

Risk, capacity and making decisions about CTOs – a report from ‘the CTO study’

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THE UNIVERSITY OF
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Executive summary

1. The two customary justifications for ‘involuntary’ or ‘coercive’ treatment of mental illness are either: that without treatment the mentally ill person might be likely to seriously harm themselves or others; or, that the person lacks capacity to refuse treatment but that treatment would be in the person’s best interests and consented to by a substitute decision-maker.
2. These concepts are more complex in the setting of community mental health care as levels of acuity and clarity of risk and capacity are often viewed through different prisms by different stakeholders.
3. The lack of any valid consensus on models of ‘risk’ and ‘capacity’ often complicates clinical and legal decisions relating to the use of community treatment orders (CTOs).
4. Between 2009 and 2012, the Centre for Values Ethics and the Law in Medicine (VELiM) at the University of Sydney conducted a research program on behalf of the Mental Health, Drug and Alcohol Office (MHDAO) of NSW Health.
5. Thirty-eight participants – including clinicians, consumers, carers and members of the Mental Health Review Tribunal (MHRT) – participated in the research project by taking part in in-depth interviews. This interview data set was analysed using qualitative methodologies.
6. The researchers noted that while there were significant overlaps in how groups of participants conceptualised ‘risk’ and ‘capacity’, each participant group emphasised different aspects of these constructs :
 - a. In the domain of risk, clinicians and MHRT participants predominately saw risk in terms of risk of harm and risk of poorer clinical outcome, whereas consumers and carers were more likely to conceptualise it in terms of social and interpersonal adversity.
 - b. In the case of capacity, clinicians and MHRT members based their views on legal and medical constructions relating to the ability to make reasonable choices about health, whereas consumers and carers emphasised that severe mental illness brought about incapacity to partake a social role. In the light of the existing medico-legal constructs of capacity, it may be prudent to categorise this phenomenon as ‘capability’.
7. From these data the study proposed a model of risk incorporating the domains of :
 - a. Risk of harm to self or others
 - b. Risk of social adversity
 - c. Risk of excess distress
 - d. Risk of compromised treatment
8. The proposed model of capacity incorporates the domains of :
 - a. Capacity to manage the illness
 - b. Capacity for self-care
 - c. Capacity to maintain a social role
9. Future research is required instrumentalising these concepts and assessing their application in medico-legal settings.

Part 1 – Background

1.1 Introduction

In most international jurisdictions, there are essentially three criteria in the process of civil commitment or involuntary psychiatric treatment either as an inpatient or in community settings – being a danger to self, being a danger to others, or being gravely disabled. Many see these criteria as manifestly inadequate because mental health laws based on such premises result in delays in treatment. Delays may force many people with mental illness to suffer deterioration in their mental health to the point where their illness poses a danger to their own or other's welfare, has led to offending and criminal sanction, or loss and irreparable damage to social supports.¹

The two broad moral justifications of involuntary psychiatric treatment are based upon 'risk of harm' or 'capacity'.

Risk of harm in mental health legislation

In mental health legislation, the 'harm principle', as first elaborated in John Stuart Mill's *On Liberty*,² is usually defined in terms of the construct of 'risk'. Risk is a term that has multiple meanings in different disciplinary contexts, although all approaches to 'risk' attempt to apply knowledge to an area of uncertainty.³ The notion of 'risk assessment' is usually considered as the process of categorising individuals by their perceived likelihood of causing serious harm to themselves or harm to others. In the insurance industry, actuarial assessment is a mathematical discipline aimed at computing a probability of adversity, based upon a broad consideration of variables. As a form of knowledge, the concept of risk speaks to an evaluative process that estimates the probability of a negative event. The estimation of risk is subject to 'bounded rationality', that is, the effect of particular biases on how such information is handled. In a culture that is averse to risk, bounded rationality is clearly more likely to favour an overestimation of risk.³ Applying actuarial approaches to risk in mental health is a process of using known risk factors to categorise people by relative likelihood of future harm.⁴ Despite this approach providing significant reliability, the poor predictive value of such assessments means that it has little or no clinical utility. Notably, around one-quarter of all dangerous acts are predicted by psychiatrists.⁵ As a discipline, psychiatrists are usually inaccurate in overestimating risk.⁶

A system of coercive treatment based up risk categorisation will subject many people to coercive psychiatric treatment who will never go on to seriously harm themselves or others. There is also evidence that mental health laws based upon risk categorisation are associated with significant delays in people accessing treatment in their first episode of psychosis.⁷ In addition to the consequences of self-neglect and damage to reputation, finances, career and relationships, such delays in treatment lead to poorer prognosis after treatment. Many patients who may never satisfy the legal test of likelihood of serious harm may be denied access to treatment as their illness do not lead to such concerns.⁸ By promoting risk of dangerousness as a feature of mental illness within the community, such laws promote stigma in relation to psychiatric disorders.⁹

Capacity as potentially reflected in mental health legislation

The state can enforce psychiatric treatment – through detention, administration of treatment or imposition of obligations in community care – ostensibly under the rubric of *parens patriae*, literally translated as 'parent of the nation'. This originally referred to the power of the sovereign to intervene against an abusive or negligent parent, legal guardian or informal caretaker, and to act therefore as the parent of any child or individual who was in need of protection. This notion of an inherent power of the courts originated in 13th Century prerogative powers of the crown and was formalised in the 16th Century within the British equity (Chancery) courts, a jurisdiction inherited on the establishment of modern day Supreme or High

courts. The original invocation of *parens patriae* referred to safeguarding the interests of incompetent adults or children.¹⁰ The *parens patriae* doctrine should be distinguished from the *in loco parentis* doctrine, in that the latter involves care that is 'temporary in character'.¹¹

The 'capacity' justification for involuntary psychiatric treatment is based upon the notion that people should not be deprived of access to treatment merely because they lose the ability to either understand information relevant to the accepting the treatment or the ability to weigh that information in context to come to a decision. Unlike other pretexts for the application of *parens patriae*, the capacity argument is limited to enforcing an intervention to ameliorate the specific impairments of mental illness which preclude the sufferer from seeking or accepting treatment. The supposition is that the person has a right to treatment and the effects of the mental illness deny that right to the sufferer. In legal and medical settings, capacity has tended to be focused upon decisions regarding the right to refuse treatment or other time and task-specific decisions.

Both 'risk of harm' and 'capacity' have different conceptualisations in different settings. In many considerations of 'risk of harm' and 'capacity' and mental illness, arguments focus upon acute and severe disturbances of mental state that necessitate detention in hospital inpatient settings. In the setting of longer term community-based involuntary treatment, these concepts of 'risk of harm' and 'capacity' have less instrumental value as decisions about ongoing ambulatory treatment in otherwise stable or less acute illnesses require more contextualised descriptions.

From this perspective, this study sought to address the following questions:

- How do different stakeholder groups conceptualise 'risk' and 'capacity' in the setting of community-based involuntary psychiatric treatment?
- How do these concepts affect decision-making among different stakeholders in relation to CTOs?
- Can a comprehensive, consensually valid model of risk and capacity in the context of decisions around CTOs be described?

1.2 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.¹² In 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'.¹³

'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.

1.3 The 'CTO project'

This study was commissioned by the Mental Health, Drug and Alcohol Office of NSW Health to address the question of how 'risk' and 'capacity' can be better conceptualised in the setting of decisions around CTOs in NSW.

The study was funded by a discretionary grant from NSW Health of \$115,624 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 Sydney Law School at the University of Sydney.

Investigators

The principal investigators of the project were:

- Clinical Associate Professor Michael Robertson – Chief Investigator (VELiM and Discipline of Psychiatry)
- Professor Alan Rosen (School of Public Health, University of Wollongong) and Clinical Associate Professor (Brain and Mind Research Institute, University of Sydney)
- 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 principle researchers, the project also sought the ongoing involvement from various 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 detailed report of the project’s expenditures is included in Appendix 6.1.

Conduct of study

The study was conducted between July 2009 to August 2012. Administrative and academic activities were based at VELiM at the University of Sydney. The research was conducted with the approval of the following ethics committees:

- University of Sydney Human Research Ethics Committee
 - Consumer and carer interviews – approved 6 April 2010 (reference number 12583)
 - MHRT member interviews – approved 10 January 2012 (reference number 14421)
- Sydney Local Health Network (formerly Sydney South West Area Health Service) Ethics Review Committee
 - Clinician interviews - approved 3 February 2011 (protocol number X10-0338 & reference number HREC/10/RPAH/596)
 - Site authorisation (Sydney Local Health Network RPAH Zone) – 23 March 2011(reference number SSA/11/RPAH/125)
 - Site authorisation (South Western Sydney Local Health District) – 1 October 2011 (reference number SSA/11/LPOOL/110 & local reference 11/090)

Copies of the relevant ethics committee approvals are included in Appendix 6.2.

Part 2 – Methods

2.1 Research questions

The investigators sought to derive an idiographic model of the constructs of ‘risk’ and ‘capacity’ as applied to deliberations over the use of CTOs and to determine how such constructs may influence decisions made by different stakeholders in this area. An idiographic approach aims to understand the meaning of specific and subjective phenomena, in this case, ‘risk’ and ‘capacity’. The research questions were formulated as:

1. How do mental health professionals, consumers, carers, and MHRT members conceptualise ‘risk’ in the context of decisions about involuntary psychiatric treatment in the community?
2. How do mental health professionals, consumers, carers, and MHRT members conceptualise ‘capacity’ in the context of decisions about involuntary psychiatric treatment in the community?
3. Can a comprehensive model of the concepts of ‘risk’ and ‘capacity’ that is consensually valid across all four participant groups be formulated?
4. How might the concepts of ‘risk’ and ‘capacity’ influence decisions in relation to the use of CTOs?

2.2 Sample acquisition

Recruitment

The participants were recruited concurrently from each of the four groups using a theoretical purposive model of sampling. 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.

Participants in the study were recruited using a variety of methods. Clinicians were recruited through the distribution of an invitation to participate by health service managers. Interested potential participants were then recruited using a ‘snowball’ method of acquisition, through which the study was recommended to future participants by current participants through their professional networks or relationships. In the case of consumer and carer participants, an invitation to participate was circulated through non-government organisations (Carers NSW, the Mental Health Coordinating Council, and NSW Consumer Advisory Group – Mental Health Inc). This was further disseminated 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. Consumer and carer participants received \$40 at interview to go toward any public transport, taxi fares or parking fees associated with their attendance. In the case of MHRT participants, an invitation to participate in the study was circulated by the Tribunal to all its members. Members interested in participating in an interview then contacted the Tribunal Registrar to arrange an interview with a member of the research team.

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 enabled the investigators to build a comprehensive model of the concepts of risk and capacity from as many different perspectives as possible within the different groups. Where possible, this meant that participants from different disciplines in the clinician and MHRT groups were included, in addition to different demographics of consumer and carer participant groups.

Data saturation

The investigators concluded that the data had reached saturation at the time of the analysis of the interview of the 35th participant. A further four interviews were conducted to test this assumption and complete the process of maximum variation sampling. The investigators sought to confirm saturation by triangulation of the data coded separately by two members of the team (MR and 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.¹⁴ Triangulation usually involves comparisons from the data source, investigator, theory, and method.¹⁵

2.3 Interviews

The investigators opted to conduct the study using in-depth semi-structured interviews conducted in a variety of sites. The interview structures are included in Appendix 6.3. In the case of clinician participants, interviews were conducted in clinical sites within the former Sydney South West Area Health Service. MHRT participants were interviewed either at the MHRT offices in Sydney or, where appropriate, in their other workplaces. Interviews with consumer and carer participants were held in offices of the NSW Consumer Advisory Group – Mental Health, Carers NSW, and Mental Health Coordinating Council. Consumer participants were not recruited from or 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.

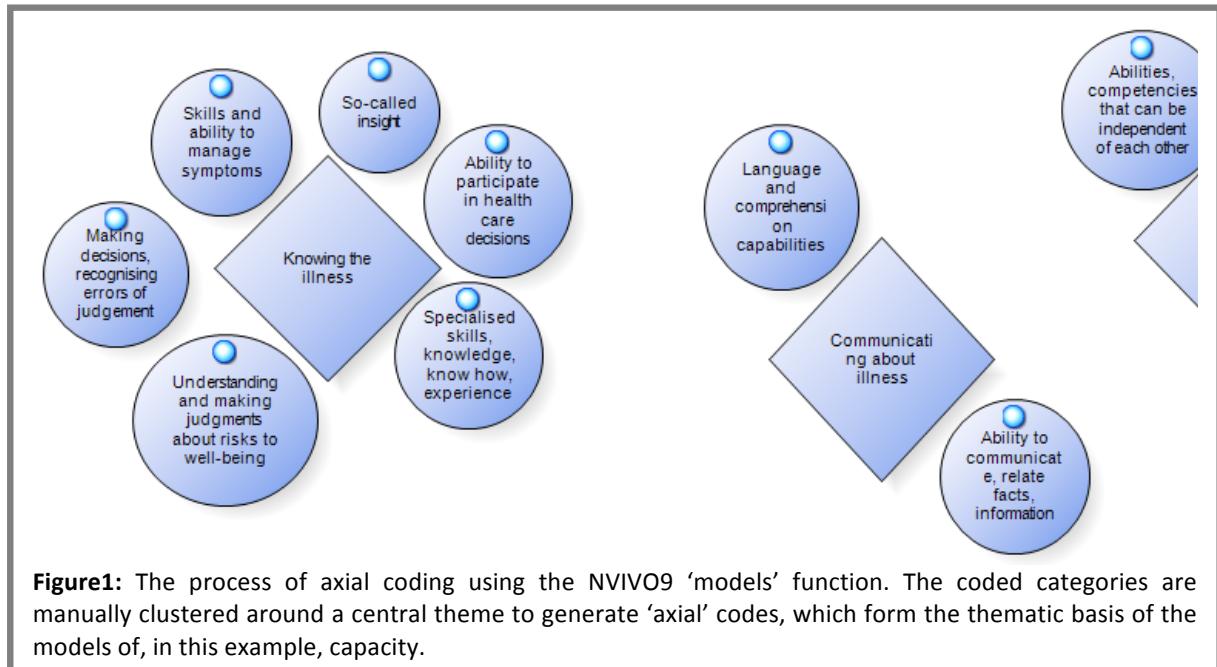
In the conduct of the interviews, the investigators prompted the participants to speak from their unique understanding of CTO use by providing narrative accounts of their experience of CTO processes. In the case of clinicians or MHRT participants, this involved their reflection upon specific examples of dilemmas in decisions around CTOs in their professional experience. In the case of consumers and carers, this involved a process of constructing a personal narrative of their direct or indirect experience of the use of CTOs.

The interviews were recorded digitally and transcribed. The interview transcripts were then de-identified, removing any details that might identify individual participants and compromise participant confidentiality. Given the interviews were conducted in a specific site, the investigators opted not to report age ranges to protect confidentiality. In the clinician sample, details of disciplines and clinical settings were noted, but they have not been reported as characteristics of any individual participant in order to protect their confidentiality.

2.4 Analysis

The investigators analysed the data using the NVIVO9 computer program¹⁶ which enables different coding strategies and cross checking of different concepts across the sample. The investigators utilised the general inductive method¹⁷ of data analysis. In this method, the interviews are coded initially using initial, *a priori* codes (in this case, codes of 'risk' and 'capacity'). As the data is coded, new themes are identified and a coding structure then develops. After an initial process of 'open' coding of the data,¹⁸⁻²⁰ 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 then clustering them around a central theme (see Figure 1). This facilitated the emergence of a number of themes, which formed the basis of the different models of risk and capacity among the participant groups.



In the final phase of data analysis, the investigators assessed the emergent models of risk and capacity in the light of the established literature in both areas in order to theorise the data analysis into a comprehensive model of risk and capacity.

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' beyond the initial coding categories of 'risk' and 'capacity', 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

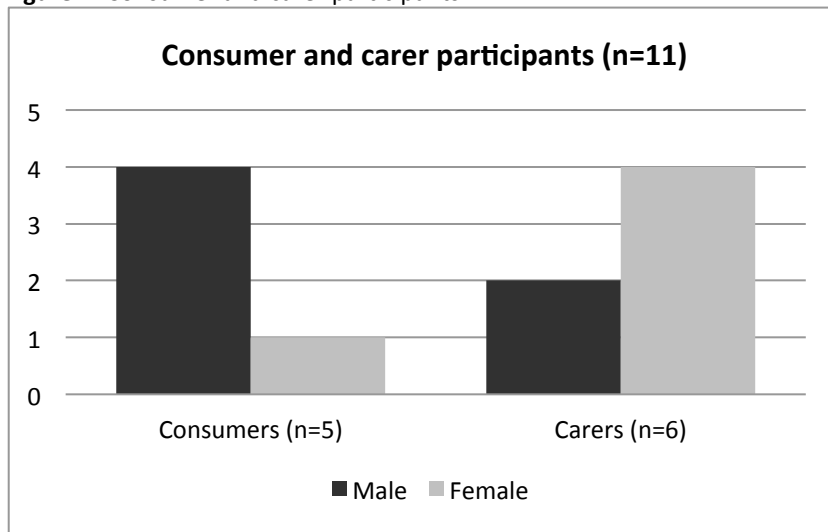
3.1 Population

The study sample is shown in the figures 2 to 6.

Consumer/carer participants

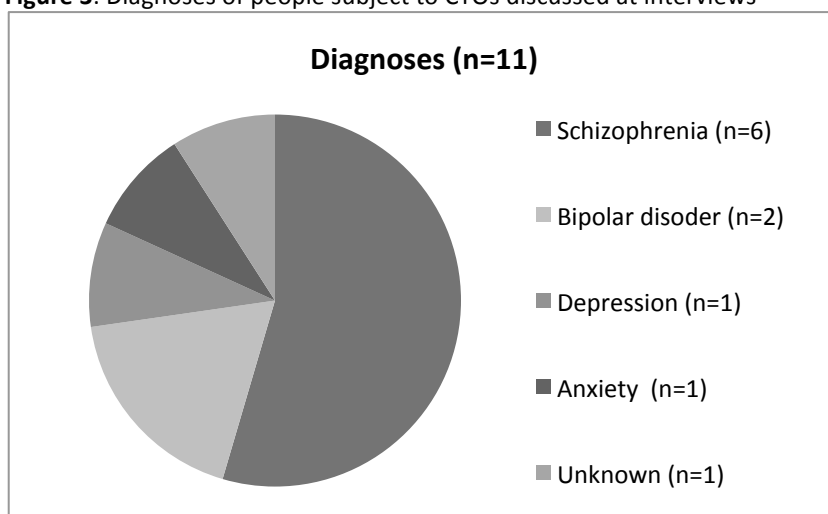
Five consumers and six carers participated in interviews. Six were men and five women from metropolitan or regional/ rural areas. Among either the consumers or the relative of the carer were diagnoses of schizophrenia, depression, bipolar disorder, and anxiety.

