live alone and what not, and sometimes we just need someone to talk to, and the case manager can sometimes put us in touch with other people to help us, or they have different ideas for our lives.’

The feeling of isolation, being ignored and misunderstood extended to carer participants. One spoke of the isolation they felt in being unable to speak of their experience, explaining it in terms of their previous responses to the predicament of an acquaintance who had a son with a mental illness:

‘People don’t understand, and you can’t blame them. I mean I always think back before my son got ill 20 years ago, I had a, it wasn’t a close friend, just an acquaintance, and her son had a mental illness, and he was a big boy, and I was scared of him, and I didn’t know what to expect. And I can understand how people feel.’

A consumer participant spoke of the lack of understanding many people had in regards to mental illness and its effect on people:

‘But even my best friend said “there’s nothing wrong with you”, but sometimes ‘I feel f***ed man, I really do, you don’t get it, I think I’m going to die.’

In the light of isolation and a virtual alienation from the community, many of the participants described the experience of feeling let down by the community. One consumer participant described feeling:

‘...very alone, you feel very isolated. So there needs to be help available. I think there’s not enough said about mental health, there’s a lot of people, since it’s happening to myself I’ve met a lot of people who have had experiences, and I
think there should be more help readily available, and people shouldn’t be so scared to talk about it.’

3.3.3 Loss and trauma
The experience of CTOs was also one of loss and trauma. The experience of severe mental illness engendered a sense of grief and loss, existential challenge and an overall sense of distress (Figure 7).

Figure 7: The theme of loss and trauma

One carer participant spoke of the profound sadness of his or her son’s predicament with severe mental illness:

‘To see a young man, lying around in the bed doing nothing, it breaks our heart. It’s terrible.’

Another carer participant described his or her consumption by grief and how the need to care for two children – including one with a mental illness – taxed their resilience:

‘It was a disaster, I wasn’t coping. I was working, I was trying to hold down a job and found that I couldn’t do it...So I’ve eventually retired from my work, after taking all of my leave, a long period of leave, so that I could just focus on being a carer.’

A consumer participant spoke of the ‘shock’ associated with the process of involuntary psychiatric treatment and the gradual realisation of how unwell they actually were:

‘Yeah, well it was a shock, it was definitely a shock being on a CTO, because I didn’t understand what it all meant, and even when I did understand what it meant, it was still a shock, definitely. I thought I was put into a category of, you know I’d seen a lot of people on CTOs and they seemed, what I thought sicker

Community treatment orders: the lived experience of consumers and carers in NSW
than I was, but really I was sick you know, I didn’t realise that I was sick, but I ended up realising that I was sick, once I started getting better.’

The losses experienced by consumers with severe mental illnesses also extended to key relationships in their life, especially family. One consumer participant spoke of the trauma of the loss of relationships in the course of a severe mental illness:

‘Yeah, they can get scarred by [the loss of] relationships, relationships they’ve had since they’ve been very young, strong relationships can go down the drain.’

A carer participant noted the existential component of the losses associated with severe mental illness and the stigma associated with involuntary treatment. In recounting a ‘heartbreaking’ moment of existential clarity his or her sister experienced they noted:

‘...her core issue when she still talks to me, she’ll talk to my brother and I and she’ll say “how come it worked out for you guys, how come you guys got married and had kids, why didn’t it work out for me, why haven’t I got someone for me”, that basic core thing. That’s the heartbreaking stuff, I know it sounds really simplistic, but when she is truly grieving and saying that stuff.’

Another carer recalled his or her son’s realisation of the gravity of his illness and its destructive effect upon him:

‘For us, he said: “I’ve lost my privacy, I’ve lost my independence, I’ve lost everything”’.

The theme of loss extended to loss of access to treatment and dedicated clinical services, particularly when a person’s illness improved to the point that a CTO was not necessary. One carer participant described how his or her son lost access to care when a CTO lapsed:

‘...he came back home and the case manager was coming to visit him. Initially they come once a week, then it becomes twice a week, then it becomes once a month, and as soon as he was coming off a CTO she just said “oh I don’t think you need me anymore now”. So we’d lost the case manager.’

In some circumstances, the loss involved the loss of clinical gains when the CTO had lapse.

A consumer participant spoke of the effects of becoming unwell again:

‘Not taking medication, and using illicit substances, high levels of stress, yeah relationships going wrong and stuff.’

A carer described the catastrophic effects of loss of clinical progress emerging from recurrence of illness following his spouse’s disengagement with care:
'So those sorts of things that would worry me if she got really unwell I think her self-care and her living skills, her demeanour, her relationship with her relatives and friends would all suffer. And maybe she would say strange things which would be disturbing, which would cause distress to others.'