Figure 2: 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 3: Diagnoses of people subject to CTOs discussed at interviews

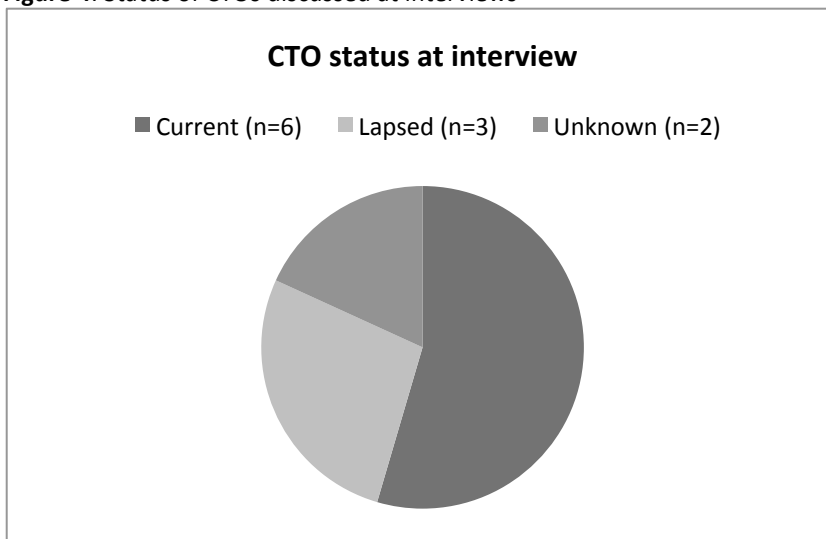


One issue of note was the difficulties in recruiting consumers subject to CTOs through non-clinical pathways. In opting to not recruit through treating clinicians, the yield of suitable participants was lower than anticipated. Moreover, several suitable participants agreed, and

either later withdrew or were unable to participate. This is in line with the experiences of other researchers in this area.²¹

Also noteworthy that it is possible, as with other research about CTOs,²¹ 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 a current 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.

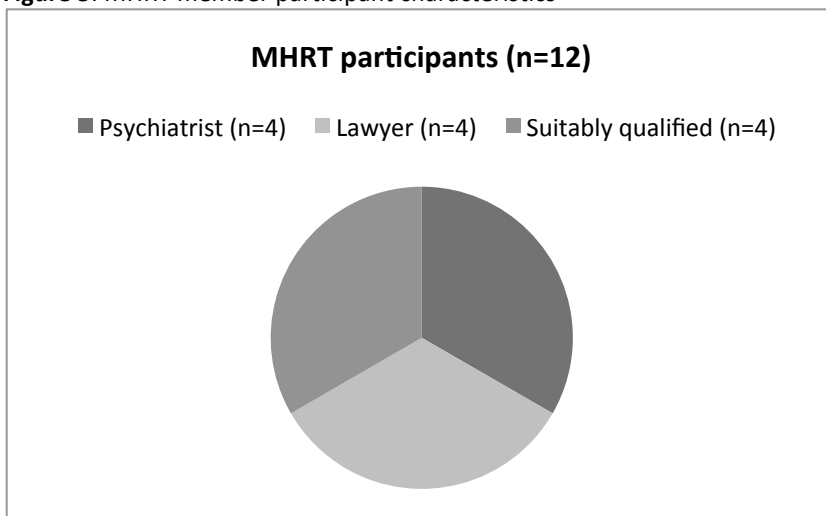
Figure 4: Status of CTOs discussed at interviews



MHRT member participants

Twelve MHRT members participated in the interviews. Of these five were women and seven were men. Four were psychiatrists, four were lawyers, and four others were other 'suitably qualified' members.

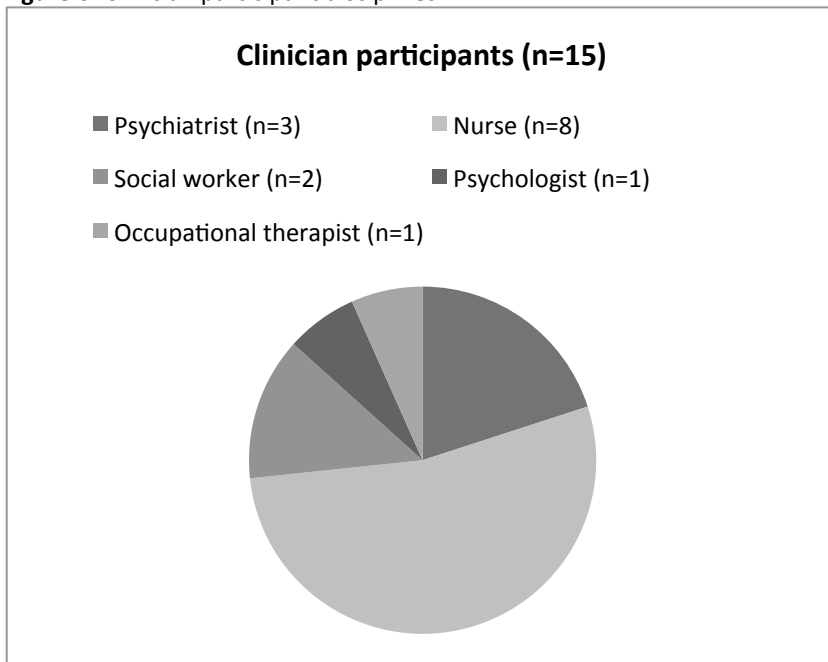
Figure 5: MHRT member participant characteristics



Clinician participants

Fifteen clinicians participated in interviews. The sample included three psychiatrists, eight nurses, two social workers, one psychologist and one occupational therapist (four men and 11 women). The various clinicians had worked in inpatient and community mental health settings and their clinical loads included general adult mental health, youth mental health, older person's mental health and Aboriginal mental health. Participants worked in regional and metropolitan settings.

Figure 6: Clinician participant disciplines



3.2 Data analysis

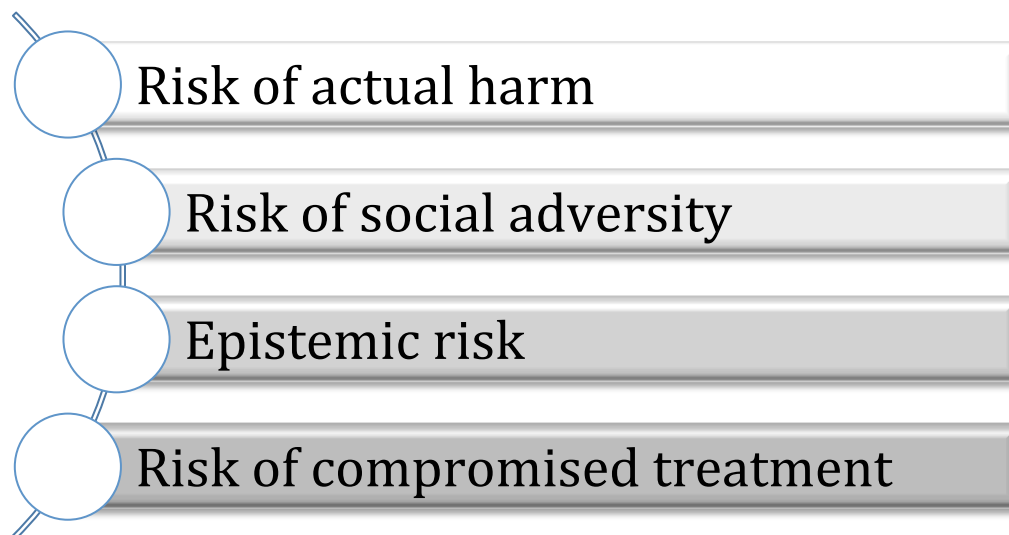
3.2.1 Risk

Clinician and MHRT member perspectives on risk in community-based involuntary psychiatric treatment

The analysis of the data from clinician and MHRT member participants revealed significant overlap in how risk is conceptualised. The analysis is presented in this section as a composite of clinician and MHRT member perspectives. Themes that are unique to either group are also described within this section.

Risk, as conceptualised by the interdisciplinary perspective of clinicians and MHRT members, had four thematic components: 'Epistemic', 'Social Adversity', 'Actual Harm' and 'Compromised Treatment'. The hybrid model of risk from clinician and MHRT participant perspectives is shown in Figure 7.

Figure 7: Hybrid model of risk from perspective of clinician and MHRT participants



'Actual harm'

In conceptualising risk, both clinician and MHRT members integrated the intuitive notions of actual harms – death by suicide or misadventure, harm to others, damage to property, self-neglect, decline in health, or damage to property – leading to adverse legal consequences or material disadvantage to the consumer in the case of damage to their own property. Most of the narratives of the problems of specific consumers and specific situations described the danger posed by a particular mental illness.

Risk of harm was defined as an evolving concept, in that a particular element of risk would cascade to other forms of harms:

'Where there's a question mark, and obviously there has to be some view from the treating team that this individual needs an order, otherwise if they don't have an order, they're very likely to not take their medication. And following on from that, there is the risk of relapsing, and following on from that of course, there is risk to themselves or others as a result of the relapse. So they're all the pathways.'

Beyond the general concept of 'dangerousness' both groups acknowledged deterioration in physical health as a potential harm:

'Well physical health, that's an interesting one isn't it, because when you think about, once again; well medication that we're actually getting these people to take, or forcing onto them, is toxic medication, really a lot of it, it's going to make people gain a lot of weight, it's going to make people have medical issues, if not immediately, certainly down the track, but I don't know what the alternative is.'

The notion of iatrogenic harm arose in the notion that a poorly controlled mental illness would lead to the use of treatments that posed a higher risk of harm, such as weight gain or accelerated cerebrovascular disease. This was particularly the case in regards to older patients with established health problems:

'Although that's true across all ages, with people who are older they are more likely to have other physical problems which could be exacerbated by being on the medication.'

Both groups acknowledged that the traumatic experience of mental illness was in itself a form of harm.

This traumatic experience emerged as a consequence of the process of detention and hospitalisation:

'He then became acutely psychotic for the first time after a long period of being quite well, which led to quite a frightening admission to hospital yet again, which actually was quite traumatic for the whole family, but particularly for him.'

The trauma of the symptoms of mental illness, usually psychotic, also formed the basis of harm:

'He'll tell you about delusions about people draining blood from his penis, about being bashed up by people with baseball bats, these are all these frequent delusions that he comes out with, but they're definite delusions.'

MHRT member participants additionally saw harm in terms of increased number and lengths of hospital admissions. One MHRT member participant described the idea of 'risk pathways' – referring to a downward trajectory brought about by recurrences of illness, progression from non-compliance, risk of relapse then risk to self.

'Social adversity'

Both clinician and MHRT participants expanded the conceptualisation of risk beyond harm to the impairment of social role or disadvantage in the social system and the adverse consequences this involved. Both groups saw interpersonal failure and vulnerability as a consequence of mental illness:

'In the clinical notes there was evidence that if the CTO is not made, the client doesn't take the medication, it disrupts her relationship with her family, because she lives in the same house with them, she becomes unwell.'

The loss of the ability to discharge a social role formed part of the formulation of risk in this setting:

'And there's a difference when they're actually able to cope, to have a life, to deal with their children, to deal with their partners, to go to work, all those things are signposts that things are getting better.'

Beyond the diminished capacity in social roles was the notion of the loss of opportunity consequent upon mental illness:

'That those people, they run the risk then of damaging family relationships, or even assaulting family members, or getting AVOs because they've attacked a neighbour, or losing their housing commission, or losing their jobs, and doing further damage to the functional status. So aside from the brain damage that you get every time that you get sick, or aside from the problems that just being sick present, it takes longer to get better, you never return to exactly the same level as you were, and it just does more damage. It's the bigger picture, and losing so many things that that's likely to happen when they stop their medication, and when they get unwell again.'

Clinicians and MHRT members regarded the risk of exploitation, in a variety of domains, consequent upon a mental illness as part of the concept of risk:

'Well I mean it very much depends on the individual, but exploitation of a financial manner, or sexual exploitation, those things are; I suppose financial in this age group it's more likely to be financial exploitation. But sexual [exploitation] does happen, and then it's very difficult for people to get believed.'

Both clinical and MHRT participants referred to the established principle of 'dignity of risk', referring to the principle of allowing consumers the liberty to exercise autonomous choice where there is an element of risk involved:

'It's a balance; I mean ideally you would like to think that you give people the dignity and the autonomy to make their choices about turning up and getting treatment. The trouble is, this particular person won't do that, and so, and when he doesn't take medication he gets very sick very quickly, and then it means another long hospitalisation.'

While MHRT members valued the autonomy of the patient in light of the construct of 'dignity of risk', this was not to a point of neglect of the hazards of over-estimating capacity:

'I'm sympathetic to the dignity of risk, but I'm not sympathetic to the dignity of risk if it involves catastrophic relapse, where a person or others are significantly endangered. I mean it's difficult to just talk about it in a general sense, to walk through it is a lot easier... I like the idea. I think you know, I do I like the idea, I think that it's an important concept, it's tied into the idea of being able to recognise that people should have the responsibility to, or we should recognise that people at some point, need to have the responsibility to make decisions for themselves.'

MHRT members graduated social disadvantage as a component of risk into the realm of an impaired or compromised role as an autonomous social actor. One aspect of this is the loss of agency by the consumer, manifesting as the compelling intercession of third parties in decisions about treatment and lifestyle choices, as a component of risk:

'Yes, that's the other question that we ask. Because to clients in general, they feel a CTO is an imposition via a legal method to control their lifestyle, and if they don't have that over their head they won't take the medication. But at the same time they feel it's a legal order,

and they don't want that dangling over their head. From a client's point of view, they feel it's a restriction on their lifestyle, their liberty. But then the whole idea of CTOs, is for it not to be too restrictive. If an order is not made, the evidence shows that some of them don't take their medication, they become unwell and they're back in hospital again.'

'Compromised treatment'

MHRT and clinician participants conceptualised the notion of 'compromised treatment' as a component of risk. This speaks to the impact of a consumer's mental illness upon the nature and potential benefits of their clinical care. Participants considered that a person with a poorly controlled mental illness would experience clinical care that was more focused on risk. This focus upon risk led to a poorer quality of care through the patient's illness being defined by its risk, rather than their experience of the illness:

'But yeah if...something bad has happened in the past, and understanding of it is expressed, if it's appropriate, remorse is expressed, and people make clear efforts to stay well, to make sure that nothing happens again, those are the kinds of things that make me think that the risk has reduced.'

In a related concern, one clinician participant referred to the effect of the consumer's mental illness on all other interactions with health services or social institutions as 'diagnostic overshadowing'. In this process, the person and their particular need was only regarded in terms of their illness:

'The fact that somebody has been admitted to a hospital with a mental illness; basically we call this diagnostic overshadowing, we see it quite a lot. Because we've got a public hospital here that hasn't got a mental health component to it other than us going in there on a consultative basis, and we have some beds that we keep people in there voluntarily, if we sent somebody in there that's had, or somebody presents that's had a history of a mental illness, automatically they might present with a broken leg, or they might have something, we will be asked to come and see the person regardless of whether they need to see somebody for their mental illness or not.'

MHRT members were concerned about the impact of mental illness upon the consumer's therapeutic engagement in care, and in particular the distress caused by the legal procedures around the process of making CTOs and the negative effect it had on the therapeutic alliance:

'And the other reason is that you need to look at the therapeutic relationship, so if it's going to damage the therapeutic relationship with the case manager or the client, then you need to consider whether six months would be better as opposed to 12 months. And the other reason why we grant the 12-month order is, okay first it's not opposed, distresses the client, other members, against that background, work constraints and everything else, so that is factored in.'

One MHRT member participant described how the effect of legal process on the therapeutic relationship might warrant pragmatic decisions in the application of the *Mental Health Act*:

'This was one of those instances where I explained to the case manager, ordinarily if the criteria is satisfied, the tribunal will make a CTO for a period of six months, but in your application you've asked for 12 months, so what are the extenuating reasons here. So the family had put this she is quite ill, it distresses the client, it affects the relationship if they

were to come to the tribunal once every six months, and so this is one of the reasons.'

Therapeutic engagement problems nominated by MHRT members also arose from the apparent difficulties that busy mental health service clinicians faced in caring for consumers with significant needs and the effects of clinician 'burnout' on the care of such patients:

'I am worried that they're not as well resourced as they could be, there is a lot of burnout with case managers, and I do worry that with people leaving the service, that those sets of important skills are lost, and therefore patients are the people that will suffer.'

'Epistemic'

The epistemic component of 'risk' in the context of involuntary psychiatric treatment in the community primarily addressed questions of knowledge of the phenomenon. The participants spoke of the challenge of arriving at a substantive definition of risk, the prediction or quantification of the risk posed by a person's mental illness, and how risk may be determinative of treatment and legal decisions. The epistemic theme also acknowledges the problems arising from the intersection of legal and medical discourses of risk. Clinicians working from the disciplinary perspective of medicine approach risk as a measurable, preventable or naturalistic phenomenon. Legal practitioners and community representatives approach risk from the legal disciplinary perspective, qualifying the phenomena in the terms of legal or statutory definitions.

Clinicians grappled with the complexity of diagnoses and treatment decisions and had a particular 'witnessed' or firsthand knowledge of risk. This translated into different perspectives on the use and instrumental value of CTOs:

'As a case manager, I would prefer the least restrictive option, which is trying to engage with clients rather than bring a CTO, and a CTO I see is a force of a negative sort of aspect of therapy to engagement. So I usually don't make a CTO a lot, I don't make that decision a great deal, it usually comes from hospital or the doctor, and myself as a case manager. ... I'm just trying to engage with them as much as I can, when there's a high risk, that's when I can consider, but I try as best I can to try and find rapport, to work with them before I'm really serious about applying for a CTO. I think that's a very, very last resort for me.'

One of the implications of CTOs as legal constructs that have instrumental value in a clinical domain is the misconstruction of a CTO as a punishment for non-adherence or engagement in treatment, as against a means of ensuring the patient has access to care:

'I think that firstly, I mean the CTO, the main thing that I believe is that they are not... I don't think they should ever be seen as punishment, that would be if I could drum anything home, I wish everybody would live in a world where we had, that people saw it as a treatment tool rather than a punishment. I've seen such good outcomes from people on CTOs that outweigh the bad ones.'

Clinicians grappled with the estimation of risk, how it fluctuates with the vicissitudes of the illness, and how their disciplinary perspective influences their appraisal of risk. Clinicians tended to conceptualise risk beyond specific risk of harm (described in depth in a later section).

'...one of the reasons we thought about a CTO was that, not because we thought it would necessarily help contain any aggression or violence on his part...we thought it was very, very likely that this person, when discharged out into the community, would for a period of time engage with the community health team, would probably remain medication compliant, and then start to kind of drift back into that kind of itinerant behaviour.'

CTOs had a complex relationship with the conceptualisation of risk. The application and enforcement of CTOs were in large measure determined by the appraisal of risk. One participant described the problems of enforcing a CTO in the care of a patient who had been severely depressed and suicidal, yet whose mental state fluctuated, as did the risk of suicide. The enforcement of a CTO mandated a specific, consistent pattern of interaction and decision-making with the patient. This often posed a challenge in clinical care:

'She was only on one for a couple of months before she killed herself, so it was sort of all new to her ... I think if we had had maybe a bit more time before the unfortunate end, we were starting to say, "we need to talk to the doctor and we need to tell the private psychiatrist that this is what we are doing, this is how we are going to do it". And we would have done that. So we had a treatment plan, we had it all in place, but we weren't enforcing it.'

The interdisciplinary discourse over risk provided the basis of communication between clinicians and tribunal members. Prioritising risk in the context of involuntary psychiatric treatment served as the basis of most forms of communication about the patient and their illness within and between disciplines:

'So, it's a way of prioritising which patients need greater attention and greater follow up from clinicians. And I guess it's a way of sort of alerting clinicians to the higher risk that's involved with some patients over others too.'

Participants from the MHRT tended to focus on the history of risk and its broad definitions. This deliberation usually focuses upon the legal justification for CTO as being strong or weak:

'We get very upset quite a bit at how bad some of the (applications) are, they'll often put someone up for a CTO because somebody told them to, or they've been on one for the last X number of times so why not – very little reconsideration or thought about whether this is a period that you're working with somebody to get them to be more independent and self motivated to look after themselves and so on.'

In taking the legal disciplinary perspective, MHRT members seemed to have a higher tolerance of risk in these decisions.

'But obviously you don't want any major misadventure, but I think that I would probably rather err a little bit on that side than on the side of not taking any chances...and so if you see somebody relapsing, you do something about it, and you give them a chance, and you may well do it again.'

The capacity to apply for a CTO from a community setting as provided in the 2007 revision of the *Mental Health Act* seemed to be conceptualised as a 'safety net':

'I think where somebody is saying that they want to come off an order, and they appear to be saying "I want to do it for myself, I know I have a problem, I just don't want to be on an order", I'm sympathetic and most of the colleagues I've worked with will give it a try, particularly now we've got that little bit of a safety net.'

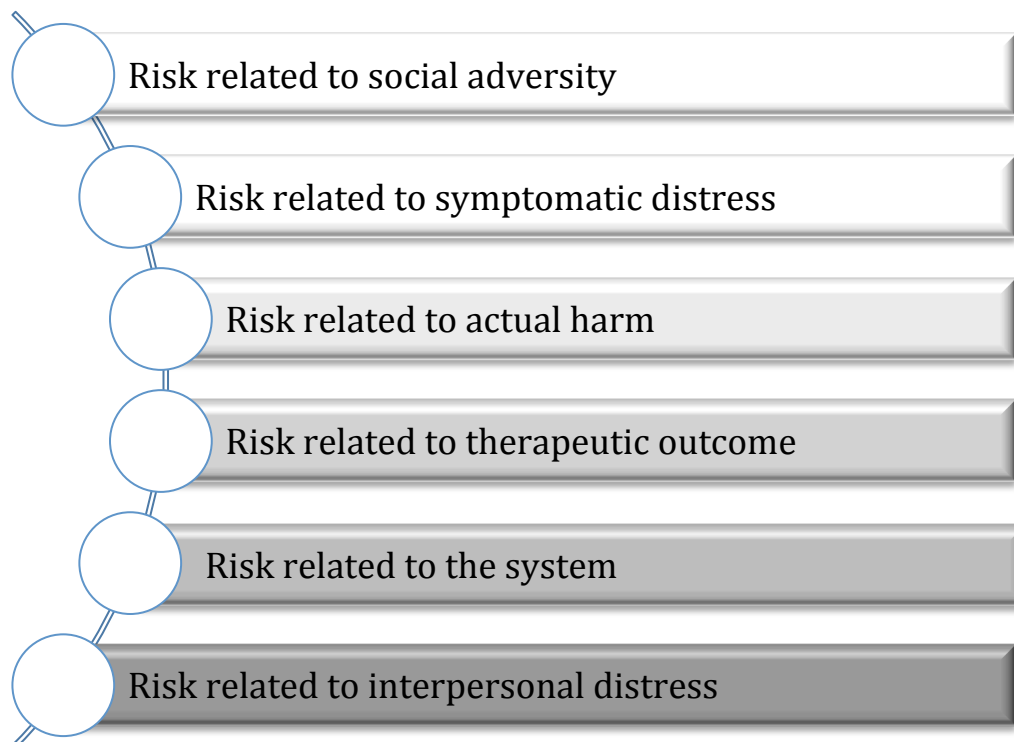
MHRT members spoke of their decisions in terms of integration of statutory criteria, the clinical history of relapse, and previous history of harm. Despite the *Act* not stipulating particular diagnoses in terms of determining the use of CTOs, MHRT members acknowledged diagnosis as determining such decisions:

'What we were able to clutch at was that she actually hadn't been given a diagnosis of schizophrenia until this admission – all the other stuff had been sort of personality, drug use, everything else. And so there was no history of a diagnosis, and then a refusal of non-compliance. We were then able to say "right, well okay we can make an order, because it's a first diagnosis", and get them to it in that way. That's a sort of legal case that cropped up.'

Consumer and carer perspectives on risk in community-based involuntary psychiatric treatment

The analysis of the data from consumer and carer participants also saw overlap in how risk was conceptualised by the two groups. Risk, as conceptualised by consumer and carer participants had six thematic components: 'Social Adversity', 'Symptomatic Distress', 'Actual Harm', 'Therapeutic Outcome', the 'System' and 'Interpersonal Distress'. The model of risk from a consumer and carer perspective is shown in Figure 8.

Figure 8: The model of risk from the perspective of consumer and carer participants



'Social adversity'

Both consumers and carers defined the risk of social adversity in multiple domains. Social disadvantage included aspects of material disadvantage such as financial insecurity, homelessness, isolation, exclusion, or vulnerability out in the community. A severe mental illness often posed a risk of many 'legal problems' such as being at increased risk of committing a crime or having their behaviour while ill criminalised. Participants also noted the risk of cumulating minor infringements for misdemeanours such as fare evasion, minor drug offences or property damage.

A number of the participants emphasised their concerns about how a mental illness led to encounters with the criminal justice system by noting the number of people with mental illness in the prison system. One carer participant noted that:

'We're locking more people up, and a lot of people in gaols, and you probably know, that a lot of people in prison have a mental illness, and they're not being adequately treated. They're being treated for their criminal behaviour, but they're not being treated for their mental health problems. Admittedly they may have done something wrong, but people with a mental illness probably, usually they're more recipients of harm than harming others, proportionally much more so.'

Many participants saw mental illness as posing a risk of dwelling in the realm of second-class citizenship, manifesting as disenfranchisement and disempowerment. Apart from the well-documented problems of stigma in the community, suffering a mental illness diminished or discredited the reputation of a person. This led to other forms of disadvantage such as diminished capacity for flourishing by being denied access to means of developing life skills or being denied opportunities. One consumer participant reported that his or her behaviour while unwell saw him or her banned from a local café and subject to an Apprehended Violence Order, thus contributing to his or her social disadvantage:

'Yes, just whether I was imposing on a life of the young woman and the people in the café, and whether I do something that for some reason, which they eventually did, they asked me not to go back. And actually the girl filed for an AVO, so I'm complying with that as well, I agreed to that, so I'm just living away from those places now.'

Part of the experience of second-class citizenship was a sense of 'injustice'. While many participants spoke of encountering different forms of injustice in many aspects of their lives, many as an unjust process saw the actual process of applying the *Mental Health Act*. One consumer participant reported:

'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...think at times I felt it was a bit unjust to go through the motions I went through with different ones making decisions for me, but I believe that eventually justice will prevail and there'll be an outcome. But I believe we have to abide by certain principles to stay out of trouble too, but I've been prone to make errors of judgement. So there's a measure of injustice at times, but sometimes we bring things upon ourselves don't we?'

Some participants reported a sense of a loss of freedom arising from being subject to involuntary psychiatric treatment. Speaking of his or her reluctance to be on a CTO because of the loss of freedom implied by the constraints of the order, one consumer participant stated:

'Well I knew it meant being on medication, and I had been free of those constraints for a number of months, and I felt that my life was better without seeing doctors and taking medication. So I knew when the mental health team arrived, that it would mean all of that again in my life...in a way it may seem like one's incarcerated or something as such, to go to hospital and do all these things.'

Loss of freedom also appeared to manifest as the loss of a right of 'negative liberty'. A carer spoke of their relative's sense of loss of freedom in his life:

'For us, he said, "I've lost my privacy, I've lost my independence, I've lost everything".'

Within the domain of lost negative liberty was an umbrella concept, often termed 'dignity of risk', or the freedom to make mistakes. Several participants noted that in many interpersonal relationships, people suffering severe mental illness did not have sufficient freedom to have the agency to explore the different aspects of choices they could make in their lives, denying them the opportunity for personal growth or authentic existence. A consumer participant noted that part of their adverse experience of illness was the constraint he or she felt in being subjected to proxy decision making:

'...but I also recognise that I can make errors of judgement. So I suppose we're all prone to that, but you know some people are wiser than others, and it's good to listen to the thoughts of others and think about what you are doing. But I think at times I felt it was a bit unjust to go through the motions I went through with different ones making decisions for me, but I believe that eventually justice will prevail and there'll be an outcome.'

'Symptomatic distress'

Both consumer and carer participants described the risk posed by severe mental illness in terms of the harm of disruptive or distressing symptoms, which left a person feeling 'threatened', 'distracted' or 'frightened'. A number of carer participants saw the risks inherent in psychotic symptoms as manifesting as neglecting other parts of the person's life to their clear detriment:

'He can't prepare a meal properly or plan the meal, to go and buy the food, to bring it home, and then do the process, leaving the grill on or leaving the oven on and things like that, there's a risk of doing that. Forgetting appointments, that's another thing. Everything becomes too complex. Like he did a few hours work, casual work, therefore he's required to report to Centrelink – forgot to report to Centrelink, so the pension didn't get paid, all that. All those things make life more complex, more difficult.'

In some circumstances the psychotic symptoms directly caused the person to experience specific disadvantage:

'Well he has the auditory hallucinations, the voices, and I think he blames them on anything electrical. He won't even have a kettle now in the kitchen, he threw his kettle out because whatever vibrates in the kettle and electricity, that's what he blames for the voices. He's very anti anything electrical.'

Another participant described how his or her psychotic symptoms seemed to dominate almost all parts of his or her life:

'I had about three or four different voices in my head at once, and one was a girl's voice, and they were running my life. I fell in love with one of the voices, the girl I actually fell in love with like, you know what I mean, it was just a very weird experience...it affected me greatly because it took up all my time. It took up all my time, and even when I was trying to go to sleep, I could hear voices, so it was affecting my sleep totally. I'd wake up in the middle of the night and hear voices, and instantly as I wake up there's this woman's voice talking to me and it drove me mad. I ended up breaking the window.'

The trauma associated with psychiatric symptoms and its inherent distress was another focus of the consideration of the risk of a severe mental illness. One consumer participant likened the traumatic experience of psychosis to being attacked:

'Well it's a mental attack, if you are being attacked – a lot of the time now it's just a matter of being spoken to. But it's not a physical attack, it's a mental attack. So it's not as if you are being beaten with a rod or anything, so there is some discomfort, but it's something you are able to endure, and it takes your mind into different areas, and it can be quite distracting, and sometimes you need someone there to help you manage things.'

One carer described how distressed his wife became when experiencing psychotic symptoms:

'It's very distressing for her...I can see that she can suffer from her auditory hallucination or voices may give her a lot of anxiety, a lot of agitation, and I can see that she suffers distress by that.'

One consumer spoke of the fear he experienced:

'I was scared to stay in my unit, I thought this is going to be my turn. I keep thinking I don't want my mother to wake up to find me dead here.'

The process of apprehension and initial restraint was particularly traumatising for a number of the participants. A carer described how her relative suffered through the involvement of the police in implementing the *Mental Health Act*:

'And the situation is that the doctors or any of the hospital staff can't touch the patient, so they had to call the Police, even in the hospital grounds. So he was trying to run from the Police, and they had to use capsicum to detain him, and it was an awful situation for me to see. And in the hospital grounds the Police had to get hold of him, use the capsicum spray, that's how they could get him back into hospital.'

'Actual harm'

'Actual harm' is often conceptualised as harm to physical integrity. Suicide and misadventure were two obvious manifestations of the potential harm of a severe mental illness, although a number of consumer and carer participants highlighted the issue of iatrogenic harm due to the increased use of antipsychotic medications. One dimension of harm was the noted effects of weight gain and its downstream effects on morbidity. Another dimension was the difficult to tolerate effects of medication and its effect on the morale and quality of life of a consumer. One carer participant noted of his or her relative:

'Sleep, very sedating. That was one of the big ones. The other ones might've been lack of motivation, lethargy, maybe some other things. I know, there might be constipation, problems with bladder, might've been sexual dysfunction, generally can frustrate you because it can take the life out of you, you need the life. It can make you very de-spirited.'

A consumer noted the effects of medication on his or her quality of life:

'I've lost my sex drive a little bit, not greatly, I've still got a sex drive but because I'm on methadone too and that affects it too. So I've lost my sex drive a little bit.'

In some circumstances, medication made consumers agitated and suicidal. One carer described:

'In fact the medication he was taking was leading him to be suicidal, he said he didn't want to be more in this world, he said he'd had enough.'

In addition to suicide or misadventure, many participants regarded victimhood as a potential risk of severe mental illness. Some examples of such concerns were the person being lured into a pattern of psychoactive substance misuse, being exploited sexually, and vulnerability to assaults or theft.

The alternate of the risk of actual harm was the dissonance between the conception of harm held by consumer and carer participants, and those who provided clinical care or held positions within the MHRT. One consumer participant noted the disparity between his or her formulation of the risk posed by illness and that of the clinicians involved in their care:

'But obviously that's their experience because they have trained in this for many years, and that's their perception of a patient, and my perception is obviously different to their perception.'

Occasionally this disparity was interpreted as direct manipulation of the truth, albeit well-intentioned. One carer participant described an MHRT hearing in which the risk of actual harm was considerably overstated:

'I thought some of what he said was manufactured, I didn't think it was correct. I think he had to influence them, because they were the fors and we were against, if we were against – they were the fors, they were applying for the CTO, the hospital, and we were the ones that could have been against it at the hearing. So to make his case stronger I think he may have said things that were exaggerated. I remember at the time, some of the things he said I thought, "That's not right". I didn't express it.'

On occasions this manifested in reverse, where the consumer or carer participant considered their position one of risk of actual harm and the system being indifferent to anything other than a specific consideration of risk:

'...they got me to see a psychiatrist, and he said, "Oh there's nothing wrong with you, just take some pills"... If I'd lied and said I have feelings of suicide or depression, they probably would have seen me....but the funny thing is I've never used the public health system; I've had to lie to use it. I really have had to lie to get help. And I knew I could have lied more by answering questions in a different way, but then I thought, "Maybe they would lock me up".'

'Therapeutic outcome'

Another dimension of the risk posed by severe mental illness was in the realm of impaired or poor therapeutic outcome. This may have manifest in the development of additional problems such as depression or anxiety or medical co-morbidities. A recurrent concern among carer and consumer participants were the effects of the impaired insight associated with severe mental illness upon many aspects of therapeutic outcome.

One carer spoke of how a lack of insight was associated with a relative continuing to break the law:

'And I guess you know, having no insight, he can't reason that five years ago when he was; he was sent to prison for breaching an AVO, you know I don't know what would have happened if ... So if I hadn't been here, he would probably still be going backwards in and out of hospital in [CITY] and trying to avoid any intervention from the Health Department, and becoming very unwell.'

A carer reported that the question of insight was often more evident when the consumer disagreed with the clinicians, who themselves were unclear of the nature of the problem.

'Interestingly enough, the treating team present to a tribunal for a CTO, when they're applying for a CTO, and they constantly say, "Oh, as [X] remains completely insightful around her condition", and I sit there in wonderment, and I kind of think how can she be insightful about a condition that even now you're admitting she didn't have? You can't have it both ways... So you want to say that she's got this condition that's complex and it's psychological and it's cognitive dysfunction, you want to say that in one hand, and then you say, 'Oh but we can't do any treatment because she won't engage and she's insightful".'

Such circumstances lead to higher levels of constraint or coercion in management. Given the psychological and physical consequences, many participants saw this as an intrinsically harmful process.

The risk of 'chaotic care' was also evident in the narratives of many consumer and carer participants. Chaotic care involved frequent or unnecessary hospitalisations, poor quality of care, or lack of continuity of care. In some cases, the financial disadvantages consequent upon severe mental illness created problems in accessing specific aspects of care, such as medication or allied health services. A consumer participant noted that his or her needs were long term but the ability to form a long-term relationship with a clinician was affected by his or her illness:

'I do believe I'll have it for the rest of my life, but it would be nice to be able to follow up, continuity, review, the normal things, how you're going, or we've tried this do you want to try this.'

A carer participant noted that their relative experienced discontinuities in the care as a consequence of their legal status:

'The difficulty is while they're on the CTO they are case managed, while they're not on the CTO they're not case managed. So there's no continuity really.'

Another carer participant noted that breakdowns between different components of the health system led to their relative being lost to care:

'Well the GP is supposed to give you the prescription, but the GP is so busy, if you don't turn up, nothing happens, you just fall through the cracks.'

Some consumer and carer participants noted that severe mental illness impairs care through the process of the clinical focus being specific to mental not physical illness. One carer

participant noted that his or her relative's mental illness led to health consequences that were not acknowledged in the same way as their mental health:

'She's got one problem at the moment, she's a very heavy smoker, and she uses cigarette smoking as a form of self-medication. And the trouble is that she doesn't want help for it, and there's nothing you can do, she's not compelled to stop smoking. And it's frustrating the GP at the moment because he sees her possibly, is it emphysema, he's worried she's going to get emphysema, and she's smoking very heavily and she's coughing a lot, which is not good. So I wish there was a CTO that said "you're not so smoke more than 10 cigarettes per day, or otherwise we'll come and..." [laughs].'

Another carer participant noted that the impact of hospitalisation and enforced treatment consequent on their relative's physical health was a risk:

'...they smoke like chimneys. They're put on medication that's photosensitive, out in the courtyard with no shade, no sunscreen, smoking. I'm not a smoker, I have to accept that that. I know how difficult it is for them to give up and that's not my fight at the moment, my fight was about getting off this chemical overload, which was the substance use, the antipsychotic medication, which were a dreadful and harmful mix for my sister, and that was really what I was concerned about.'

Therapeutic outcome for a person suffering from a severe mental illness also manifest as delay in accessing treatment. One consumer participant spoke of the effect of his or her illness on delaying access to care, which led to harm arising from worsening illness and how this cascaded into other aspects of their life:

'But that was probably two years after the incident that started all this. It doesn't help – you need it early. I won't call it "early", you need rapid intervention – you can't just sit there, because in the meantime I got worse. ... They should be able to get people access to services faster; I think things wouldn't get worse for people... You go downhill, of course you do, it's very frightening.'

One carer participant noted that the CTO applied to their relative had countered the effect of the illness on their relative's capacity to seek care in a non-acute state and their concern at the failure of the system to address this:

'But, unless I was there to point out the fact that [X] knows that on the 30th of September his CTO runs out, on the 1st of October, he's off in his car, and who's going to stop him? He knows, he's not dumb, he knows that that's his window of opportunity. And he was planning to go. And actually I was the one, it was on the Wednesday, and I pushed, pushed, pushed, and I said, "Look unless you get this CTO in today", because I'd rung the Tribunal, and they said, "The last date we've got is the 30th". So I wrote a letter, and I just said, "Look, if he goes up there and kills himself, you're slack in your duty of care".'

Another carer participant despaired of the fact that his or her relative's delay in treatment resulted in them being unable to work and *'going down in the gutter'*, arguing that:

'If they acted in the first place, instead of ordering this medication and that medication and go along for weeks and months and years...he would be at work, he wouldn't be off work, he'd be able to work. But I don't know, this is the thing we experienced, that's the thing we experienced.'

It was clear that a having severe mental illness led to vulnerability in the post-acute period in that not engaging in ongoing care undermined the gains made in treatment. A carer participant reported that:

'So this is a person who has been in hospital, he is discharged, and there's no follow-up about his medication. So what's the point in having him in there for four months, and just send him to a place where they don't check whether he's had his medication? I mean what she said is, "Oh we just ask them, 'Have you had your medication?' Or we check in the drawer if the medication is taken". But no one physically sees that they take it. He was losing it, and I could see he's getting sick again, and he was mixing with that friend again and using more drugs.'

Another carer participant was concerned that their relative's lack of insight and incapacity to engage in treatment in the period following discharge made the entire traumatic process of involuntary hospital admission almost futile *'because putting all this hard work that I see in the hospital, and then throw it out the window'*.

Many consumers, as a consequence of their severe mental illness, suffered harm under *'uninformed treatment decisions'*. This phenomenon emerged from the effects of illness and prevented the consumer engaging fully in care. Being unable to engage in a treatment program resulted in poorer care, as a consumer's problems were neither well understood or addressed in clinical treatment. A carer participant noted of his or her relative:

'...they don't really know him as well as I know him. I'm the one telling them that he's not filling up his medical organiser, that he's forgotten his appointments, that he's doing this, doing that – they don't know those things, they don't see him go shopping, or have to do this, or you know. They don't see that, they're relying on the information from me.'