Distress was a theme that emerged in the interviews. In some cases, beneath the travails of mental health systems, medico-legal processes and advocating on behalf of services for a particular person, lay the simple distress of the tragedy of a mental illness. One carer spoke, movingly, of his or her spouse's occasionally profound distress:

'...she doesn’t have a quality of life, she loses her quality of life. It’s distressing to see her becoming sad. That’s another thing sometimes she will maybe cry or burst into tears at whatever.'

3.3.4 Resistance and resignation
An integral part of the experience of CTOs is that of an exercise of coercive power. This process comes to be associated with processes of resistance, submission and the experience of disempowerment or discrediting (Figure 8).

Figure 8: The theme of ‘resistance and resignation’

Many of the consumer participants described experience of being compelled by CTOs. One described a CTO:

'Well it felt like I was being watched closely and monitored, and sometimes I think back and remember my life when it was without as many constraints.'
The same consumer participant described the negatives of any ‘threat’ and ‘constriction’ in their relationship with a case manager:

‘But to assign someone to a case manager is a good idea I think, as long as you don’t feel like you’re being threatened or constricted in your movements.’

Other consumer participants described the experience of a CTO as one of being monitored, or feeling surveilled, intruded upon, or constrained. As one consumer described, the machinations of a CTO imparted a structure to his or her day, which while minimally disruptive, was experienced as an intrusion:

‘Well I didn’t know how often I would be checked up on, and all that sort of stuff, and found out that it was on a daily basis. At the start it was daily, so you know I dealt with it, it was pretty easy to deal with because the guys just turned up in the afternoon, it was just one tablet given to me, but I was looking forward to not being on the CTO.’

One consumer participant equated the experience of a CTO with the prospect of his or her being penalised or punished:

‘When I was discharged from hospital, that was proviso that I undertook a CTO for six months, otherwise, if I broke the CTO I’d have to go back into hospital.’

Ultimately, a CTO brought about a process of submission in the person. In many instances, the submission was to appease others, not directly engaging with the process of treatment. As one consumer participant noted:

‘But I am doing it to comply at the moment and keep my parents happy and the doctors happy.’

In other circumstances the process of resignation also involved the consumer acknowledging the instrumental value of the CTO in ensuring their ongoing engagement in the process of treatment. One consumer participant saw the CTO as:

‘...just a piece of paper to say you’re being watched for the next six months. But it didn’t make me feel irritated or stressed or anything, I thought okay that’s going to last until... they’re just making sure that I’m on the medication for the next six months.’

A carer participant noted that his or her son submitted to the process of the CTO and engaged in the process of care. This was couched in terms of the oft-used concept of ‘compliance’:

‘He’s fine, he accepted it. He was quite happy with the CTO, he knew it was coming, he was surprised to see me there, but he’s very compliant.’

Implicit in the process of submission to a CTO was an experience of disempowerment or feeling discredited. This frequently manifest in the consumer being subject to the decisions of others. One consumer participant reported that he saw that he was
subject to such power but chose to see the benevolent intent of the clinicians tasked with administering the CTO in his care:

‘I tend to view the people just as friendly associates and there’s something to do each fortnight or each three months or whatever the cycle is in terms of seeing people, and just try and get along with them. It’s up to each one how they mind their routine and look after themselves’.

The lack of choice or say in treatment, while disempowering, served the role of ensuring the consumer received treatment, which ultimately reduced the likelihood of further coercion through renewals of CTOs due to further instability in the illness. One carer participant noted that:

‘If there hadn’t been a CTO to keep him on the medication, well I guess he would have come to the Police notice and they would have taken him in as an involuntary patient, and he would have been placed on the CTO again. But it’s not very nice to let, if you can prevent that happening, it’s better.’

In the alternate, there remained the perception among some of the participants that the process of implementation and renewal of CTOs was both circular and little likely to integrate the perspective of the person on their treatment. One consumer described that:

‘I’ve told the doctor, “I’m compliant with the medication, I don’t want the injections”, but they’ve said “no, you’ve got to stay on it until the thing runs out”. Then it comes up the possibility of renewal for another six months.’

This process sometimes was most apparent at the point of initiation of the CTO, with this consumer participant describing their CTO hearing as a fait accompli:

‘I think it was sort of a case of banging your head against a brick wall, it’s really like what’s the point, you know in the end what he’s [decision-maker] going to say, but you have to do it anyway.’

In the process of resisting the coercion associated with the use of CTOs was the approach of ‘choosing battles’. One consumer participant was able to articulate a quite balanced view of the benefits and injustices of his or her CTO, opting to focus on their recovery and addressing other concerns later:

‘I think there’s a positive in the dealings with the health profession, and any other injustices will have to be worked out later I suppose, because we can’t solve the world’s problems overnight.’