'System'

Like the clinician and tribunal participants, consumer and care participants acknowledged the risks posed by the effects of severe mental illness on the interaction with *'the system'*. One problem domain was the problem of *'access block'*. This emerged in the setting of inadequate or poorly resourced services.

Consumers living outside a metropolitan area and its comparatively better developed mental health services encountered this frequently. A consumer participant acknowledged that he or she would encounter significant problems accessing care away from their metropolitan residence:

'I'd be terrified to go out there [OUTSIDE CITY], there'd be nothing there. I feel safe here [IN CITY]...I minimise the risk because I'm here.'

A carer participant noted that his or her relative relocated to a regional area and was unable to access any care:

'He actually went to the country last year; services in the country are appalling, in fact where he went there is just no service, it's just non-existent.'

Many consumer and carer participants raised concerns about how severe mental illness led to people *'falling through health system gaps'*.

A consumer participant noted that CTOs had an effect of preventing someone with a mental illness from avoiding treatment in the health system:

'I think it can be good in some ways because if they're not compliant with their medication they can be hospitalised, and they may need to be hospitalised, rather than if they're not on a CTO and not compliant, they just pass through the system'

A variant of this problem was the apparent indifference of the system to respond to the particular needs of the consumer or carer. A carer participant described their experience of being unable to communicate with clinicians in a mental health facility on the basis of the specific restrictions described in the *Mental Health Act*:

'..they said, "Oh he hasn't nominated you as his carer so you can't say anything", and I said, "But he's sick". When they're sick, they can't nominate you as a primary carer, but use your common sense, he's nominated some friend of ours in [INTERSTATE CITY], who we haven't seen for ten years. I said this lady lives in [INTERSTATE CITY], she's not even a relative, can't you use your common sense that how can a person who is in [INTERSTATE CITY] be his primary carer, when if you look at all his correspondence, he's been living at home with his mother?...some of the nurses were good, they could understand, those who know me, but the newer ones, they were just going by the rules.'

Another carer participant voiced concern that his or her relative was *'thrown in the company of people in all different conditions'*, and so they went *'backwards'*.

Many of the participants asserted that CTOs were used as a means of overcoming problems with *'the system'*. One carer participant described that focus on staff safety often led to access block. In describing the problem his or her relative's experienced in accessing care, they noted that mental health staff would not visit her at her home:

'They don't do home visits because they've assessed my sister's house as unsafe, so once again they depend on her to present.'

This practice led to the consumer in question defaulting on treatment.

Many of the risks associated with severe mental illness and the system involved an *'unsatisfactory patient journey'*. A recurrent observation was a sense of *'powerlessness'* within the health system. A carer in a regional setting described the disempowering effects of not having access to information about his or her son who had been injured:

'So I rang them in the morning and I said to them, "He needs to be hospitalised, and could you tell me what the procedure is?" And I didn't know that [OTHER REGIONAL AREA] doesn't have an inpatient ward, it's a small hospital, but I didn't know the system, I've come from [INTERSTATE] and I haven't been here that long, so I didn't know the system – all I knew is [REGIONAL AREA] and [OTHER REGIONAL AREA], and they said, "Oh yeah, we'll let you know". And I rang [REGIONAL AREA] again and I said, "My son is in the emergency in [OTHER REGIONAL AREA], he's got a history of mental illness, he's had three episodes in [INTERSTATE], and could you talk to [OTHER REGIONAL AREA], I believe there's no inpatient ward there, could you find out from them what the procedure is?" And they said, "oh yeah, yeah". Then I got a call from [REGIONAL AREA] and they said, "Oh, all I can tell you is we spoke to [OTHER REGIONAL AREA] and your son has been released". And I said, "He's just had a major accident, he's written off his car, he's got a head injury, where's he going?"'

Through the effects of their illness, consumer participants often felt vulnerability within the system. A consumer participant described an interaction with clinicians where she felt particularly vulnerable:

*'I'd had breakfast, and I'd had my shower and I went into my room to get dressed, and two people came to my door, and one of them, I think was a doctor, she was an older lady, and then one of the nurses. And I was only in my dressing gown and a pair of pink ugg-boots. And they said to me, "Can you come with us, we're having an interview with you upstairs"...so I'm in this room with all these people in a f***ing white dressing gown and a pair of pink ugg-boots, and I remember standing up and turning around to walk to leave the room, and feeling so uncomfortable, that I didn't have my clothes on, and I'm having to sit in front of all these people.'*

A carer participant spoke of his or her female relative being particularly vulnerable in a care setting:

'She is in her late 30s, female, in a predominantly male complex; very little supervision, and she's constantly said to me, "I'm the only female, I'm the only girl here, I don't want to go into the groups with the guys, I'm the only girl". And she was the only girl in a cottage, because you had cottages set up. And it's poorly supervised. They did put another girl in the cottage with my sister, at my insistence, but she's since gone and they haven't done anything to replace.'

'Interpersonal distress'

Severe mental illness also brought about the risk of distress in interpersonal settings. Severe mental illness strains or adversely effects established relationships. Another form of risk in the interpersonal domain was of exploitation in many forms such as financial, sexual or through defrauding social institutions by misusing the person's entitlements. Severe mental illness posed a risk through increasing vulnerabilities associated with mixing with antisocial peers. A consumer participant noted that while ill, he or she would consort with a peer group whose drug use imperilled their health:

'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 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.'

A carer participant noted that his or her relative was vulnerable to adverse interpersonal influences when ill:

'...if he meets inappropriate friends, which there are a few around here, and they are using drugs, what he can't have is marijuana, even a week of marijuana is enough to push him the other way.'

3.2.2 Discussion: The many faces of risk

While unable to make generalisable findings, this project identified a number of important concerns in the accounts of risk provided by participants from different groups.

First, it was evident that clinician and MHRT participants distinguished their accounts of risk by their concerns about the epistemic aspects of risk in addition to focussing on physical harms. By contrast, consumer and carer participants conceptualised the risks of severe mental illness in terms of:

- failures of the system in responding to need
- social disadvantage or adversity in its many forms including stigma & discrimination
- interpersonal difficulty, and
- the distress of their illness.

While the analysis of the data indicated that there were overlaps between the different discourses on risk – particularly in regards to the problems posed by ‘the system’, social disadvantage and risk of actual harm – they also differed in the emphasis or focus of these components. Moreover, the causative properties of different aspects of risk differed. For example, clinician participants were more influenced in their thinking by notions of actual harm or questions of quantification of risk, whereas consumers and carers were motivated more in the light of the distress of mental illness and the manifold disadvantage that emerged from such illnesses.

What is clearly evident is that any model of risk in the setting of involuntary psychiatric treatment in the community requires the integration of the differences in risk discourses, specifically in terms of the epistemic and physical harm focus of clinicians and MHRT decision-makers and the subjective experience of disadvantage from consumers and carers.

Other researchers have made these observations. Ryan (1998) utilised a mixed methods study of factors of perceived risk related to people who experience serious mental illness in the UK.²² The study also focused upon four stakeholder groups: service users, their carers, mental health professionals and the general public. The research identified six factors of perceived risk: underclass, medical disempowerment, threat, vulnerability, self-harm and dependency. Like the findings from this study, Ryan determined that risk in the setting of the management of severe mental illness in the community is a multi-dimensional concept covering both risks *faced* and *posed* by people living with mental illness. It was notable that five out of the six risk factors identified in the study related to risks faced by consumers, rather than risks their illness and its consequences posed to others.

One aspect of the excessive focus upon dangerousness in clinical and legal discourses of risk is stigma and the many problems associated with it. Many of the themes that emerged from this study’s data could fall under the rubric of stigma, even though the explicit use of the term by the participants was minimal. Erving Goffman initially described stigma in relation to mental illness as a process of ‘spoiled identity’²³ and many of the examples of the phenomena described in the study involved people with mental illness being identified in profoundly negative terms.

The discourse of risk in the lay media appears to differ from that of the consumer and carer participants. The overwhelming conclusion from the literature in the field is that mental illness is portrayed negatively in the media. One UK study looking at media content in 1996 found almost half of the content was negative in regards to mental illness.²⁴ Violence is a prominent theme in media portrayals of mental illness.²⁵ It is also evident that media exerts a significant influence upon attitudes towards mental illness and its treatment.^{26, 27} One study found stigma as having multiple components – ‘social distance’, ‘dangerous/unpredictable’, ‘weak not sick’, ‘stigma perceived in others’ and ‘reluctance to disclose’. Despite recent efforts at educating the public about the stigma of mental illness, perceptions of the mentally ill remain in the realm of

'psychokiller / maniac', 'indulgent', 'libidinous', 'pathetic and sad' and 'dishonest', hiding behind 'psychobabble' of doctors'.²⁸ The theme of negative self-appraisal and the marginalising effects of stigma within the community are also reflected in the literature. A survey by SANE Australia found that 76% of consumers and carers experienced stigma at least every few months. Moreover, virtually all people suffering from mental illness believe that portrayals of mental illness in the media had a negative effect, in particular, 'self-stigma'.²⁹

A number of the participants mentioned explicitly the concept of the 'dignity of risk'. The 'dignity of risk', or the 'right to failure', was a value first championed by advocates for people with physical disabilities. To many, the option of being able to take a risk is a greater imperative than the actual choice³⁰ and the process of recovery is not complete until the individual achieves a level of autonomous function that allows them to take risks and make mistakes in order to grow.³¹ Indeed, it is arguable that the ultimate moral focus is not the consequences of a risky decision but the capability and processes in which the decision to take risk is made.³²

Many of the participants from all groups described the risks of unemployment, poverty and second-class citizenship as arising from severe mental illness. The experience of severe mental illness manifests as the propensity of a person with a mental illness to have lower expectations of themselves and their lives. This is particularly the case in a person with a severe mental illness seeking employment in an open market.³³ Unemployment rates for people with serious and persistent psychiatric disabilities are typically 80-90%.³⁴ Prospective employers are frequently reluctant to hire someone with past psychiatric history or currently undergoing treatment for depression, and approximately 70% are reluctant to hire someone with a history of substance abuse or someone currently taking antipsychotic medication.³⁵ The experience of such discrimination leads many people with mental illness to view themselves as unemployable and stop seeking work altogether.³⁶

The epistemic aspects of risk that concerned the clinician participants were oriented around quantification and mitigation of risk. This has been argued as a preoccupation of modernist disciplines, such as medicine, arising from the concept of the 'Risk Society' elaborated by both Giddens³⁷ and Beck.³⁸ The concept of the 'Risk Society' is that in a future-focused 'modern society', risks (both man-made and natural) can be appraised and in some way mitigated. In clinical circles this exists in the notion of 'risk assessment' – the process of estimating the likelihood of dangerousness, such as completed suicide or harm to others. In the insurance industry, actuarial assessment of risk is a mathematical discipline aimed at computing a probability of adversity, based upon a broad consideration of variables. Such an approach has been applied in criminology in the prediction of recidivism in sexual offences.³⁹ Actuarial approaches to risk assessment in psychiatry attempt to integrate different situational and clinical factors in different populations at different times.⁴⁰ The actuarial approach to risk assessment provides little more than passive prediction and is inferior to a standardised clinical assessment.⁴¹ The distinction between prevention and prediction is important, in that a recent UK review indicated that while around 28% of dangerousness was predictable, 65% was preventable.⁴² The predictive capacity of psychiatrists in regards to future harm perpetrated by their patients has been shown to be low, with estimates of accuracy varying from 30-60%.⁴³ The principal failing of psychiatric risk assessment is a tendency to overstate risk.⁴⁴

The analysis of the data coded from the varied perspectives of study participants provided many emergent themes, creating a more comprehensive model of risk. The significant difference in how risk was conceptualised by participants is not a surprising finding, as the different discourses of risk across disciplines arises from a variety of epistemic bases. In a comprehensive review of the concept of risk, Althaus argued that, ultimately any conception of risk represents an attempt to apply an ordered form of knowledge to the unknown and that any discourse of risk acted as a 'mirror' to the 'preoccupations, strengths and weaknesses of each group'.³

From this realisation, a more comprehensive model of risk necessitates the merging or integrating of different discourses of risk. Wilkinson, writing from the perspective of the phenomenon of 'Risk Society' argued that:

'In mental health policy and practice, several meanings of risk are embodied in individuals under the sign of "threat"; but this is by no means the only set of risk-associated meanings imperative in mental health networks, where risk in its actuarial and health insurance meaning, the risks accruing to individuals from the severe mental illness they suffer, and the risks contemplated, weighed and countenanced by treating professionals, name only some ingredients in a rich stew of risk discourses'.⁴⁵

The findings of this study are a strong endorsement of this view.

3.2.3 Capacity

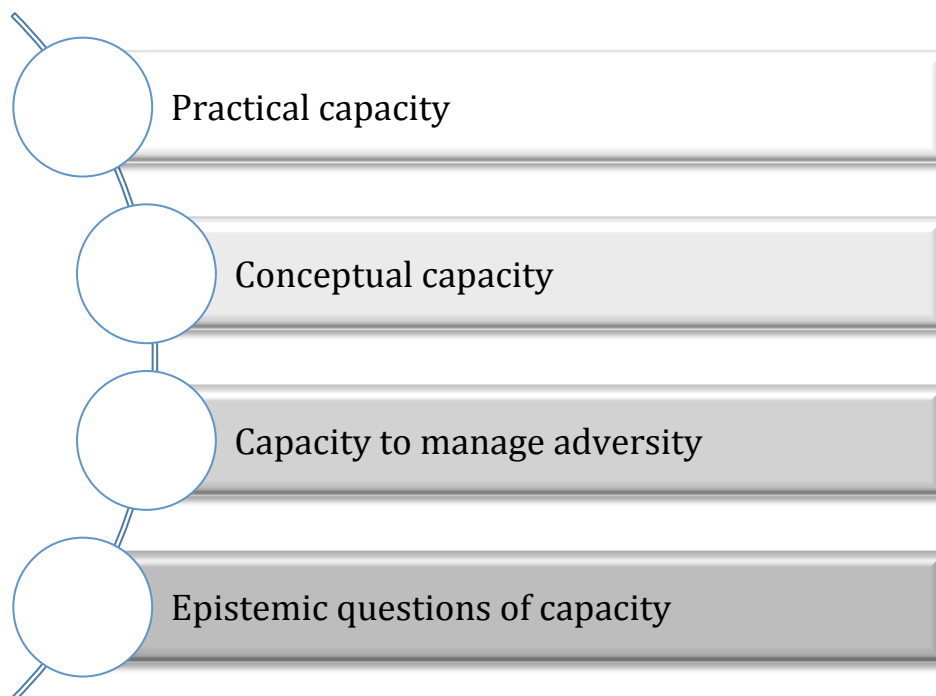
Clinician perspectives on capacity in community-based involuntary psychiatric treatment

Analysis of the data provided by clinician revealed four domains of capacity impaired by severe mental illness:

- practical capacity
- conceptual capacity
- the capacity to manage adversity
- epistemic questions of capacity.

This model of capacity is shown in Figure 9.

Figure 9: A model of capacity from the perspective of clinicians



'Practical capacity'

The domain of 'practical capacity' integrates themes related to how the person dealt with matters at hand. Such challenges included managing challenges in different areas such as daily demands as a member of a community, mental and physical health, and engaging in interpersonal, therapeutic and institutional relationships.

One of the capabilities impacted by severe mental illness was the capacity to engage in different areas of the consumer's life such as with families or social supports, therapeutic relationships, or in treatment choices. In many circumstances, clinician participants saw that CTOs provided a proxy means by which consumers and their carers would have their needs advocated for:

I've been exposed to the idea that a CTO will somehow help ensure that that person gets the care that they should be having. ... We've got the community treatment order, it's

therefore a kind of legal reason for someone to have the care that they should have anyway.'

Clinicians, particularly case managers, saw utility in CTOs in prioritising within the system the needs of the consumers under their care.

'...when somebody is on a community treatment order, the system expects you to keep working with them... that if somebody is on an order, then they have the safeguard of getting a certain priority – you're not going to discharge them because you've got too many clients, that sort of priority. So it's an obligation from the mental health service's point of view.'

The capacity to engage in the social system was also a focus of clinician participants. This often manifested as the effects of illness leading to the consumer disengaging from basic processes such as maintaining tenancy or financial responsibility while ill:

'But it's that real, what comes down to that fear of someone's social environment falling into absolute disarray whilst they're an inpatient, because when it does happen, when someone is an inpatient, everything falls to shit on the outside, and the absolute distress they experience once they are well, it's absolutely horrible. So we try and do everything we can to make their social environment as intact as possible.'

In many circumstances, severe mental illness led to incapacity to engage in family or other interpersonal relationships:

'This woman was a registered nurse, and very smart lady and she had a husband, she had children, before the illness debilitated her. So we want to get some gain back that she can be involved with society, because she's very withdrawn.'

The impairment of capacity to engage practically also required a form of practical wisdom; this was related to questions of 'how to?' or 'when to?', as reflected in the Aristotelian notion of 'phronesis'. Phronetic capacity included the ability to communicate, make healthy choices, maintain social support, and manage the symptoms of a mental illness. It also reflected the capacity to negotiate means to having one's needs met, such as within complex health services or social institutions:

'Well all that package is there, because they're not in a vacuum. So for a lot of people that I see, most people that I see probably are on a pension, not particularly working, they may be in housing with Department of Housing, or they may be living with their families, a lot of them are in housing on their own, limited supports, limited finances, very little options in terms of social activities.'

Clinician participants also regarded impairment in the capacity to prioritise and maintain self-care as a significant concern:

'Just judgement that impairs on their ability to; I suppose it would be maintain, you know what they've got, and those basics, the whatever they are, Maslow the more basic sort of things, shelter and that kind of thing.'

¹Maslow, A. (1943). "A Theory of Human Motivation." *Psychological Review* 50: 370-396

Apart from attending to instrumental needs, clinicians also saw that the treatment of severe mental illness had an aspiration of facilitating the pleasurable or hedonic experience of participating in different aspects of life:

'The family were certainly agreeing with that, because they saw him a lot better, that he was actually quite relaxed, he was going playing cards with his old friends, and was really very relaxed.'

One clinician participant regarded the consumer's perspective of what pleasure they sought from life as being the most important focus of care:

'I think first of all I'd want to know what the client considers important to their happiness and wellbeing, and that's different for everyone.'

Another, more complex area of capacity was the idea of 'plausibility' or 'credibility'. Rather than reflecting objectively sound aspects of insight or judgement, this aspect of capacity was the consumer's ability to present a credible or plausible version of their particular plan for themselves that might be at odds with the views of their carers or their clinicians. In a paradoxical sense, this capacity was part of the origins of sources of incapacity such as impairment of insight. This issue often came into focus over questions of the need for coercion in treatment, such as whether to admit to hospital:

'And so what happened with this young man, with a couple of his relapses, he would be unwell in my mind, certainly not in his, and there was even a point at which I had breached him into hospital on one of his early CTOs, where the consultant who also knew him, told him that he thought he shouldn't be in hospital.'

This same clinician participant remarked that this plausibility raised his or her concerns about how unwell the consumer might be:

'Yeah, usually though that doesn't strike me then as uncertainty about whether to renew, usually in that circumstance I'm thinking I should renew, if I think that I'm being in a sense sold a line, then I'm fairly clear that maybe a new application needs to be put in.'

In some circumstances, credibility or plausibility manifested as the person's presentation not conforming to the socially constructed habitus of a 'mental health patient'. One clinician participant remarked of a patient under his care:

'But it seemed to be someone who didn't look like a mental health patient. She didn't look unwell, she looked like a doctor who looked after herself and was well read and looked the part.'

Another manifestation of this was the capacity to 'reason in the irrational':

'So would be doing things for psychotic reasons and would come up with supposedly rational explanations. These are the people that are trained to pick up mental health problems, were convinced by it.'