A corollary of resisting a CTO is the expectation of punishment or some form of severe consequence, itself a concern. One carer participant described his or her anxiety about the possibility of their mentally ill relative being in breach of her CTO and the distressing consequences this would lead to:
‘I was a bit worried about it, I was worried because I thought if she missed, I was worried that she would be punished if she missed two days or three days, but I don’t think they would have been that hard. But it was in the back of my mind that they would be very hard on her if she didn’t take her injection exactly every fortnight exactly on the day she is supposed to have it.’

The perception of CTOs as punitive also emerged from the lack of understanding that was common among participants, particularly the consumer participants. One consumer participant stated that his or her fear of the CTO and its perceived punitive nature came from misunderstanding:

‘Yeah it was just a shock that I was placed on a community treatment order because I didn’t really understand what it was about, and when I read what it was about, it seemed to be quite strict. So I was a little bit worried about what I can do and what I can’t do and stuff like that.’

In some circumstances, resisting a CTO seemed justified where there seemed to be inadequate treatment being offered. A carer described his or her interaction with the clinicians involved in their sibling’s care, particularly in relation to the quality of care being offered and the failure of the clinicians involved to provide adequate information and time to process it:

‘And I’ve said to them, “Look, you guys are the experts at engagement, my experience is if you tell her and give her correct information and give her enough time to digest it, she often comes back to me having thought on it, and tells me. But her first answer is always no. And you take that and block her from care, because you asked her and she said no”. And I just said to them, “Look I’m constantly frustrated, my brother and I are constantly frustrated by this”, I said, “Of course her first answer is no, she doesn’t trust you. And you give such silly explanations. Give her good information, give it to her in writing, in a form that she can understand, let her sit on it, come back and see if she’s got any questions. You know what, she’ll tell you.” That’s my experience of her, I don’t know why they find it so hard.’

3.3.5 Vulnerability and distress
Akin to the experience of loss and trauma associated with a CTO, was the experience of vulnerability and distress. This vulnerability emerged in terms of the interaction with systems and services, a lack of experience or nuanced knowledge of the process, and the impact of the illness on the consumer’s relationships (Figure 9).
The distress associated with the experience of a CTO is intertwined with the distress of the illness itself. One carer participant described the distress his or her relative experienced when ill:

‘So those sorts of things that would worry me if she got really unwell I think her self-care and her living skills, her demeanour, her relationship with her relatives and friends would all suffer. And maybe she would say strange things which would be disturbing, which would cause distress to others.’

Another carer participant noted that his or her relative become profoundly distressed when they defaulted on treatment:

‘...he was off the medication, that was the last CTO, and he started to decline, his behaviour became bizarre, he was hallucinating, delusional.’

The problems of escalating symptoms of illness and associated adversity also contributed to distress. One consumer noted that when ill he was harmed by his behaviour, causing him great distress:

‘I broke a window, I’ve broken a couple of windows, I got aggressive, I hit a lot of things; I did never hurt anyone, but I hurt myself, to the point where I couldn’t bend my hands like that, I couldn’t clench a fist because I’d been hitting things so many times. And this was all through the mental, ...not being well.’

Being mentally ill in itself was distressing, and often led to distressing consequences of hospitalisation and more coercive experience of treatment in order to recover. One consumer participant noted of their decline and its consequence:

‘I was mixing with the wrong sort of people, and smoking a bit of marijuana, not taking my medication, so I had a psychosis, or a manic episode, I’m not sure

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Figure 9: the theme of vulnerability and distress

- Illness
- Relationships
- Systems and services
- Lack of experience or knowledge
which one, but yeah, so I was hospitalised for quite a while, it would have been about 12 weeks, and I got better during the process.’

The symptoms of illness are in themselves distressing and are part of the distress of the experience of being subject to a CTO. One consumer described a profoundly disabling consequence of severe psychosis:

‘It’s affected me, it’s really made me a lot more scared of life. I used to go out at night and do all those sort of things, I don’t do that anymore, I don’t like going out at night. I don’t even like going out during the day. I get a little bit scared. And yeah, that’s mainly the main thing of what it’s done, it’s made me scared.’

In other circumstances, the distress was that felt by relatives as a consequence of the person’s illness and its effect on their behaviour. A carer participant recounted:

‘I was scared, I was actually scared of him before he got into the hospital and had any treatment, because I was so unfamiliar with what was going on and he had a way of telling us what to do basically. But now since he’s been on medication that’s changed, and I think he’s learnt also to live with the symptoms to some degree, whereas it must have been just so terrifying in the beginning for him, to be seeing and hearing things that other people weren’t.’

The feeling or experience of vulnerability also related to the experience of problematic interaction with the health system. Many consumer and carer participants described a sense of feeling abandoned by the health system. One consumer participant recalled:

‘But I went there [to the health centre] and I was crying, and I said “are you going to turn me away, nobody wants to help me”.’

A carer participant noted that in regards to providing adequate and timely care:

‘The system is not 100% right, and I believe that they recommend people to go to hospital when they are really bad. They don’t act on time for a person to save them going down in the gutter. If I can put it that way.’

Some participants found their interaction with the system as a source of injustice, indignity, and difficulty.

A consumer participant described a sense of indignity of having to present regularly for an injection of depot antipsychotic, often administered by a student or junior member of staff:

‘... Like ask them what do they think of the injection process, having to go to hospital every second week and have the injection and have the student nurses watching over and all that process, it can be a bit humiliating I think.’

Some of the participants described the vulnerability as being in terms of being subject to poor practices under legal order. A carer participant described his or her perception
of the obligation of the mental health system to provide care that was ‘safe, ethical and legal’:

‘I think it’s reasonable that people, if they’ve had their rights taken off them, if they have been an involuntary patient, if they’re now going to be maintained in the community on a CTO, I think it’s reasonable to expect that they’re going to be provided safe, ethical, legal care. And they don’t get it. There’s a cohort of people who do not get that. My sister is not the only one.’

A consumer participant reported that his or her symptoms were poorly controlled by treatment, which in their estimation rendered its enforcement under a CTO as ‘somewhat unjust’:

‘Well my moods are affected of course by the voices. At the moment I’m on good terms with them and they’ve even been quiet. But it seems somewhat unjust when you are continuing to have mental attacks, and the medication isn’t helping.’

A carer participant reported that, in his or her estimation, the care their relative received was inadequate due to the excessive workload:

‘All they do is come out and give him a tablet, that’s it. They’ve got 40 people to see a night, they just don’t have the time. So you can’t blame them. But I would really like everyone with a mental illness to have an active case manager, not one that you have to approach and get them to help you. It just doesn’t happen.’

The experience of vulnerability often emerged from the consumer or carer’s lack of experience or knowledge of the illness, its treatment or the mental health service. One consumer participant reported that his or her distress was heightened by their lack of knowledge or understanding of the situation:

‘Yeah it was just a shock that I was placed on a community treatment order because I didn’t really understand what it was about, and when I read what it was about, it seemed to be quite strict. So I was a little bit worried about what I can do and what I can’t do and stuff like that.’

A carer participant reported that the process of facing a series of ‘unknowns’, from the legal process of civil commitment to the inpatient episode was a major part of their distress:

‘Well to be honest, we were sitting in the, it was [CITY] Court, where the magistrate ordered the mental health assessment – I remember just sitting there thinking “how are we going to manage this?” Because the magistrate does his or her job, just processes the next number through, and that’s it, the court doesn’t have any involvement in informing people, so it’s not until you get to the hospital where they all seem too busy to really engage much.’
Part 4 – Discussion

According to the theory that emerges from our analysis of the data, the experience of living under a CTO in NSW is a mixture of distress and of acknowledgement of the value of the process (Figure 10). This generalised across both the consumer and the carer participant groups.

**Figure 10: The lived experience of CTOs in NSW: a model**

Within the contributions of the participants, there was ample acknowledgement that CTOs ultimately serve a role for the benefit of those to whom they are applied. This view is qualified by the clear assertion that the system has a responsibility to provide safe and effective care under the provisions of a CTO. In a number of the narratives provided, there were both direct and indirect experiences of sub-optimal care, usually the result of excessive demands on particular health services and the overall deprivation or social injustice faced by many suffering from severe mental illness. In many circumstances, carer and consumer participants saw that the mental health system was burdened by the failure of other parts of the community or social institutions to provide the necessary care or support needed by such people.

The distress, isolation, grief and loss experienced by those affected by CTOs appeared to be a part of the experience of a severe mental illness. Putting aside instances where CTOs were implemented poorly, the kind of illness and level of disability experienced by those who needed such treatment interventions was an intrinsic source of distress and the need for a CTO emerged from that illness and by extension that distress. In essence, the experience of distress around a CTO seemed to be indistinguishable from the distress of the severe illness that necessitated it.
That being the case, many experienced CTOs from a position of lacking knowledge and experience. All of the consumer participants and many of the carer participants described the experience of CTOs as being characterised by problems with communication and understanding. Much of this difficulty is seen in the initial phase of CTOs, particularly the point where the decision to apply for the order is communicated to the patient. The legal processes and understanding of rights was frequently impenetrable to many of the participants. Little wonder that many of the participants experienced CTOs as a form of unilateral restraint or punishment for non-adherence to treatment, rather than a mutually binding treatment contract.