'Conceptual capacity'

As against practical capacity, clinician participants also described the impairing effects of severe mental illness on a person's capacity to conceptualise aspects of their life choices, particularly in

regards to the management of their illnesses. This is more akin to the medico-legal constructions of 'capacity' usually utilised in assessing competence in various domains. In the light of the findings emerging from the analysis of the study data, it is important to distinguish the phenomenon we observed from these established constructs, perhaps warranting the use of a different term such as 'capabilities'. In the rest of this discussion, the use of the term 'capacity' refers to this observed phenomenon.

The process of integrating different aspects of information in order to arrive at a formulated knowledge or understanding of different aspects of life was frequently impaired by severe mental illness. Capabilities such as cognitive function, judgement or insight into the consequences of various choices were central to this. Critical to the capacity to manage the illness was the capacity to recognise deterioration in mental state or identify and act upon the early warning signs of relapse or deterioration in some aspect of the illness. The ability to learn from experience was also seen as instrumental in the capacity of formulation. One aspect was learning of the effects of being ill:

'And there's a difference when they're actually able to cope, to have a life, to deal with their children, to deal with their partners, to go to work, all those things are signposts that things are getting better, and they can reflect, "I couldn't do that then, but I can now".'

Another aspect was learning of the benefits of treatment on the capacity to live a flourishing life:

'They start to recognise that they did have a mental illness, and that there's a link between having a mental illness and being well and medication...they start saying things like, "I don't mind taking this medicine, because it's keeping me well".'

The ability to conceptualise the limitations brought about by a severe mental illness was part of this capacity. One clinician participant described how part of the therapeutic process was to assist the patient to recognise the limits brought about by his illness, and how to factor these into his future life choices:

'So in terms of setting up his goals, they were quite unrealistic, and it was very difficult, particularly with odd advice coming from the psychologist that he was seeing, it was difficult to kind of draw him into sort of setting some realistic goals towards recovering enough to resume some kind of social role.'

Allied to the recognition of limitation was the capacity for independent but critical self-appraisal. In some circumstances, the challenge for the consumer or the carer was to transcend the clinical nihilism that often surrounded severe mental illness, particularly in the domain of involuntary psychiatric treatment. One clinician participant described the effect of 'micro-cultural' beliefs in some settings of the health service on the patient's appraisal of themselves and their illness:

'I think micro-cultural beliefs about people's capacity to recover and engage with treatment. So health service beliefs, that some people will never be able to be off involuntary treatment orders.'

The negative self-appraisal often colluded with the almost reflexive process of seeking to renew CTOs based upon the apparent clinical nihilism:

'I think we did it very reluctant to stop them, there was that mindset of once someone's on a community treatment order, keep it rolling, keep it going, and sometimes not much thought would be given to why, and it would just happen.'

'Capacity to manage adversity'

Severe mental illness often brought about adversity in the lives of consumers. Many of the clinician participants recognised the need for the capacity to manage this adversity in its many forms. Primary among these was the capacity to manage loss, such as the loss of agency, loss of role or loss of status.

One area of adversity represented something of a paradox – the adversity arising from problematic responses, attitudes or behaviours of family members in regards to the use of CTOs or even the most elementary engagement in clinical care. This represented a form of 'extended incapacity' in that the effects of severe mental illness upon the consumer's capacity to make choices in the light of their illness was either compounded (or not buffered by) the capacity of their families or carers to do so. One clinician described his or her difficulty in dealing with a family:

'Who doesn't want the CTO to be renewed...I think it's important to have the views of the family and why they feel that this will work, but there has been once or twice, a couple of times I've actually said, "Look I can't make a judgement because some of the information I have doesn't seem right, and the different information seems to not gel, and maybe there needs to be some more discussion".'

This manifested in one instant in the case of:

'...a young man...with a very severe, what seemed like a severe depression, but in fact it had some psychotic symptoms, pre-morbid anxiety, ended up having a manic episode, stripping himself in the middle of the road, and very difficult to treat because family were very reluctant to either; very worried about side effects. So always very difficult to engage, because there was always sometimes a split between the family, where one wants him to have this medication, or we don't want you to do it.'

Another clinician described the need to intervene specifically with a family who lacked capacity in regards to treatment decisions about a family member with a mental illness. If the person was unable to recognise the presence of illness, this made them vulnerable to be misled in choices:

'I can remember cases where it needed a little bit of active intervention to get family members to understand that yes, there was a time limit to how long we could hold off, on a treatment that they were worried about and concerned at the severity of it and the bad press, and something that we knew is very effective under those sort of conditions.'

'Epistemic questions of capacity'

As was the case with risk, clinician participants had specific epistemic concerns about how they conceptualised incapacity in the context of severe mental illness in the community. Part of this involved the overall capacity for making appropriate judgement. As is the case in the literature, clinician participants considered capacity as a construct specific to particular decisions, such as deciding to accept treatment for a mental illness:

'I think when you're looking at the CTO, that if someone, you can have someone who says, "oh yes I have schizophrenia", but then doesn't want to know what that involves at all. So they will say, "yes I do have schizophrenia, but I really don't think that I need to have any treatment".'

Many of the clinician participants were also concerned with the variegated nature of capacity, particularly mindful of the different discourses on the phenomenon:

'Capacity is a big thing when we think about it in terms of guardianship and financial management orders, so capacity is always a big question for social work. And that I tend to be quite clinical about in terms of referring it to the neuropsychologist, and asking the neuropsychologist "does this person have capacity to make this, this or this decision?" And then, once again I've got a great level of faith in other neuropsychologists, and a great level of faith in their expertise, and whilst my instincts may tell me something about someone's capacity, it's not something that I am trained to assess...So in terms of capacity, that's where I will literally just make that referral, and ask the question, "I need to know if they have capacity for this, this and this", and I'll go with what the report back says.'

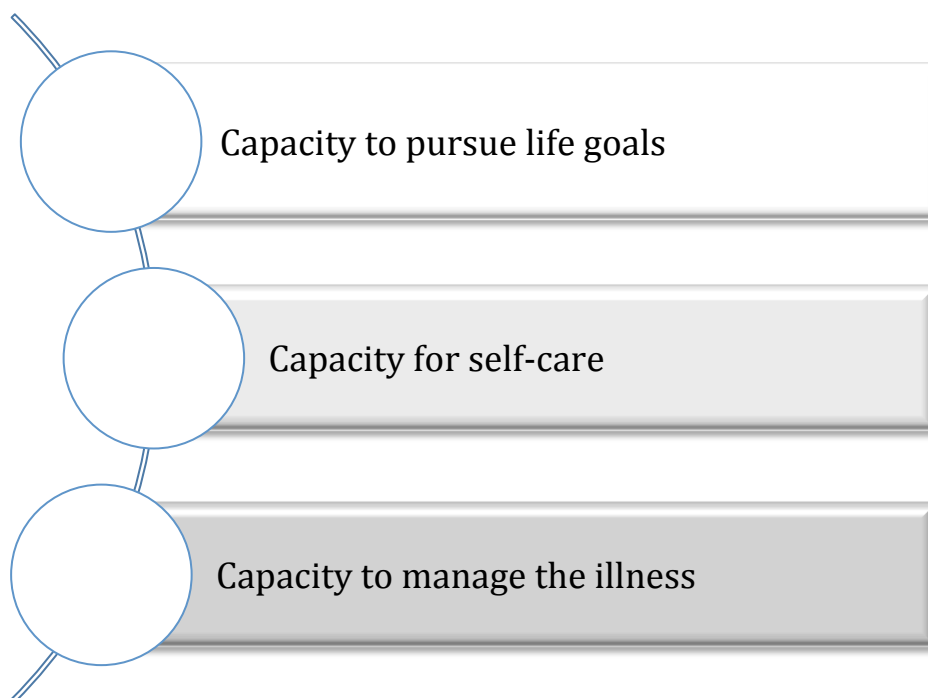
Consumer and carer perspectives on capacity in community-based involuntary psychiatric treatment

The perspectives of consumer and carer participants on impairment of capacity arising from severe mental illness related to three broad domains:

- The capacity to achieve goals
- The capacity for self care
- Capacities around the illness – to know the illness, to communicate about the illness, and the capacity of achieving and maintaining recovery from the illness.

The model of capacity is shown in Figure 10.

Figure 10: Capacity from the perspective of consumer and carer participants



'Goal focused capacity'

Throughout their interviews, consumer and carer participants described the most disabling effects of severe mental illness relating to how the person was able to achieve 'life goals'. These goals included the fundamental challenges of establishing, maintaining and evolving supportive

relationships, which provided scope for support and flourishing of interpersonal networks. The capacity to seek and maintain financial independence through employment, using sound judgement in spending decisions was also frequently noted. One consumer participant noted the impact of his or her illness upon both the goals of education and employment:

'Yeah, like I tried to go to university and like I finished the first two years before I got sick, and then I had trouble finishing Third Year, and I kept starting it and then deferring, and I didn't end up finishing Third Year. So things like that, like studies, and work, I go to work and get sick and then I come back and then I'm not able to function as well as I could and I lose my job.'

A carer participant expressed his or her son's 'lack of support system or friends, or something to do', stating that:

'I know from speaking to other people, other parents, that they feel the same as I do about their son. You've got to be pretty high functioning to go and join most of these groups, and most of them aren't. So the resources are there and they're probably best intention, but they're not meeting the needs of everyone, it's only a small functioning group that are using them.'

Some goals were seen as 'other regarding' in that they pertained to fulfilling obligations to others, either in direct interpersonal, financial or community relationships. One consumer participant noted:

'Because I live on my own and I do everything by myself, I have a cat to look after, so I'm more concerned about my finances and being able to fill all my obligations to be responsible for paying rent, for paying my bills, for feeding the cat, luckily I had my neighbour who looked after the cat for me. I was more concerned about getting better in myself and getting back to normal.'

Many such goals related to personal achievement, milestones or simply being able to survive and flourish in the community. Some of the participants spoke of the capacity for the person to engage in various processes.

A carer participant noted of his or her sister that, while she acknowledged the need to achieve such goals, her illness impaired motivation, organisation and interpersonal efficacy, which were all requisite to the actual process of engagement. As such, the CTO represented a type of 'proxy' capacity:

'You've identified that her motivation to seek help, or her skills in seeking help are deficient, and that she's going to need support to engage in health services... so generally with the CTO it falls into that same category.'

As much of the legal, community and medical definitions of capacity indicate, there are frequently lacunae as well as preserved aspects of capacity. These preserved aspects of capacity were often unusual but sometimes instrumentally valuable. One carer participant noted that despite being severely psychotic, his or her son remained a very capable driver:

'Well interestingly enough, he's had his driver's license the whole time he's been ill, and he's actually a much better driver than I am. I've been in the car with him when he's been so psychotic, I thought he was going to kill me a couple of times, and yet his driving was impeccable. [laughs] So I don't know.'

'The capacity for self-care'

As a component of capacity self-care was distinct from goal focused capacities. Coping with the disabling effects of the illness in providing for their own needs was an important part of the capacity for self-care. One carer participant noted of his or her son:

'Like he could be planning to go and do a bit of shopping in Woolworths, you can get him to the supermarket, if he's not medicated, he's been off his medication for a while, he will be distracted, really put off the whole task by the voices, to the point where he'll just put things down or have to walk out. So the simple thing like going to buy food, it's just everything you know. If he's so disturbed by the voices, he'll just have to lay down on the bed and stay there, he just can't do anything.'

The capacity for self-care was linked to the capacity for independent living within the community. Severe mental illness disrupted this capacity, either through the problems of disorganisation, apathy, amotivation or avolition or through the disruptive effects of psychosis. One carer participant recalled his or her son destroying property while unwell:

'...he was hitting his head against a brick wall, throwing himself at the wall and ripping out the lights.'

A carer noted that his or her relative had complex needs in order to care for herself. These needs resided in interpersonal and health care needs:

'She needs meaningful activity, and up in our area there's a compared volunteer friendship program, and I thought that would be good. Because it's not so much clinical care she needs, she needs activity and engagement. So I was looking at that. Because of her vocal cord dysfunction, if it was you or I and we had vocal cord dysfunction, we would be referred to a speech therapist and a psychologist, so our little team would be a GP, a speech therapist, and psychologist.'

'Capacity around the illness'

The prominent focus of statements made by consumer and carer participants about capacity related to capacity around the illness. The domains of capacity included knowing the illness, communicating about the illness and managing ongoing recovery from the illness.

'Knowing the illness'

The capacity to make informed decisions, in particular decisions about health care reflected the person's knowledge of the illness. A frequent issue was the knowledge surrounding the relationship between treatment adherence and improvements in mental health. For some consumer participants, the link between medication and relief from distress or problematic symptoms was a process of gradual understanding. After recovering from one of many episodes of psychosis, one consumer participant noted:

'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.'

A carer participant noted that in some circumstances, there was a specific lack of knowledge borne of the person's incapacity to associate medication with potential benefits.

One carer participant despaired of this specific lack of capacity for the knowledge of the benefits of treatment:

'So my argument is look if they're mentally ill, the law says that they can't make decisions – why is the decision not to take a known drug that helps them; it doesn't make sense, it just doesn't make sense to me.'

Another domain of knowledge of the illness was the specific language of mental health care. This linguistic knowledge traversed psychopathology, treatment and mental health law. In some circumstances the use of language created a knowledge gap between the consumer and the clinician. A consumer participant reported of his or her conversation with their treating psychiatrist:

'Well one word that the psychiatrist I saw previously introduced was delusion, which I felt for her it seemed it was a delusion, but for me it was something quite real happening, so I felt that she was questioning my ability to relate facts. I'm not sure whether she has the same picture or was just procedure to use that word, I'm not sure.'

The capacity to make sound decisions based on a synthesis of available knowledge was also a component of capacity impaired by severe mental illness. One consumer participant noted that his or her illness caused incapacity to make sound decisions about health, prompting them to conclude that:

'Sometimes you're not always in the right frame of mind to decide, so sometimes you've got to let other people decide for you I think.'

Often this insight emerged after recovery from an episode of psychosis, necessitating the proxy decision-making made possible by CTOs. One consumer participant conceded that:

'...in hindsight you can reflect on it and say "yeah, perhaps it may be the right decision".'

In some circumstances, knowledge of the illness reflected the capacity to make judgements as to what might detrimentally affect the illness and necessary steps to improve the situation. This might take the form of recognising specific early warning signs of deterioration in mental state, or awareness of the potential impact of non-specific stress or adversity on a person's mental health. One consumer described that:

'So yesterday it was a case of like, I'm feeling really stressed like I really need to talk to somebody, so I'm needing help just now, I need support. So I was out with my friends just now and I'm telling them how I'm feeling, I'm not feeling well, and I just need to make sure that I'm taking my medication to keep me well.'

Consumer and carer participants referred to the capacity to manage symptoms. For most this involved understanding the benefits of treatment, in particular medication. A consumer participant noted that:

'...I thought to myself, if I don't take my medication I'm going to end up in hospital, because I'm going to be sick, they will put me in hospital, and I thought start taking the medication.'

In some interviews, consumer participants demonstrated a sophisticated understanding of their medication regimes, which they regarded as a significant capacity:

'Because it takes about two or three weeks to work the medication, I think, it really takes a long time. And I'm glad I take the tablets, I don't want to take the injection, because with the tablets I know I've got it every day, I know it's in my system....'

Many of the consumer and carer participants recognised that the capacity to identify and manage symptoms, often through the use of medication, was apropos of the concept of insight frequently used by clinicians and MHRT members. One carer spoke of his or her relative exhibiting quite enlightened views about psychotropic treatment in the light of previous experience:

'...I had suggested that he needs the injections, and even [X] knows that, he's got that insight. I think when he was there about five years ago he said to them, that's how I remembered it, he said, "I respond to my old medication, so that's what I think I need". So he's very, very smart. And there was some medication they wanted to put him on, and he refused, he said "I don't want that". And he does research himself, so he's read the Mental Health Act and everything. So he knows what works for him.'

Both consumer and carer participants spoke of the need to be possessed of specialised knowledge in managing their interaction with the mental health system, particularly in the domain of the application of the *Mental Health Act*. Throughout the interviews there was direct and indirect reference to the need to advocate on one's own or someone else's behalf with the mental health system. This required specific skills, experience or knowledge to enable a person to participate in the specific medico-legal processes within the mental health system, particularly in relation to the operation of CTOs.

A carer participant remarked about the complexity of processes around the application of CTOs:

'I know some things about it, I'm not an expert on CTOs, but I know some things about CTOs. ...No, I hadn't experienced the whole process, the legal, it's a legal process. ... See a CTO is a legal matter, it's a legal medical matter isn't it when you think about it.'

A consumer participant remarked on the complexity of managing their affairs in the light of the application of CTOs to the management of their illness, in particular the complexities of legal discussion over the application of the *Mental Health Act* to their care:

'You don't know what's going on, then you're speaking to a lawyer and they're telling you your rights, "you have a right to not let them force their way into your house" or something like that. So I don't think there's enough care given to what's going on in your head, the thinking of legalities. I mean I'm not a legal person, I'm not a bloody lawyer, I don't want to be in with the lawyers and like with my work at the moment, people have said you can complain about how you are being treated at work, but I'm not the type of person who wants to go through these channels, you don't want to go to court, and you're a mental health patient and you've got a lawyer telling you what to expect.'

In some circumstances, participants described the need to ensure that the consumer or his or her carer was aware of the possibility of the mental health service not responding to the specific needs of the patient in a given circumstance. A carer participant reported that:

'I am aware that you have to be really on top of what's going on there, just don't assume that they're doing everything correctly, and always ask who the nurse is and try and make contact with the nurse every time you go in, ask to speak to the doctor, ask the doctor to ring if you can't see them face to face.'

'Communicating about illness'

Consumers and carer participants elaborated the capacity to communicate with clinicians both specifically and about the illness. In many circumstances this presupposed that basic comprehension had not been impaired by the illness. One consumer spoke of an acquaintance having difficulties comprehending information provided to them about the process of a CTO application:

'Well even if it was explained to him he wouldn't understand it. So it might have been explained to him but he didn't understand it...maybe even an interpreter should come in and explain to them what the CTO is about.'

'Recovery from the illness'

The concept of 'recovery' as elaborated by consumer and carer participants was clearly evident throughout the interviews. The tenets of the 'recovery approach' – 'hope', 'secure base', 'self', 'supportive relationships', 'empowerment and inclusion', 'coping strategies' and 'meaning' are distributed throughout the analysis of the data. The umbrella concept of 'recovery', as against other forms of improvement, emerged as a substantive concept in some of the interviews.⁴⁶ Several of the consumer participants voiced the aspirational goal of recovering from their illness. One consumer participant professed of his or her journey from illness:

'I was more concerned about getting better in myself and getting back to normal...I was always really focussed and just wanted to get better.'

For another consumer participant, recovery in the short term comprised modest goals of symptom control and maintaining a measure of health, with a longer-term goal of restoring a vocational role:

'I think I'm going to learn to live with it, and live with it well, because I'm 42 and I'm quite healthy for my age, and I'm not silly, I reckon I can go back to work in a couple of years when I get stronger, and that's my goal...it made me realise that hey you know, I can get rid of this illness; or not get rid of it, but I can stop the voices. And that was the main thing, the voices was the main thing. I didn't have any visuals, but the voices. And it stopped that. So that as a big, a really big thing to stop.'

By contrast, a carer participant despaired of the incapacity of his or her relative with a mental illness to realise and work towards recovery from that illness:

'But we are still concerned that he will probably relapse, because he has nothing to do. He's 43 years of age, he should be at work and he should be doing something. But unless he gets rehabilitation that can offer him something, I know it will take a long time, but if you don't start it, just put a stop there, that's it.'

Another carer acknowledged the limits of a limited focus to care for his or her relative and her incapacity to realise goals of supportive relationships and empowerment and inclusion:

'She needs meaningful activity, and up in our area there's a compared volunteer friendship program, and I thought that would be good. Because it's not so much clinical care she needs, she needs activity and engagement.'