While the problems of communication may have been due to the clinicians or the service involved, or the distress of an episode of severe illness (particularly where there has been a traumatic experience of involuntary hospitalisation), or the effects of the illness itself on comprehension of events, much of the distress related to the experience of a CTO derived from these difficulties in communication and understanding.

Problems accessing adequate or appropriate services were a significant part of the lived experience of CTOs of carer and consumer participants. Much of the difficulty resided in the process of engagement. This process was either facilitated or compromised by CTOs, however many participants noted that CTOs were often a proxy for a form of advocacy for services. While effective, this often resulted in the paradox of services declining once a person was well enough to be taken off a CTO.

The model of the lived experience of CTOs for consumer and career participants derived from this grounded theory research can be distilled as one of profound ambivalence. As a part of the tragic journey taken by consumers and their carers in the course of a severe mental illness, CTOs are associated with distress and a sense of loss, isolation and disempowerment. Many experience the constraint and intrusion associated with CTOs as an affront and either a punishment for being ill or a loss of rights. This negative experience is compounded by problems with communication and understanding, some of which is attributable to illness, some to isolated instances of problematic interaction with the mental health system. In the alternate, consumers and their carers see the benefits of CTOs in terms of reducing the severity of illness and the concomitant risks and disabilities that flow from this. This latter assumption is predicated on the adequate performance of mental health services in the application of such orders.

The findings of this research are in general agreement with other studies in that the loss of autonomy and constraints associated with a CTO are balanced with clear benefits. Carers in general saw CTOs applied by competent services as being of great benefit. The distress around the experience of CTOs is difficult to disentangle from the distress of a severe mental illness. Improvements in communication between clinicians and consumers and their carers, ensuring ease of access to competent services, and taking care to ensure carers and consumers understand as best they can all aspects of the process of CTO, will seemingly contribute to reducing this distress.
Future directions
From this research, it is evident that the distress arising from being subject to a CTO can be assuaged by those tasked with their implementation by:

i. focusing upon clearer communication about the order (including strategies to ensure consumers and their carers are aware of the specifics of the order)
ii. developing strategies to improve access to services for mental and physical services and other social institutions, and
iii. acknowledging that the CTO is a part of the overall distress of a severe mental illness.
Part 5 – Appendices

5.1 Financial report

5.2 Ethics approvals
5.1: Financial report
An income and expenditure statement for the CTO project appears on the following page. The statement reports on the project from its commencement up to the preparation of this report (31 August 2012). It was prepared by the Sydney Medical School – School of Public Health, University of Sydney.
# THE UNIVERSITY OF SYDNEY

## Sydney Medical School

**Health Admin Corp 10 Robertson** - (University Account Code: K2621 R2731)

### Income Statement for period ended 31 August 2012

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<td><strong>Income</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Research Payment Income</td>
<td>95,624</td>
<td>20,000</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td>95,624</td>
<td>20,000</td>
<td>-</td>
</tr>
<tr>
<td><strong>Expenditure</strong></td>
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<td></td>
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<tr>
<td>Research Employee Salary</td>
<td>45,755</td>
<td>47,769</td>
<td>9,728</td>
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<tr>
<td>Airfare - Trial Interviews</td>
<td>336</td>
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<td>-</td>
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<td>Accommodation - Trial Interviews</td>
<td>77</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Travel - Clinical Trial Interviews</td>
<td>-</td>
<td>-</td>
<td>107</td>
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<tr>
<td>Research Training Course</td>
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<td>-</td>
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</tr>
<tr>
<td>Clinical Trial Interview Costs</td>
<td>-</td>
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<tr>
<td>Clinical Trial Interview Postage</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Clinical Trial Interview Transcription Service</td>
<td>615</td>
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<td><strong>Total Expenditure</strong></td>
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<td>49,131</td>
<td>12,262</td>
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<td><strong>Surplus/(Deficit)</strong></td>
<td>47,841</td>
<td>(29,131)</td>
<td>(12,262)</td>
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<tr>
<td>Funds Carried Forward as at 1 January</td>
<td>-</td>
<td>47,841</td>
<td>18,710</td>
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<tr>
<td><strong>Total Accumulated Funds</strong></td>
<td>47,841</td>
<td>18,710</td>
<td>6,448</td>
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I certify that this Income Statement for CTO Health Admin Corp Project has been prepared in accordance with the University's accounting practices and procedures.

Nirav Bajoria  
Finance Manager  
Sydney Medical School - School of Public Health  
3 September 2012
5.2: Ethics approval

*Consumer and carer interviews*

University of Sydney Human Research Ethics Committee – reference number 12583 (approved 6 April 2012):

- Approval letter
- Invitation
- Participant Information Statement
- Consent form
- Interview topics
Dear Dr Robertson

I am pleased to inform you that the Human Research Ethics Committee (HREC) at its meeting held on 6 April 2010 approved your protocol entitled “Community Treatment Orders (CTOs): improving clinical decision-making”.