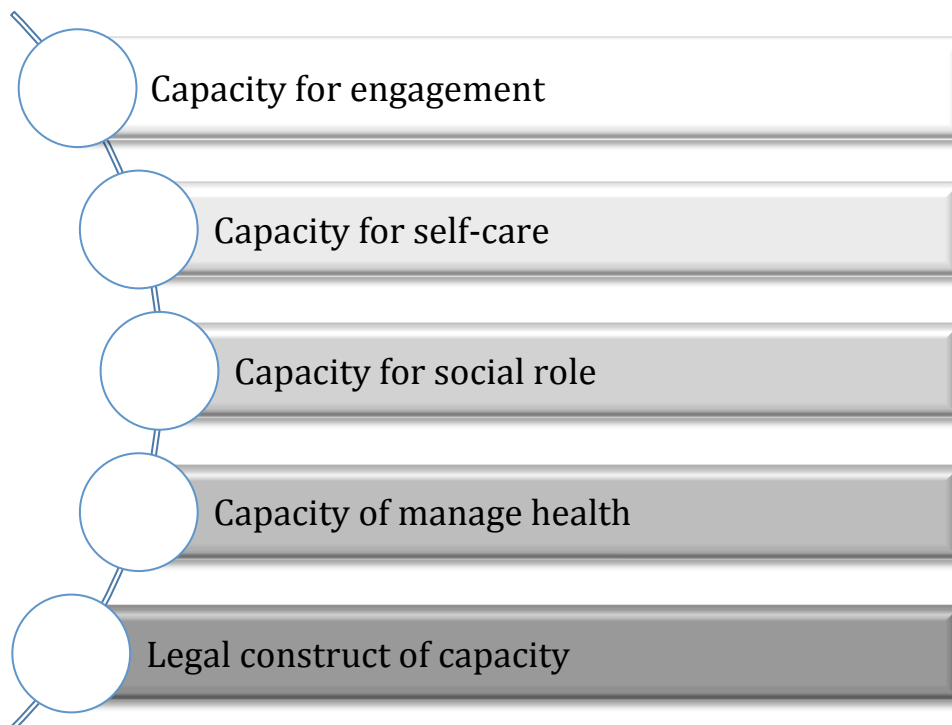
MHRT member perspectives on capacity in community-based involuntary psychiatric treatment

The analysis of the data from participants from the MHRT defined five domains of capacity impaired by severe mental illness -:

- Capacity for engagement
- Capacity for self-care
- Capacity for social role
- Capacity to manage health
- Legal construct of capacity.

The model of capacity from the perspective of MHRT participants is shown in Figure 11.

Figure 11: Capacity from the perspective of MHRT participants



'Capacity for engagement '

MHRT participants held similar views of the scope of capacity for engagement to other participant groups. Severe mental illness impaired the person's engagement in relationships with their families, friends and acquaintances. More broadly, severe mental illness precluded engagement in the social system as a member of a community. The derangements of insight, cognitive function and judgement arising from severe mental illness impaired the person's capacity to engage in the process of treatment. In accounting for the decisions made in regards to CTO applications made on behalf of people with severe mental illness, one MHRT participant deliberated on the complexities of capacity in terms of tasks, the effects of particular disorders and the stage of illness:

'I think that more broadly, I mean I think of, it's important for the tribunal, I hope that I do this in hearings, is to consider people's ability to weigh up decisions concerning their

mental health treatments, to consider their capacity to do so, and to use that as something in the mix, in determining whether or not an order is required. Because if people come to the tribunal come, because there are obviously a whole spectrum of people with people who have been very sick for a long time, often very impaired, people who might be developing an illness for a first time which is not an extreme form of the illness, who might be able to respond to treatment and demonstrate an understanding of the need to stay well...So it is something that is present in my mind in hearings, and it is something that I think of consciously at hearings, whether or not people are able to make decisions for themselves, whether or not they're able to do that in an informed way.'

Being possessed of these capacities invited a positive right to agency in decisions about a person's life. An MHRT member noted that decisions about involuntary psychiatric treatment in the community invited questions about positive and negative rights of liberty:

'...just because a person has a mental illness, doesn't mean that they lack capacity to make decisions. The fact of being mentally ill doesn't rob people from being able to make decisions about their mental health and other important life decisions. So if it was ever introduced as something under the Act that the tribunal would have to weigh up in making orders for treatment, I think it's probably a move I would welcome, it's more in keeping I suppose with philosophy which does probably, is closer to trying to protect people's civil rights.'

A more complex form of engagement in the process of treatment and recovery involved the capacity to reflect upon the experience of a severe mental illness, its impact on the person's life, the benefits of treatment and the broader questions of meaning and the self posed by such a catastrophe in a person's life. One MHRT participant commented on the complexities of coming to terms with a severe mental illness and the adaptations a person has to make in their life in such a circumstance:

'I don't think they understand it; let me go back a bit, you can explain what capacity is, so whether they understand what's happening to them, whether they understand that the hospital team is there because the team feels that if they don't take the medication, something is likely to happen to them. So some clients don't accept the fact that they've got an illness or issue of whether or not they have got capacity to understand, or the capacity to consent to treatment, especially involuntary treatment. And thirdly of course, if they do understand, but they feel they don't need the medication, so you come back to the first question, do they have capacity to understand the fact that they do have this illness, or they've got partial insight. With capacity in general, some clients may point towards the fact that this is their personality, but then there's a clear diagnosis, you need to weigh that against it. And sometimes, I think you need to be mindful of whether they have got capacity to understand what's happening to them, you need to take into account environmental factors in a hospital setting, and then they are going to be put on a CTO.'

'The capacity for self-care'

To MHRT members, capacity for self-care involved decisions and capabilities that improved and maintained quality of life. Life quality involved liberty, freedom from distress, opportunity and flourishing interpersonal relationships. A precondition to this was the person's capacity to manage the symptoms of their illness.

A precondition to the capacity for self-care was resilience. As one MHRT participant noted of a person before an MHRT hearing into an application for a CTO (the person in question had experienced a severe, disruptive mental illness yet still retained intellect and aspired to develop work and living skills under a rehabilitation program):

'Well I mean he said to us that he had become much more resilient, but if one was to look at his history of, he had an enormous number of admissions, if I was to solely make the decisions based on the person's history, then we would never have let him out. But you know, he seemed to, he's very intelligent, that helps when you're articulate and are able to put your case, but we did have good corroborative evidence from his mother, about how he's going. It was interesting that the treating team wanted to keep him there for rehabilitation for work skills and life skills, and I said well surely those rehabilitation opportunities can be offered under a community treatment order, and should be able to be offered under a community treatment order.'

In the alternate, the absence of capacity for self-care emerged as the propensity for neglect, which was a concept that frequently featured in the deliberation of MHRT members on questions of involuntary psychiatric treatment. One MHRT participant noted that beyond questions of harm from misadventure, the deliberation of MHRT members included questions of incapacity for self-care manifest as neglect:

'I mean it could be risk of aggression or violence, but equally it could; and that's I suppose a little bit more, if there was a serious incident, well at least we know what that was and so on. But it can also be risk of living in squalor and being evicted, and damaging your reputation, and not looking after your diabetes. So it can be a whole risk of deterioration in self care and so on. So we'd look equally at that though.'

In MHRT hearings into questions of involuntary psychiatric treatment in the community, many members seek specific evidence of capacity or incapacity for self-care from the clinicians applying for CTOs:

'Some case managers are very close to their clients, and they go and visit the client, with their permission of course, just to ensure that they are taking their medication...But you will have a sense of how the client is living in the home environment, so whether the place is looked after, whether the client's done the washing, see whether there are dishes in the sink, and talk to the neighbours, they will give you an indication as to whether or not they have received any complaints; take a walk with them down the street to the café that they go to, you get a sense of their surroundings as well, moving away from the home to a place outside. So those sort of things come into play.'

'The capacity for maintaining a social role'

MHRT participants considered frequently how severe mental illness disrupted the capacity for a person to maintain a social role. This invites comparison with Classical notions of the capacity to partake in citizenship, akin to the capacity for engagement. Like 'practical capacity' defined by clinician participants, the wise application of skills in dealing with the complexities of the social system, what was termed in antiquity as 'phronesis', was a fundamental construct of capacity in the view of many MHRT participants. One domain of phronesis was a sense of empowerment. One MHRT participant noted that one of the aspirations of treatment enforced by the legal mandate of a CTO was to enable the person to share the wisdom of their experience of illness and recovery with others:

'Trying to give something back to the client and to give them a level of empowerment as well, because it's to do with them, it's not to do with anyone else. We interfere with their body, we need to ensure we do that in a restricted way. I've heard great success stories of someone coming off a CTO and some of them go back to the community and talk about their illness, and try to help other people, educate them, and learn more about it. You see that from a coalface...'

Phronesis lies beneath the capacity to function as a social actor. In borrowing from the sociological construct of social action usually attributed to Max Weber⁴⁷ this view accepts and assumes that humans vary their actions according to social contexts and how it will affect other people. It also assumes that when a potential reaction is not desirable, the action is modified accordingly. Social action occurred in realms such as educational and vocational function, independence and self-sufficiency. One MHRT participant couched recovery in terms beyond remission from symptoms referring to:

'...the length of time to recover from an episode, the length of time that it takes to do all that leg work again to get to a point of self-sufficiency and wellness, and being able to live independently and happily.'

Part of the capacity to participate in a social role and partake social action is the capacity to present credibly in the light of a severe and disabling illness. One MHRT participant commented upon the apparent dissonance of the credible presentation of a person who had previously been disabled by a chronic and severe mental illness:

'...let's say where a CTO is being applied for and you don't feel there's sufficient evidence to grant one, but the person has got a pretty chequered history and so on, and it's kind of like you need to respect the current presentation and where the person is at, but you're also balancing that with the history and so on. I mean I can think of a couple of situations where I've been fairly confident that the person will stay all right, they presented a very good and strong case for where they're at and so on, except again they relapsed.'

Part of the impairment of capacity to participate in a social role emerged as a consequence of impaired volition. Many MHRT participants commented upon the insidiousness of the impairment of volition associated with schizophrenia, even in the face of expressed intentions to engage in life:

'Look I don't think you can order people to go to TAFE, one of the problems, particularly with schizophrenia for example, is you have people with prominent negative symptoms, where they just; they can often give you the right answers, they just couldn't organise themselves out of a wet paper bag. Their executive functioning skills and planning skills are so impaired, even if they know what would be a good thing for them, they just can't quite organise it.'

Another MHRT participant commented that many of the consumers subject to applications for CTOs were profoundly disabled by the 'negative symptoms' of severe, chronic schizophrenia:

'...they tend to withdraw, they tend to; they can't get themselves organised, they can't get out of bed to make the appointments and things like that, because of these negative symptoms.'

'The capacity to manage health'

The capacity to manage health had twin domains of the person dealing with intrinsic limitations in themselves and limitations presented by the mental health system. The incapacity in this domain emerged from what is traditionally referred to as 'lack of insight', although one MHRT participant saw a separate process of the denial of illness as a defence:

'...but if you've got insight but no way to determine your life, you're really high risk of suicide, because it's the "oh my God, I'm mad, but I'm going to stay locked up here", or "I've

ruined my life” or whatever. And the insight is not really the determinant of how well you’ll get on in life, I don’t think.’

This is by no means unique to mental illness, although another MHRT participant seemed to view this process of denial as a defence as being intrinsic to insightlessness:

‘...they don’t want treatment, because most people we see really don’t believe they have a mental illness, and don’t believe they should be taking medication. Denial is a common feature of mental illness, of psychotic illness. So you’ve got to be able to deal with, how you work around denial, how do you work around those things.’

Being possessed of the capacity of insight allows the person to make worthwhile choices about their illness. This sometimes necessitated strenuous advocacy for a particular choice in treatment. One MHRT participant noted:

‘I once had a complaint where the woman wanted to be on oral medication and not injections, I mean I only raise this because of the recent decisions about that, and she kept trying to tell the treating team about physical problems she believed she was having, they said “go and see a GP”, the GP would say “go and see the mental health team”, and she was just going backwards and forwards. She actually wasn’t objecting to the involuntary treatment, she was objecting to the injections. And through the commission complaint, it did get negotiated that she could have a trial on oral medication.’

In the eyes of MHRT participants, the capacity to manage health involved the capacity to manage the mental health care system. This was significantly impaired by severe mental illness and as a consequence, CTOs function as a form in indirect advocacy. One MHRT member noted:

‘And that’s everybody’s concern, that services say ‘it’s the only way you’ll get follow up is if you’re on a community treatment order, otherwise we won’t follow you up’ sort of thing.’

Some MHRT members saw CTOs as having the instrumental value of protecting personal and therapeutic relationships by externalising conflicts or tensions over treatment.

‘In some ways it’s also good because it [CTO] reduces the conflict; I mean once the decision is made that they are on a CTO, it’s a force out there that’s obliging them to do what we think they need to do. And so I think it reduces conflict both with the service and often with family members, because it’s pretty tough when you’ve got a parent standing over you or whatever and saying “take this now”, and you don’t want that to be happening and so on. So it does distance the authority to some extent, and allow, sometimes it doesn’t of course, it does just the reverse, because they see the service as an enacting what they don’t want and so on. But it can have a benefit in that way.’

Many consumers suffering severe mental illness often faced the problem that treatment offered little more than basics. In the light of the ‘recovery model’ of patient journey, this is a constant refrain for MHRT participants in deliberating on questions of involuntary psychiatric treatment in the community:

‘I always ask the case manager, “well what else are you doing for the client”, so it’s not just about for me, and I think it’s really important and I think it’s being recognised more and more, and it’s part of the whole recovery model of mental health, that what else are you doing for the client, depending on their age, if they’re young, are they involved in some sort of education, are they involved in some sort of vocational activities, what are they doing with themselves, what are they doing with their life. Because you find some people, especially with severe schizophrenia, will just be sitting at home all day watching television

and smoking or something. So it's also I think an opportunity to say well what else is happening in this client's life, and what else is your service providing.'

'The legal construct of capacity'

Many MHRT participants were cognisant of the multiple discourses over capacity. Given the remit of the MHRT was the appropriate implementation of the *Mental Health Act (2007)* the legalistic discourse over risk dominated much of their deliberations. These focused specifically upon questions of capacity to decide about treatment for severe mental illness and on the context of this capacity, e.g. inpatient versus outpatient setting.

One MHRT member seemed to grapple with the lack of a statutory definition of capacity in NSW in his or her deliberations:

'The problem of capacity as far as psychiatry is concerned, is a very awkward one, because in the UK for instance, they brought out a Capacity Act, and people are admitted to hospital under the Mental Capacity Act...The problem with capacity, is nobody has clearly defined what is the difference between capacity and insight. The two are interfaced and overlap. And that is still an area of philosophy and semantics, which is going to have to be sorted out. You could even say quite simply, well people who don't have insight are lacking capacity. But are people who lack capacity insightful to the fact that they have got an illness?'

Another MHRT participant spoke of the quasi-legal construct of capacity in his or her deliberation on questions of the implementation of CTOs:

'I think that more broadly...to consider people's ability to weigh up decisions concerning their mental health treatments, to consider their capacity to do so, and to use that as something in the mix, in determining whether or not an order is required.'

Another MHRT participant appeared to link the legalistic concept of capacity with the realities of clinical practice, albeit in an aspirational vein:

'...it's a matter of really weighing up all the evidence and trying to make the best decision one can, bearing in mind that resources will always be limited. In a perfect world, we would have, I reckon we wouldn't even need CTOs, in a perfect world, if we had enough case managers out there who were skilled enough to develop a good relationship, have the time to develop the therapeutic relationship with patients, and be in a position to monitor medication compliance and put all the leg work in so it's a more cooperative and voluntary arrangement. But that is really pie in the sky stuff.'

3.2.4 Discussion: The elusive nature of capacity

The concept of capacity is elusive. This may in part be attributable to the different meanings of the term and its use. Like the concept of risk, no comprehensive or mutually agreed definition exists and it remains situated in different discourses such as in law and medicine. The term 'capacity' is polysemous and the multiple definitions relate to ability, efficacy or potential. Capacity is used synonymously with the term 'competence', although the latter also resides around abilities, particularly in relation to specific tasks. All participants in this study acknowledged that the intrinsic impairments arising from severe mental illness impacted upon capacity, and that any measure that sought to better such incapacity, either treatment, substituted or proxy decision-making, should enhance the person's abilities in responding to specific challenges.

Unlike the data for risk, there was a significant degree of *overlap* in the conceptualisation of capacity amongst the groups. Participants across groups acknowledged that part of the construct of capacity in the context of severe mental illness was the capacity to manage the illness – this encompassed the ability to recognise symptoms, seek and engage in treatment, negotiate complex and at times inflexible or inadequate health systems, maintain the benefits of treatment, flourish in a journey along the lines of the 'recovery' paradigm and manage future challenges or affronts to health.

Participants across groups acknowledged the capacity to care for one's self – including domains of physical health, accessing adequate social resources, dealing with complex social institutions, limiting scope for exploitation or victimisation and establishing and maintaining supportive and nurturing social and interpersonal relationships.

The third domain of capacity acknowledged across the participant groups was the capacity to function in a social role. This invariably involved the capability for social action. Social action requires the ability to assess the nature of a social interaction, formulate and enact a response and reflexively modify these actions in the light of observations of the responses of the other actors in the social situation or social system. This manifested as the capacity to enact certain roles in educational, vocational or interpersonal domains. In some instances, the capacity for social action involved a generative process of assisting others suffering from severe mental illness.

In a similar vein to the concept of risk, MHRT and clinician participants grappled with epistemic questions of capacity in clinical and legal domains. The lack of a universal definition or conceptualisation of 'capacity' or 'competence' was a background concern in many of the interviews.

In the North American literature, the concept of competency is not exclusively psychiatric as it also resides in law and social settings.⁴⁸ In legal settings, capacity is task specific⁴⁹ and as far back as the 1940s it was acknowledged that mental illness itself does not present grounds to presume incompetence or incapacity.⁴⁹ In 1977, Roth and colleagues elaborated a construct of competency, applied to the specific capacity to consent to psychiatric treatment. The components of this model included the capacity to evidence a choice, the reasonable outcome of such a choice, a choice based on rational reasons, the ability to understand treatment options, and demonstrating the actual understanding. None of these were a satisfactory or comprehensive account of capacity in treatment decisions.

Definitions of 'functional capacity' in the scientific literature involve the extent to which the person's understanding, knowledge, skills and abilities meet the demands involved in making a particular decision within a given context.⁵⁰ The problems with this construct are the fluid nature of some of the impairments, defining a threshold of impairment and distinguishing between conceptual and functional impairments.⁵¹ The most authoritative empirical study of capacity in relation to treatment decisions was the MacArthur study, which sought to elaborate

a clinical construct of competence to consent to treatment, using four ‘sets of abilities’ related to four legal standards.⁵²⁻⁵⁴ These four abilities included:

- i. Understanding treatment disclosures (UTD) – encompassing the ability to paraphrase information, recall details and recognise elements of information about treatment
- ii. Perceptions of disorder (POD) – was the capacity to both recognise the features of a disorder and acknowledge the benefits of treatment
- iii. Thinking rationally about treatment (TRAT) – is the ability to make a decision about treatment and justify the decision
- iv. Expressing a choice (EC) – described the ability to select and maintain a choice without ambivalence.

In an empirical study, the investigators compared subjects suffering from schizophrenia, depression and ischaemic heart disease. They demonstrated that subjects with depression and schizophrenia showed poorer understanding UTD, TRAT and POD, which was more pronounced in schizophrenia.⁵² These findings form the basis of the clinical assessment of competency to consent to medical or psychiatric treatment and are of critical importance to mental health legislation.

In the United Kingdom, there are more formal statutory definitions of incapacity. In British law, capacity is defined as a functional concept determined by ‘the person’s ability to understand, retain, and weigh up information relevant to the decision in order to arrive at a choice, and then a capacity to communicate that choice’.⁵⁵ The UK Law Commission defined incapacity as a person being unable by reason of ‘mental disability’ to make a decision of a matter in question. This arises from the inability to understand relevant information and make a decision based on that information.⁵⁶ The UK’s *Mental Capacity Act* (2005) links incapacity to the presence of an impairment of a disturbance in the functioning of the mind, leading to inabilities in the realm of:

- i. understanding the information relevant to a decision
- ii. retaining the information
- iii. utilising the information as part of the process of making decisions, and
- iv. communicating the decision.

In the UK, an adult is presumed to have capacity to withhold consent unless demonstrated otherwise and that presumption can be rebutted based upon difficulties involving thought, affect and cognition associated with serious psychiatric and intellectual disabilities. Despite the clarity of the legal definitions, there are many conceptual and practical problems with this approach.⁵⁵ In clinical settings, the proposed means to improve capacity include attention to communication problems, improving how information is provided, ameliorating the effects of a mental disability, addressing the patient’s sometimes inherent pessimism, avoiding coercion and acknowledging religious, cultural or spiritual beliefs.⁵⁷ Under law, the courts seek to address incapacity by considering advance directives, proxy decision-making or substituted judgement. The latter is based upon speculation of the nature of the decisions likely to be made by the person if competent and utilises a ‘best interests’ test.

There are no uniform Commonwealth laws in relation to capacity in Australia, not least because under the Constitution this is principally a matter for state and territory law. In Queensland the *Guardianship and Administration Act* (2000) defines capacity under a ‘decision-specific’ approach. Schedule 3 of the Queensland *Powers of Attorney Act* (2003) defines capacity in terms

of understanding the nature of decisions about a particular matter, freely and voluntarily making decisions about the matter and communicating the decision.⁵⁸

By contrast, in NSW there is no single definition of capacity, but rather it resides in a number of common law or statute definitions. The NSW Department of Attorney General and Justice published a 'Capacity Toolkit' for legal practitioners in relation to decisions around medical treatment, lifestyle and finance averring the general principle of establishing that the person understood the facts, understood the main choices that exist, evaluate and compare the consequences and understand the effect of these.⁵⁹ In 2006, the then Department of Ageing, Disability and Homecare formulated a policy defining capacity:

*'Capacity is subject to fluctuations and is influenced by the internal and external environment of the individual. Ultimately, individuals must be able to understand the information relating to decisions they are required to make, and the effects of those decisions.'*⁶⁰

As yet, there are no comprehensive tests of capacity in the setting of mental health law in NSW.

Part 4 – Proposed models of risk and capacity – towards improved decision-making

In the light of the analysis of the qualitative data and the survey of the relevant literature, the investigators propose the following models of risk and capacity. These models refer specifically to the conceptualisations of the two constructs across all groups of participants and are contextual to the setting of severe mental illness in a community-based care setting. In elaborating these models, the investigators seek to define constructs of risk and capacity that are consensually valid, appropriate to the clinical context, and supported as far as possible by the relevant medical and legal literature in the field.

The instrumental value of such models is to facilitate conceptualisations of risk and capacity to form the basis of sounder decision-making in regards to questions of the initiation, renewal or cessation of CTOs. The models of risk and capacity are comprehensible to consumers, their carers and families, clinicians and MHRT members. These models also allow a broader consideration of the grounds to justify decisions in regards to involuntary psychiatric treatment in the community.

In graduating the clinical and legal arguments for or against involuntary psychiatric treatment in the community beyond the limited scope of ‘harm’, there is potential for earlier initiation of treatment, greater consumer and carer participation in treatment decisions, more transparency and accountability in decisions around CTOs, and suitable frameworks for proposed treatment plans as the basis of specific CTOs.

4.1 Risk

In the proposed model of ‘risk’ (Figure 12), there are four domains:

- i. **Risk of harm to self or others** – encompassing suicide, misadventure, neglect, exploitation or victimisation and deteriorated physical health
- ii. **Risk of social adversity** – encompassing homelessness, poverty, isolation, deprivation, limited access to services and social goods
- iii. **Risk of excess distress** – emerging from the symptoms of mental illness, interpersonal conflict, the trauma of mental illness and coercive inpatient treatment and distress emerging from the traumatic affronts to the self of severe psychotic or mood disturbance, and
- iv. **Risk of compromised treatment** – manifesting as delays or loss of treatment opportunities, iatrogenic harm from treatment decisions emerging from more severe illness, psychiatric and medical co-morbidities and inability to participate along a ‘recovery model’ of treatment.

Figure 12: Proposed model of 'risk'



Case example: Mr V

Mr V a man in his mid-forties has suffered from chronic schizophrenia since his late teens. He maintained independent accommodation in a Department of Housing unit and was engaged with the local community mental health service. Mr V suffered from morbid obesity, Type II diabetes and hypertension.

Throughout the course of his illness, Mr V had suffered at least three severe psychotic episodes, characterised by persecutory delusions, terrifying auditory hallucinations and panic attacks. His last hospital admission under the Mental Health Act had been precipitated by his being apprehended by police after barricading himself in his apartment.

During the admission, Mr V had been restrained and secluded on several occasions and had suffered an oculogyric crisis due to high doses of 'Clopixol Acuphase'. It was in the nature of Mr V's illness that deteriorations in his mental state were gradual and tended to manifest in his disengaging from treatment and neglecting the management of his diabetes. He had defaulted on rent and had lost his apartment previously, forcing him to relocate to crisis accommodation in another area.

Mr V's illness had been managed with a CTO for the previous 18 months. He received regular intramuscular injections of risperidone as against previous treatment with aripiprazole, which had not led to weight gain. In the course of the most recent order, he had attended all appointments and participated well in sessions with his case manager. He regularly saw his GP and organised his diabetic management independently.

The issue confronting Mr V, the clinician's tasked with his care, his family and the members of the MHRT is the nature of risk posed by Mr V's illness. He was enjoying comparatively good mental health and proceeding along a recovery-based model of care. He was independent in managing his physical health and personal affairs and was capable of taking greater responsibility for decisions about his care.

Under a limited 'risk of harm' consideration, the arguments for ongoing treatment under a CTO were comparatively weak. Under the proposed model of risk, Mr V's illness posed credible risks in terms of:

- i. the distress of his psychotic episodes and coercive inpatient care
- ii. the loss of his accommodation
- iii. the need for parenteral antipsychotic medication with higher risks of metabolic complications
- iv. the loss of contact with a clinical service with a detailed experience of his illness and its best care
- v. the destabilisation of his diabetic management.

Such a conceptualisation of risk could serve a more credible basis of ongoing care under a CTO in that each domain of risk could be argued independently and could serve as the basis of an agreed treatment program. Such arguments could be presented to Mr V and his family in a less emotive or confronting manner than the stigmatising experience of speculations about the risk of harm his illness posed, and could allow MHRT members to evaluate the soundness of any argument for ongoing care under a CTO made on clinical grounds and provide a more transparent and credible basis of a decision to continue such treatment.

4.2 Capacity (or 'Capability')

This is a controversial area. The question is begged as to whether it is either necessary or appropriate to couch the different themes to emerge from the data as separate from harm, particularly in the light of the problems of defining or measuring capacity in medical and legal settings. A counter argument to this proposition is that this study has merely expanded conceptualisations of harm and that, in the light of the complexity around definitions of capacity in medico-legal settings, that a second category is either redundant or misleading.

The findings of qualitative research are emergent, and to force observations into categories based on *a priori* assumptions constrains or biases the analysis of the data and the understanding which emerges from it.

All of the participants in the study spoke of the potential harms posed by a severe mental illness, yet distinguished this as a basis of involuntary psychiatric treatment from the deficits or disabilities consequent upon such an illness, which impair choices that lead to adversity such as loss of opportunity, marginalisation, and other forms of social disadvantage. To the participants, these were different from the myriad forms of harm, and appeared to present a separate category.

In the light of the extant debates and linguistic uncertainty around the medico-legal construct of 'capacity', it might be prudent to re-label this emergent theme or phenomenon 'capability'. The concept of 'capabilities' as a more comprehensive means of understanding impairment of autonomy was championed by Nussbaum.⁶¹ Rather than aspiring to a life of autonomous fulfilment, Nussbaum suggests that the interventions seeking to correct for incapacities emerging from disabilities aim for the experience of a 'life of dignity'. In focusing on human capabilities, that is, what people are actually able to do and be, interventions ought aim to establish a threshold level of capabilities beneath which truly human functioning is not possible. Nussbaum argued for 10 basic capabilities including the ability to live a normal life span, bodily health, freedom of movement secure against assault, the use of emotion, to play, to seek a safe environment and to participate in economic and political functioning.⁶²

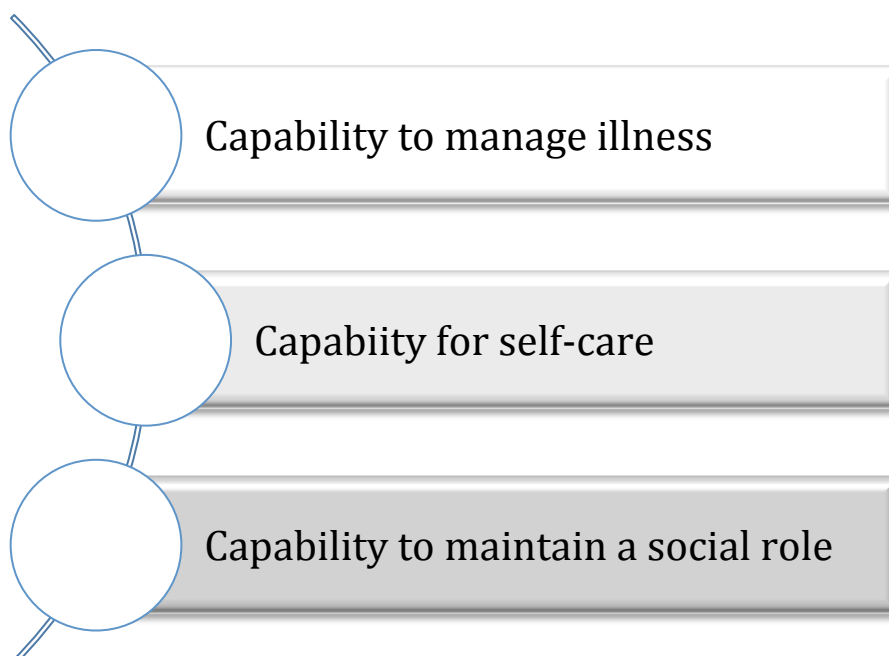
What seemed to concern the majority of participants in this regard was the impairments of capabilities arising from mental illness which precluded a dignified life. As a moral justification of involuntary treatment, this is distinct from negating the risk of harm. It is more in the realm of seeking to compensate for the effects of mental illness by proxy imposition of capability in regards to many choices that are instrumental to a life of dignity.

The proposed model of 'capacity', or 'capability', therefore moves beyond the limited legal constructs of task-specific assessment of competence in regards to treatment decisions and integrates three domains represented across all participant groups (Figure 13).

The three components to capacity or capability are:

- i. ***The capability to manage illness*** – including recognition of the features of illness including early signs of relapse or recurrence; acknowledging the effect of illness on thought, emotion and behaviour; the place of different domains of treatment; the ability to engage and negotiate a clinical service and; the ability to participate in a 'recovery' based model of care
- ii. ***The capability for self-care*** – including maintaining physical well-being and healthy lifestyle choices; establishing and maintaining a suitable ecology; and establishing and maintaining a network of professional and interpersonal caregivers
- iii. ***The capability to maintain a social role*** – including appropriate interpersonal, vocational and educational functioning; meeting obligations to others in the community and; maintaining harmonious and nurturing relationships with family, friends and acquaintances.

Figure 13: Proposed model of 'capacity' or 'capability'



Case example Ms M

Ms N was a woman in her late 20s who lived with her family. Ms N had suffered from paranoid schizophrenia since her late teens, however her illness had been episodic and there were few negative symptoms. Ms N maintained employment as an administrative assistant and, when well, maintained happy relationships with her family, colleagues and friends. When unwell, Ms N became very suspicious and hostile. In the course of one episode of psychosis she had accused her father of sexually abusing her (a claim that was false) and made vexatious complaints against several of her colleagues. She had twice failed to complete requirements for an Office Administration course at TAFE in the course of psychotic relapses.

Ms N remained well on low doses of olanzapine, with no sedation or weight gain, although a consistent feature of her illness was profound insightlessness. As a result, she frequently defaulted on oral olanzapine therapy, leading to four episodes of florid psychosis. Her psychiatrist had little alternative than to use depot risperidone which was both less efficacious and brought about akathisia and severe mastodynia and galactorrhoea. With the advent of a long-acting injection of olanzapine, her clinicians were able to ensure that she could receive maintenance therapy with olanzapine.

Three months prior the end of a CTO, Ms N petitioned her psychiatrist and case manager to change to oral olanzapine therapy and not renew her CTO. She had complied with all requirements of her recent CTO. In a prior circumstance, she had made a similar request, although her treating clinicians proceeded to apply for a renewal of the CTO. The MHRT were unable to renew the CTO as Ms N had presented well at assessment and no credible argument of 'risk' could be made in support of the application. Within weeks of being made a voluntary patient, Ms N ceased taking olanzapine and suffered a psychotic relapse necessitating involuntary psychiatric hospitalisation.

In this circumstance, the justification for a renewal of a CTO could not be credibly based upon the risk of harm. When unwell, Ms N damaged relationships with her family and colleagues, was incapable of maintaining employment or educational progress and experienced inferior quality of care. In taking a capabilities-based argument for ongoing treatment under a CTO, the proposed model addressed the deleterious effect her illness (both psychotic symptoms and insightlessness) had on her capacity to manage her illness optimally, to maintain harmonious family and collegiate relationships, and to continue social action in her workplace and career development. These criteria allowed the clinicians and MHRT members to justify their decisions to Ms N and her family, which was particularly desirable given their ambivalence towards continuing a CTO. Ms N and her family had rejected previous arguments for a CTO based upon 'risk to reputation' and speculative arguments about potential future risk were offensive to Ms N and her family. The broad capability criteria also allowed Ms N to negotiate treatment goals along the lines of minimising the effect of her illness on her family relationships, employment and educational status.

Part 5 – Future directions

This project has elaborated empirically based models of risk and capacity (or capability). While the accounts of both constructs are detailed, textured and contextualised within the relevant literature, their use in clinical practice requires further investigation and elaboration. To further develop the instrumental value of this research, the investigators propose the following steps be considered:

1. A period of consultation and respondent validation of the models of risk of capacity among the four groups
2. Instrumentalisation of the two constructs and preliminary evaluation of their utility in clinical and medico-legal settings
3. Further qualitative evaluation along a discourse analysis paradigm of the two constructs, either using case examples in focus group settings, or
4. Evaluation of the clinical and medico-legal utility of the two constructs in specific clinical settings and MHRT hearings.

6. Appendices

6.1 Financial report

6.2 Ethics approvals

6.1: 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

	31 December 2010	31 December 2011	31 August 2012
	\$	\$	\$
Income			
Research Payment Income	95,624	20,000	-
Total Income	95,624	20,000	-
Expenditure			
Research Employee Salary	45,755	47,769	9,728
Airfare - Trial Interviews	336	-	-
Accommodation - Trial Interviews	77	-	-
Travel - Clinical Trial Interviews	-	-	107
Research Training Course	1,000	-	-
Clinical Trial Interview Costs	-	-	700
Clinical Trial Interview Postage	-	-	393
Clinical Trial Interview Transcription Service	615	1,362	1,334
Total Expenditure	47,783	49,131	12,262
Surplus/(Deficit)	47,841	(29,131)	(12,262)
Funds Carried Forward as at 1 January	-	47,841	18,710
Total Accumulated Funds	47,841	18,710	6,448

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

6.2: Ethics approvals

6.2.1 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

6.2.2 Clinician interviews

Sydney Local Health Network (formerly Sydney South West Area Health Service) Ethics Review Committee – protocol number X10-0338 & reference number HREC/10/RPAH/596 (approved 3 February 2011)

- Site authorisation (Sydney Local Health Network RPAH Zone) – 23 March 2011 (reference number SSA/11/RPAH/125)
- Site authorisation (South Western Sydney Local Health District) – 1 October 2011 (reference number SSA/11/LPOOL/110 & local reference 11/090)
- Approval letter
- Invitation
- Participant Information Statement
- Consent form
- Interview topics

6.2.3 MHRT member interviews

University of Sydney Human Research Ethics Committee – reference number 14421 (approved 10 January 2012)

- Approval letter
- Invitation
- Participant Information Statement
- Consent form
- Interview topics



ABN 15 211 513 464

Marietta Coutinho
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Human Research Ethics Administration

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NSW 2006 AUSTRALIA

Ref: IM/PR

7 April 2010

Dr Michael Robertson
Centre for Values, Ethics and the Law in Medicine
Medical Foundation Building - K25
The University of Sydney
Email: michael.robertson@sydney.edu.au

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:

Ref 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,



Associate Professor Ian Maxwell
Chair
Human Research Ethics Committee

Centre for Values, Ethics & the Law in Medicine

Michael Robertson MBBS (Hons) PhD FRANZCP
Clinical Associate Professor

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Research study into Community Treatment Orders – Invitation to participate

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

For further information, please contact Edwina Light at 02 9036 3418 or edwina.light@sydney.edu.au

Centre for Values, Ethics & the Law in Medicine

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**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 whichever 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 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

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**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.

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- Associate Professor Michael Robertson (University of Sydney)
- Professor Philip Boyce (University of Sydney)
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- 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 whichever 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 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 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.

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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 YES NO
in further research

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:

Centre for Values, Ethics & the Law in Medicine

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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?

ADDRESS FOR ALL CORRESPONDENCE

RESEARCH DEVELOPMENT OFFICE
ROYAL PRINCE ALFRED HOSPITAL
CAMPERDOWN NSW 2050

TELEPHONE: (02) 9515 6766

FACSIMILE: (02) 9515 7176

EMAIL: lesley.townsend@email.cs.nsw.gov.au

REFERENCE: X10-0338 & HREC/10/RPAH/596

3 February 2011

A/Professor M Robertson
C/- Ms E Light
Centre for Values, Ethics and the Law in Medicine, K25
UNIVERSITY OF SYDNEY NSW 2006

Dear Professor Robertson,

Re: Protocol No X10-0338 & HREC/10/RPAH/596 - “Community treatment orders (CTOs): improving clinical decision-making”

Thank you, on behalf of the Ethics Review Committee, for Ms E Light’s correspondence of 11 January 2011. In accordance with the decision made by the Ethics Review Committee, at its meeting of 8 December 2010, ethical approval is granted.

The proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

This approval includes the following:

- Email Invitation (Version 2, 10 January 2011)
- Information for Participants (Master Version 2, 11 January 2011)
- Participant Consent Form (Master Version 1, 18 October 2010)
- Proposed Interview Topics (Master Version 1, 18 October 2010)

You are asked to note the following:

- **This letter constitutes ethical approval only. You must NOT commence this research project at ANY site until you have submitted a Site Specific Assessment Form to the Research Governance Officer and received separate authorisation from the Chief Executive or delegate of that site.**
- This approval is valid for four years, and the Committee requires that you furnish it with annual reports on the study's progress beginning in February 2012.
- This human research ethics committee (HREC) has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review and is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.
- You must immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
- You must notify the HREC of proposed changes to the research protocol or conduct of the research in the specified format.
- You must notify the HREC and other participating sites, giving reasons, if the project is discontinued at a site before the expected date of completion.
- Where appropriate, the Committee recommends that you consult with your Medical Defence Union to ensure that you are adequately covered for the purposes of conducting this study.