Details of the approval are as follows:

Refer No.: 12583
Approval Period: April 2010 to April 2011
Authorised Personnel: Dr Michael Robertson
                       Prof Alan Rosen
                       Dr Christopher Ryan
                       Prof Terry Carney
                       Dr Nick O’Connor
                       Dr Glenn Hunt
                       Dr Michelle Cleary
                       Prof Philip Boyce

Approved Documents:

Participant Information Statement – Consumer, V2/ Consumer/ March 2010
Participant Information Statement – Carers, V2/ Carers/ March 2010
Participant Consent Form, V2/ March 2010
Interview Topics for Consumers
Invitation to Participate

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29.
The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

### Chief Investigator / Supervisor's responsibilities to ensure that:

1. All serious and unexpected adverse events should be reported to the HREC as soon as possible.

2. All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

3. The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:
   - If any of the investigators change or leave the University.
   - Any changes to the Participant Information Statement and/or Consent Form.

4. All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. *Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, University of Sydney, on +612 8627 8176 (Telephone); +612 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).*

5. Copies of all signed Consent Forms must be retained and made available to the HREC on request.

6. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

7. The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

8. A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely,

[Signature]

*Associate Professor Ian Maxwell*

*Chair*

*Human Research Ethics Committee*
Community Treatment Orders (or CTOs) are legal orders that authorise involuntary mental health care – such as medication and therapy, counselling, management, rehabilitation and other services – for people living in the community. We are looking for people to tell us about their experiences of CTOs.

We want to find out what it’s like to be under a CTO and we want to speak to the people caring for and supporting people under CTOs. That way we hope to improve the whole process.

We would like to speak with you about your experiences, including your participation in decision-making and your reflections on the ideas of ‘risk’ and ‘capacity’. This project provides a chance to increase our knowledge about the experiences and views of people who have had a mental illness and their carers. We will use the knowledge we gather to make the CTO decision-making processes better. The project is funded by NSW Health and approved by the University of Sydney Human Research Ethics Committee.

Who is able to take part?

To be able to take part in this study you must either:

- be currently on a CTO or have been on a CTO in NSW, or
- be a primary carer to a person currently on a CTO or who has been on a CTO in NSW.

You must also:

- be 18 years of age or older.
- be able to speak and understand English.

What will it involve?

- Coming to an interview with the researcher at the offices of Carers NSW, or the Mental Health Coordinating Council, or the New South Wales Consumer Advisory Group - Mental Health Inc. For details of office locations please contact us.
- $40 reimbursement for your time and travel expenses.

If you’d like to participate, please contact us.

Associate Professor Michael Robertson, Centre for Values, Ethics and the Law in Medicine

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For further information, please contact Edwina Light at 02 9036 3418 or edwina.light@sydney.edu.au
Research study into Community Treatment Orders and clinical decision-making

PARTICIPANT INFORMATION STATEMENT

You have been invited to take part in a research study about Community Treatment Orders (CTOs). We would like to find out more about the views and experiences of those who have been on a CTO. CTOs are made by magistrates or tribunals and order involuntary mental health care – such as medication, counselling, rehabilitation and other services – for people living in the community.

This project hopes to find the things that people consider when they decide on a CTO. We want to know how people think about concepts like ‘risk’ and ‘capacity’, and we want to learn about the experiences of people under CTOs. The best way to find out what people think is to ask them, so the research will involve a brief interview about these issues. We hope that by getting your views and experiences we’ll be able to make the process of CTO decision-making better in the future.

The project is funded by NSW Health and is being conducted by the Centre for Values, Ethics and the Law in Medicine at the University of Sydney. The project investigators are:

- Associate Professor Michael Robertson (University of Sydney)
- Professor Philip Boyce (University of Sydney)
- Professor Alan Rosen (University of Sydney)
- Dr Chris Ryan (University of Sydney)
- Professor Terry Carney (University of Sydney)
- Dr Michelle Cleary (University of Western Sydney)
- Dr Glenn Hunt (University of Sydney)
- Dr Nick O’Connor (University of Sydney)

The project will be assisted by Ms Edwina Light.

If you agree to take part in this study, you will be invited to take part in an interview with a researcher at which you will be asked to speak about your experience of CTOs. The interview may explore topics such as how you came to be placed on a CTO, your views of the decisions made by the doctors and nurses and the way you were involved in the decision-making process. We’ll also ask you about your thoughts on ‘risk’ and ‘capacity’. The interviews are designed to find out what you think. There is no fixed set of questions that you must answer.
The interviews will take place at the offices of Carers NSW, or the Mental Health Coordinating Council, or the New South Wales Consumer Advisory Group - Mental Health Inc. (NSW CAG) and you can go to which ever location is easiest for you to get to. The interview will usually take 45-60 minutes. When you get there, we will give you $40 to go toward public transport or taxi fares, or parking fees to attend an interview.

All aspects of the study, including results, will be strictly confidential. The interviews will be audio taped and then the recordings will be listened to and transcribed (written down). We will not write down anything that would identify you and we’ll keep the transcripts separate from any information identifying participants. Following transcription, the audio recordings and the de-identified transcripts will be securely stored on a password-protected computer and in a secure storage cabinet at the Centre for Values, Ethics and the Law in Medicine. The information from the study will be stored for seven years after the project finishes. Only the investigators named above will have access to information on individual participants.

The knowledge we gain from the interviews will be used to develop models describing how ‘risk’ and ‘capacity’ are considered in relation to CTOs and to identify themes in the experiences of people like you. We hope to use this information to improve the CTO decision-making processes. Individual participants will not be identified in the final results which will be sent to NSW Health. We will also present the findings to scientific meetings and publish them in scientific journals, but, again, it won’t be possible to identify individual participants in these reports. We will also prepare a report so we can provide feedback to participants at the end of the project. With your permission, we will send you this report which will summarise the study’s main findings about how CTO decisions are made and how consumers, carers and clinicians understand ‘risk’ and ‘capacity’ in that context, and tell you about any scientific publications and presentations based on the findings. Individual participants won’t be identified in this report.

While we hope that this research study improves practice around CTOs, you should know that participation may not be of direct benefit to you.

**Participation in this study is entirely voluntary: you do not have to participate.** If you do participate, you can withdraw at any time without having to give a reason and without consequences. You may stop the interview at any time if you do not wish to continue, and the audio recording can be erased. Should you withdraw from the study, you will have the option of having any data already collected about you destroyed. Whatever your decision, it will not affect your relationship with the researchers, the Centre for Values, Ethics and the Law in Medicine, the University of Sydney, or any of your doctors or nurses.

Please note that the researchers cannot provide medical advice. If your participation in the interview raises questions for you about your own medical treatment and care, we will encourage you to refer to your health professionals for assistance and advice.

When you have read this information, Associate Professor Michael Robertson will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Associate Professor Robertson on 02 9036 3405.

| Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email). |

This information sheet is for you to keep.
Centre for Values, Ethics & the Law in Medicine

Michael Robertson MBBS (Hons) PhD FRANZCP
Clinical Associate Professor

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University of Sydney NSW 2006
AUSTRALIA
Telephone: +61 2 9036 3405
Facsimile: +61 2 9036 3436
Web: http://www.cvelim.org/

Research study into Community Treatment Orders and clinical decision-making

PARTICIPANT INFORMATION STATEMENT

You have been invited to take part in a research study about Community Treatment Orders (CTOs). We would like to find out more about the views and experiences of those who have been on a CTO and those who are close to them. CTOs are made by magistrates or tribunals and order involuntary mental health care – such as medication, counselling, rehabilitation and other services – for people living in the community.

This project hopes to find the things that people consider when they decide on a CTO. We want to know how people think about concepts like ‘risk’ and ‘capacity’, and we want to learn about the experiences of people under CTOs and the people caring for and supporting those people. The best way to find out what people think is to ask them, so the research will involve a brief interview about these issues. We hope that by getting your views and experiences we’ll be able to make the process of CTO decision-making better in the future.

The project is funded by NSW Health and is being conducted by the Centre for Values, Ethics and the Law in Medicine at the University of Sydney. The project investigators are:

- Associate Professor Michael Robertson (University of Sydney)
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- Professor Terry Carney (University of Sydney)
- Dr Michelle Cleary (University of Western Sydney)
- Dr Glenn Hunt (University of Sydney)
- Dr Nick O’Connor (University of Sydney)

The project will be assisted by Ms Edwina Light.

If you agree to take part in this study, you will be invited to take part in an interview with a researcher at which you will be asked to speak about your experience of CTOs. The interview may explore topics such as how someone you care for came to be placed on a CTO, your views of the decisions made by the doctors and nurses and the way you were involved in the decision-making process. We’ll also ask you about your thoughts on ‘risk’ and ‘capacity’. The interviews are designed to find out what you think. There is no fixed set of questions that you must answer.
The interviews will take place at the offices of Carers NSW, or the Mental Health Coordinating Council, or the New South Wales Consumer Advisory Group - Mental Health Inc. (NSW CAG) and you can go to which ever location is easiest for you to get to. The interview will usually take 45-60 minutes. When you get there, we will give you $40 to go toward public transport or taxi fares, or parking fees to attend an interview.