Should you have any queries about the Committee's consideration of your project, please contact me. The Committee's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Sydney South West Area Health Service website.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

The Ethics Review Committee wishes you every success in your research.

Yours sincerely,

Lesley Townsend
Executive Officer
Ethics Review Committee (RPAH Zone)

HERC\EXCOR\11-01

ADDRESS FOR ALL CORRESPONDENCE

RESEARCH DEVELOPMENT OFFICE
ROYAL PRINCE ALFRED HOSPITAL
CAMPERDOWN NSW 2050

TELEPHONE: (02) 9515 6766

FACSIMILE: (02) 9515 7176

EMAIL: lesley.townsend@email.cs.nsw.gov.au

REFERENCE: X10-0338

23 March 2011

A/Professor M Robertson
C/- Ms E Light
Centre for Values, Ethics and the Law in Medicine, K25
UNIVERSITY OF SYDNEY NSW 2006

Dear Professor Robertson,

Re: Protocol No X10-0338 - "Community treatment orders (CTOs): improving clinical decision-making"

HREC/10/RPAH/596

SSA/11/RPAH/125

Thank you for submitting a Site Specific Assessment Form for this study. I am pleased to inform you that authorisation has been granted for it to be undertaken at the following Community Health Centres within the Sydney Local Health Network (RPAH Zone):

- Camperdown
- Canterbury
- Croydon
- Marrickville
- Redfern

The approved information and consent documents for use at this site are:

- Information for Participants (SLHN Version 1, 3 March 2011)
- Participant Consent Form (SLHN Version 1, 3 March 2011)

The following conditions apply to this research study. These are additional to those conditions imposed by the human research ethics committee (HREC) that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the study and which are submitted to the lead HREC for review, must be copied to me.
4. Proposed amendments to the research protocol or conduct of the research, which may affect the ongoing site acceptability of the study, must be submitted to me.

I wish you every success in your research.

Yours sincerely,

Lesley Townsend
Research Governance Officer
SLHN (RPAH Zone)

RGO - Lesley\CORRES\X10-0338



Ethics & Research Governance Office

Locked Bag 7017, LIVERPOOL BC, NSW, 1871

Phone: 02 9612 0614

Facsimile: 02 9612 0611

1 October 2011

A/Professor M Robertson
Centre for Values, Ethics and the Law in medicine
Level 1 Medical Foundation Building (K25)
University of Sydney NSW 2006

Dear Professor Robertson

Lead HREC Reference	HREC/10/RPA/596
SSA Reference number	SSA/11/LPOOL/110
Local Reference	11/090
Title	Community Treatment Orders (CTOs): Improving clinical decision making

I am pleased to inform you that the Chief Executive has granted authorisation for this study to take place at the following Community mental Health services:

- Bankstown-Lidcombe
- Bowral-Wingecarribee
- Macarthur
- Fairfield
- Liverpool

The participant documents approved for use at these site are:

- Invitation email: version 2, 10/1/2011
- Information for Participants: SWSLHD local version 1, 3/3/2011 based on Master Version 3, 3/3/2011
- Participant consent form: SWSLHD local version 1, 3/3/2011 based on Master Version 2, 3/3/2011

Please ensure that the local versions of the above are printed on the South Western Sydney Local Health District letterhead prior to use (rather than South Western Sydney Local Health Network – name changed 1/7/2011)

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to this office.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to this office.
3. Please note that you are responsible for making the necessary arrangements (e.g. identity pass; signed confidentiality agreement and vaccine compliance as per NSW Health Policy Directive PD2011_005) for any researcher who is not employed by the South Western Sydney Local Health District and is conducting the research on-site.

Yours sincerely,

Merela Ghazal
Acting Coordinator Ethics & Research Governance
Ethics & Research Governance Office
South Western Sydney Local Health District (SWSLHD)

Cc Edwina Light

Centre for Values, Ethics & the Law in Medicine

Michael Robertson MBBS (Hons) PhD FRANZCP
Clinical Associate Professor

Level 1, Medical Foundation Building (K25)
University of Sydney NSW 2006 AUSTRALIA
Telephone: +61 2 9036 3405
Facsimile: +61 2 9036 3436
Web: <http://www.cvelim.org/>

COMMUNITY TREATMENT ORDERS: IMPROVING CLINICAL DECISION-MAKING**INFORMATION FOR PARTICIPANTS****Introduction**

You have been invited to take part in a research study into the processes of clinical decision-making in relation to Community Treatment Orders (CTOs). The project wants to find out about the views and experiences of clinicians involved in making decisions about CTOs under the *Mental Health Act (NSW) 2007*. We want to learn about how clinicians make CTO decisions, including the factors that determine their decision-making, and how they think about concepts of 'risk' and 'capacity' in relation to involuntary community treatment. The research will involve an interview about these issues and aims to use the knowledge gathered from people's experiences and perspectives to inform improvements in clinical and legal CTO decision-making processes.

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

- Associate Professor Michael Robertson (Clinical Associate Professor, Centre for Values, Ethics and the Law of Medicine, University of Sydney)
- Professor Philip Boyce (Professor, Discipline of Psychiatry, University of Sydney)
- Professor Alan Rosen (Clinical Associate Professor, Discipline of Psychiatry, University of Sydney)
- Dr Chris Ryan (Clinical Senior Lecturer, Discipline of Psychiatry & Honorary Associate, Centre for Values, Ethics and the Law in Medicine, University of Sydney)
- Professor Terry Carney (Sydney Law School, University of Sydney)
- Associate Professor Michelle Cleary (Associate Professor, Mental health, School of Nursing and Midwifery, University of Western Sydney)
- Dr Glenn Hunt (Senior Research Fellow, Discipline of Psychiatry, University of Sydney)
- Dr Nick O'Connor (Clinical Senior Lecturer, Discipline of Psychiatry, University of Sydney)

The project will be assisted by Ms Edwina Light.

Study Procedures

If you agree to take part in this study, you will be asked to sign the Participant Consent Form. You will then be asked to take part in an interview with a researcher at which you will be invited to speak about your experiences of and views about CTO decision-making. The interview will explore your reflections on CTO decision-making and your accounts of (de-

identified) patient cases, including how decisions were made about commencing/renewing/removing CTOs, and how 'risk', 'capacity', and other factors may have figured in those decisions. The interviews are designed to find out about your experiences and what you think. There is no fixed set of questions that you must answer. Interviews will take place at a mutually convenient location that will provide privacy and the ability to record the interviews, such as clinician offices. An interview will usually take 45-60 minutes.

Benefits

While we intend that this research study furthers clinical knowledge and may improve practices around CTOs in the future, it may not be of direct benefit to you.

Costs

Participation in this study will not cost you anything, nor will you be paid.

Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Should you withdraw from the study, you will have the option of having any data already collected about you destroyed. Whatever your decision, please be assured that it will not affect your relationship with the researchers, the Centre for Values, Ethics and the Law in Medicine, the University of Sydney, or the Sydney Local Health Network.

Confidentiality

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The interviews will be audio taped and then the recordings will be transcribed and de-identified. We will keep the transcripts separate from any information identifying individual 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.

The de-identified transcripts will be analysed to develop representative models of 'risk' and 'capacity' in the context of involuntary community treatment, and to identify themes in the determinants and processes of CTO decision-making. Individual participants will not be identified in the study results, which will be sent to NSW Health. The study's findings may also be presented at a conference or in a scientific publication, but, again, it won't be possible to identify individual participants in such a presentation. 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 and tell you about any scientific publications and presentations based on the findings. Individual participants won't be identified in this report.

Further Information

When you have read this information, Associate Professor 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 him on 02 9036 3405.

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health Network. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X10-0338.

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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COMMUNITY TREATMENT ORDERS: IMPROVING CLINICAL DECISION-MAKING

PARTICIPANT CONSENT FORM

I, _____ [name]
of
_____ [address]

have read and understood the Information for Participants on the abovenamed research
study and have discussed the study with _____.

I have been made aware of the procedures involved in the study.

I understand that the interview will be audiotaped, and I agree to this. 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.

I freely choose to participate in this study and understand that I can withdraw at any time. I
understand that being in this study is completely voluntary – I am not under any obligation to
consent.

I consent to:

- i) Audio-taping of my interview 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: _____

I also understand that the research study is strictly confidential and no information about me will be used in any way that reveals my identity. I hereby agree to participate in this research study as detailed above.

Name:

Signature:

Date:

Name of witness:

Signature of witness:

COMMUNITY TREATMENT ORDERS: IMPROVING CLINICAL DECISION-MAKING

PROPOSED INTERVIEW TOPICS

Semi-structured interviews with participants will explore their reflections on CTO decision-making and their accounts of having made a decision to commence/renew/remove, including how 'risk', 'capacity' and other factors may have figured in those decisions. Participants to be 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. Making decisions about involuntary treatment in the community

- a) How often do you have to make decisions about involuntary community treatment for your patients?
- b) What are the issues/factors that you find you *have to* consider when making decisions about involuntary community treatment?
- c) What issues do you think *should* be considered when making decisions about involuntary community treatment?
- d) How would you describe your experiences of making decisions to place patients on CTOs?

2. Risk

Decisions about CTOs are sometimes made because people are considered to be at risk.

- a) How do you think about the concept of 'risk'?
- b) What does 'risk' mean to you in relation to your patient care?
- c) How do you see 'risk' as part of patients' illness? And their recovery?
- d) How does 'risk' factor in your decisions about CTOs?

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 the concept of 'capacity'?
- b) What does 'capacity' mean to you in relation to your patient care?
- c) How do you see 'capacity' as part of patients' illness? And their recovery?
- d) How does 'capacity' factor in your decisions about CTOs?

4. CTO decisions

Without disclosing any details that would identify an individual, can you tell me about a case where you made a decision to commence, re-new, or remove a CTO that was:

- i. a straightforward or routine decision?
- ii. a difficult or contested decision?

- a) What were the circumstances surrounding the decision?
 - What led up to you considering to apply for a CTO (eg, what were the clinical and other circumstances and events)?
 - How would you describe your relationship with the patient (eg, new patient, long-term patient)?

- b) What was involved in making that decision?
 - What were the factors that influenced your decision?
 - How did you go about making and implementing that decision (eg, process)?
 - What was the content of the CTO?
 - Who else was involved in deliberations about the decision (eg, patient, colleagues, family/carers, Tribunal)?
 - How did you explain your decision about the CTO to the patient?
- c) What do you think it was that made your decision in this case straightforward/difficult?
- d) What was the impact of your decision?
 - On the factors that you considered in your CTO decision-making (eg, risk, capacity, other)?
 - On the patient's health and well-being?
 - On your professional relationship with the patient?

5. Other

- Is there anything that you might not have thought about before that occurred to you during this interview?
- Is there anything else you would like to tell us about CTOs?

Ref: [MF/KFG]

10 January 2012

A/Prof Michael Robertson
Clinical Associate Professor
Central Clinical School
The University of Sydney
Email: michael.robertson@sydney.edu.au

Dear A/Prof Robertson

Thank you for your correspondence dated 9 January 2012 addressing comments made to you by the Human Research Ethics Committee (HREC).

I am pleased to inform you that with the matters now addressed your protocol entitled “**Community Treatment Orders: improving clinical decision making.**” has been approved.

Details of the approval are as follows:

Protocol No.: 14421
Approval Date: 10 January 2012
First Annual Report Due: 31 January 2012
Authorised Personnel: A/Prof Michael Robertson
Prof Philip Boyce
Prof Alan Rosen
Dr Christopher James Ryan
Prof Terry Carney
Dr Nick O'Connor
A/Prof Glenn Hunt
A/Prof Michelle Cleary

Documents Approved:

Document	Version Number	Date
Invitation Email Text	Version 2	09/01/2012
Participant Information Statement	Version 1	16/11/2011
Participant Consent Form	Version 1	16/11/2011
Proposed Interview Topics	Version 1	16/11/2011

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:



Condition/s of Approval

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.
- All serious and unexpected adverse events should be reported to the HREC within 72 hours.
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
- Any changes to the protocol including changes to research personnel must be approved by the HREC by submitting a Modification Form before the research project can proceed.

Chief Investigator / Supervisor's responsibilities:

1. You must retain copies of all signed Consent Forms and provide these to the HREC on request.
2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

Dr Margaret Faedo
Manager, Human Ethics
On behalf of the HREC

cc *Edwina Light*
Edwina.light@sydney.edu.au

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

COMMUNITY TREATMENT ORDERS: IMPROVING CLINICAL DECISION-MAKING

INVITATION EMAIL TEXT

The Centre for Values, Ethics and the Law in Medicine at the University of Sydney is seeking members of the Mental Health Review Tribunal (MHRT) to take part in a study into the processes of Community Treatment Order (CTO) decision-making.

The project wants to find out about the views and experiences of MHRT members involved in making decisions about CTOs under the *Mental Health Act, 2007*. We want to learn about how Tribunal members make CTO decisions, including the factors that determine your decision-making, and how you think about concepts of 'risk' and 'capacity' in relation to involuntary community treatment.

We will be conducting interviews with interested participants and then transcribing and analysing the interviews. Our main goal is to use the knowledge gathered from people's experiences and perspectives to inform improvements in clinical and legal decision-making processes. As part of the study we have already spoken to a sample of consumers, carers and clinicians. The project is funded by NSW.

If you are interested in participating, please contact the Tribunal's Registrar Rodney Brabin, who will pass on your details to us. Please note that depending on the level of response it may not be possible for everyone who is interested to be included in the study.

Associate Professor Michael Robertson

For further information about the study, please contact Ms Edwina Light at edwina.light@sydney.edu.au or 02 9036 3405.

ABN 15 211 513 464

Michael Robertson
Clinical Associate Professor

Medical Foundation Building (K25)
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 2 9036 3405
Facsimile: +61 2 9036 3436
Web: <http://www.sydney.edu.au/>

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

PARTICIPANT INFORMATION STATEMENT

(1) What is the study about?

You are invited to participate in a study about Community Treatment Orders (CTOs). The project wants to find out about the views and experiences of Mental Health Review Tribunal members involved in making decisions about CTOs under the Mental Health Act (NSW) 2007. We want to learn about how members make CTO decisions, including the factors that determine their decision-making, and how they think about concepts of 'risk' and 'capacity' in relation to involuntary community treatment. The research will involve an interview about these issues and aims to use the knowledge gathered from people's experiences and perspectives to inform improvements in clinical and legal CTO decision-making processes.

(2) Who is carrying out the study?

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

- Associate Professor Michael Robertson
- Professor Philip Boyce
- Professor Alan Rosen
- Dr Chris Ryan
- Professor Terry Carney
- Associate Professor Michelle Cleary
- Associate Professor Glenn Hunt
- Dr Nick O'Connor

The project will be assisted by Ms Edwina Light.

(3) What does the study involve?

If you agree to take part in this study, you will be asked to sign the Participant Consent Form. You will then be asked to take part in an audio-recorded interview with a researcher at which you will be invited to speak about your experiences of and views about CTO decision-making. The interview will explore your reflections on CTO decision-making and your accounts of (de-identified) patient cases, including how decisions were made about making/not making/revoking CTOs, and how 'risk', 'capacity', and other factors may have figured in those decisions. The interviews are designed to find out about your experiences and what you think. There is no fixed set of questions that you must answer. Interviews will take place at the Mental Health Review Tribunal in Gladesville, in an office location that will provide privacy and the ability to record the interview.

(4) How much time will the study take?

An interview will usually take 45-60 minutes.

(5) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent. If you do consent, you can withdraw at any time without having to provide a reason and without affecting your relationship with The University of Sydney and the Centre for Values, Ethics and the Law in Medicine.

You may stop the interview at any time if you do not wish to continue, and the audio recording will be erased and the information provided will not be included in the study.

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. Any information identifying individual participants will be kept separate from other study materials, including interview recordings and transcripts.

The audio recordings of interviews will be transcribed and de-identified. 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.

Individual participants will not be identified in the study results, which will be sent to NSW Health. Reports of the study may be submitted for publication or presentation, but individual participants will not be identifiable in such reports.

(7) Will the study benefit me?

While we intend that this research study furthers clinical knowledge and may improve practices around CTOs in the future, we cannot and do not guarantee or promise that you will receive any benefits from the study.

(8) What if I require further information about the study or my involvement in it?

When you have read this information, chief investigator 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 A/Professor Robertson or research assistant Ms Edwina Light on 02 9036 3405 or edwina.light@sydney.edu.au

(9) What if I have a complaint or any concerns?

Any person with concerns or complaints about the conduct of a research study can contact The 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



ABN 15 211 513 464

Michael Robertson
Clinical Associate Professor

Medical Foundation Building (K25)
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 2 9036 3405
Facsimile: +61 2 9036 3436
Web: <http://www.sydney.edu.au/>

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 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 being in this study is completely voluntary – I am not under any obligation to consent.
4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.
5. 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.
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:

• Audio-recording of my interview YES NO

• My interview data being used in YES NO
future research

(If you answered 'Yes' to the future research question, 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.)

• Receiving Feedback YES NO

(If you answered 'Yes' to the Receiving Feedback question, please provide your details, ie, mailing address or email address. When the project finishes, we will send to this address a report that summarises the main findings of the study and tells you about any scientific publications and presentations based on the findings.)

Feedback Option

Address: _____

Email: _____

.....
Signature

.....
Please PRINT name

.....
Date

COMMUNITY TREATMENT ORDERS: IMPROVING CLINICAL DECISION-MAKING

PROPOSED INTERVIEW TOPICS

Semi-structured interviews with participants will explore their reflections on CTO decision-making and their accounts of having made a decision to make, not make, or to revoke a CTO including how 'risk', 'capacity' and other factors may have figured in those decisions. Participants to be 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. CTO decisions

Without disclosing any details that would identify an individual, can you tell me about a case where you made a decision to make, not make or to revoke a CTO that was:

- i. a straightforward or routine decision?
- ii. a difficult or contested decision?
 - a) What were the circumstances surrounding the decision?
 - What were the details of the application put to the MHRT (eg, what were the clinical and other circumstances/events that led to the CTO application being made)?
 - How would you describe the patient's experience with the MHRT (eg, previously been before MHRT, new to MHRT, first or repeat CTO)?
 - b) What was involved in making that decision?
 - What were the factors that influenced your decision?
 - Who else was involved in deliberations about the decision (eg, patient, MHRT colleagues, clinicians, family/carers, legal representatives)?
 - How did you go about making the decision (eg, hearing process)?
 - What was the content of the CTO?
 - How did you explain your decision about the CTO to the patient?
 - c) What do you think it was that made your decision in this case straightforward/difficult?
 - d) In situations where you were involved in any later review of the patient's case, what was the impact of your decision ?
 - On the factors that you considered in your CTO decision-making (eg, risk, capacity, other)?
 - On the patient's health and well-being?

2. Risk

Decisions about CTOs are sometimes made because people are considered to be at risk.

- a) How do you think about the concept of 'risk'?
- b) How do you see 'risk' as part of patients' illness? And their recovery?
- c) What does 'risk' mean to you in relation to a patient's care?
- d) How does 'risk' factor in your decisions about CTOs?

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 the concept of 'capacity'?
- b) How do you see 'capacity' as part of patients' illness? And their recovery?
- c) What does 'capacity' mean to you in relation to a patient's care?
- d) How does 'capacity' factor in your decisions about CTOs?

4. General/ Other

- a) How often do you have to make decisions about involuntary community treatment?
- b) What are the issues/factors that you find you *have to* consider when making decisions about involuntary community treatment? And what issues do you think *should* be considered?
- c) How would you describe your experiences of making decisions to place patients on CTOs?
- d) Is there anything that you might not have thought about before that occurred to you during this interview?
- e) Is there anything else you would like to tell us about CTOs?

7. References

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