All aspects of the study, including results, will be strictly confidential. The interviews will be audio taped and then the recordings will be listened to and transcribed (written down). We will not write down anything that would identify you and we’ll keep the transcripts separate from any information identifying participants. Following transcription, the audio recordings and the de-identified transcripts will be securely stored on a password-protected computer and in a secure storage cabinet at the Centre for Values, Ethics and the Law in Medicine. The information from the study will be stored for seven years after the project finishes. Only the investigators named above will have access to information on individual participants.

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While we hope that this research study improves practice around CTOs, you should know that participation may not be of direct benefit to you.

**Participation in this study is entirely voluntary: you do not have to participate.** If you do participate, you can withdraw at any time without having to give a reason and without consequences. You may stop the interview at any time if you do not wish to continue, and the audio recording can be erased. Should you withdraw from the study, you will have the option of having any data already collected about you destroyed. Whatever your decision, it will not affect your relationship with the researchers, the Centre for Values, Ethics and the Law in Medicine, the University of Sydney, or any clinicians involved in the care of the person you support.

Please note that the researchers cannot provide medical advice. If your participation in the interview raises questions for you about medical treatment and care, we will encourage you to refer to health professionals for assistance and advice.

When you have read this information, Associate Professor Michael Robertson will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Associate Professor Robertson on 02 9036 3405.

Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep.
PARTICIPANT CONSENT FORM

I, ................................................................. [PRINT NAME], give consent to my participation in the research project.

TITLE: Community Treatment Orders (CTOs): improving clinical decision-making

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved (including any inconvenience, risk, discomfort or side effect, and of their implications) have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher(s).

3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I understand that being in this study is completely voluntary – I am not under any obligation to consent.

6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.
7. I consent to:

i) Audio-taping
   YES ☐ NO ☐

ii) My interview data being used in further research
   YES ☐ NO ☐
   If you answered YES to Question ii), we would keep and use the transcript of your interview in future research projects about Community Treatment Orders. Your information would remain confidential - your name and all other identifying information would be removed from the transcript.

iii) Receiving Feedback
    YES ☐ NO ☐
    If you answered YES to the “Receiving Feedback Question (ii)”, please provide your details, i.e., mailing address and/or email address. When the project finishes, we will send to this address a report that summarises the main findings of the study and to tell you about any scientific publications and presentations based on the findings.

Feedback Option

Address: __________________________________________________________
__________________________________________
__________________________________________
__________________________________________

Email: __________________________________________________________

Signed: ........................................................................................................

Name: ........................................................................................................

Date: ........................................................................................................
CTO CLINICAL DECISION-MAKING PROJECT

INTERVIEW TOPICS FOR CONSUMERS

Semi-structured interviews with participants exploring topics about the experience of being subject to CTOs, participation in clinical decision-making, and accounts of concepts of ‘risk’ and ‘capacity’. Participants advised there are no fixed set of questions and interview will explore issues that arise from their own reflections.

Interview topics/questions to be based around a selection of the following:

1. Narrative account of own experience
   a) Tell me about when your doctor/s applied to place you on a Community Treatment Order (CTO)?
   b) How do you think the clinician/s made the decision to put you on a CTO (or renew a CTO)?
   c) What did they say to you about the application/renewal? How was it explained to you?
   d) Who was involved in explaining the CTO application/renewal to you? (Your cases worker/nurse? Your psychiatrist? Your family? Other?)
   e) What was helpful/unhelpful in terms of explanations about the CTO and the decision-making process around it?

2. Risk
   Decisions about CTOs are sometimes made because people are considered to be ‘at risk’. 
   a) How do you think about that concept of ‘risk’?
   b) How does that relate to you?
   c) How do you see ‘risk’ as part of your illness, and/or recovery?
   d) What decisions do you think people make about your life in relation to risk?
   e) How do you think decisions were made about risk in relation to your CTO?

3. Capacity
   Decisions about CTOs are sometimes made because people are considered to be lacking the capacity to manage their own affairs or make informed decisions.
   a) How do you think about that concept of ‘capacity’?
   b) How does that relate to you?
   c) How do you see ‘capacity’ as part of your illness, and/or recovery?
   d) What decisions do you think people make about your life in relation to capacity?
   e) How do you think decisions were made about capacity in relation to your CTO?

4. Evaluation of others’ experiences
   Think about any other people you know who have been placed on CTOs.
   a) Can you think of a case/s when you think it was a good decision to place the person on a CTO? Why do you think it was a good decision?
   b) Can you think of a case/s of when it was a bad decision to place the person on a CTO? Why do you think it was a bad decision?
6. References


