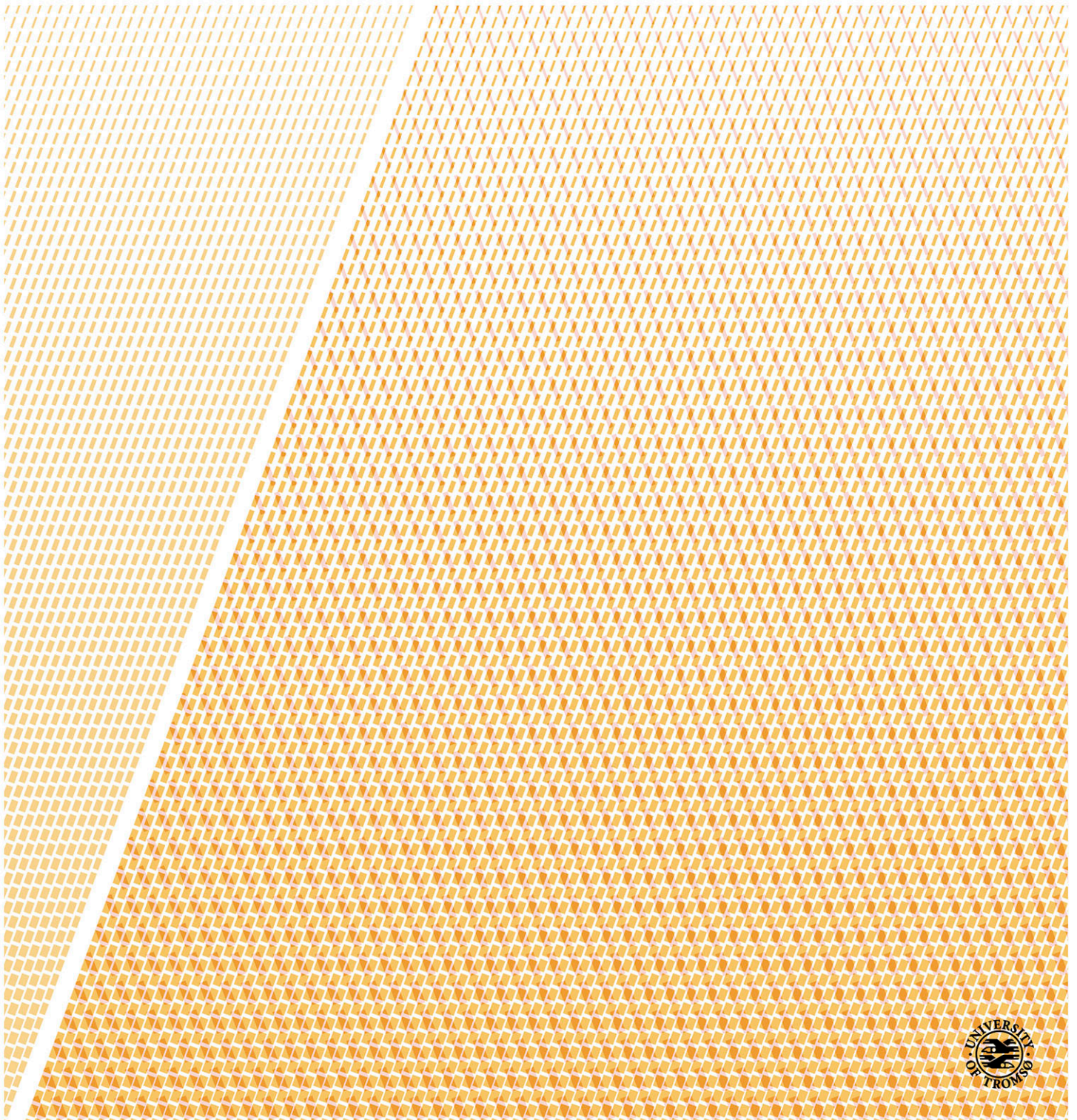


# **When coercion moves into your home**

*A study of outpatient commitment in Northern Norway*

—  
**Henriette Riley**

*A dissertation for the degree of Philosophiae Doctor – August 2016*







## **Preface**

The theme of this study is coercion in mental health care, which was a natural choice for me. I am a qualified social educator with over ten years' experience in clinical work, mostly from closed wards in psychiatric hospitals. The majority of the patients I worked with were subject to coercion, and the wards were characterised by rules and routines. I found it complex and challenging, both professionally and personally, to work with people subject to coercion. I have no doubt that some of the coercion I

have helped to administer has been necessary and sometimes life-saving, but I often went home with a lump of despair in my stomach: was it the right decision to use coercion? What would have happened if we had tried other alternatives, spent more time, and especially if we had listened more to the patient. I asked myself over and over again whether voluntariness might have been possible if the health care system could adapt more to the patient instead of the other way round.

My wish for this study is to contribute to an increased focus and understanding of how coercive outpatient mental health care is manifested by exploring the various perspectives involved.

This study is a collaborative effort between the Division of Mental Health and Substance Abuse at the University Hospital of North Norway and the Department of Community Medicine in the Faculty of Health Sciences at UiT The Arctic University of Norway, and is supported by research funding from Helse Nord.

Many people have contributed and helped me during this work. I am most grateful to all of you.

Firstly, my supervisor, Professor Georg Høyer. You have guided me safely through this work from beginning to end, and generously shared your knowledge. I am also thankful for the support you gave me at a time when my life was turned upside down. My co-supervisor Professor Geir Lorem, I would especially like to thank you for your help with the qualitative part of the study.

Without the goodwill and positive attitude of the participants, it would have been impossible to carry out this study. I would especially like to highlight the participants with experience as patients. It meant so much that you confided in me and willingly shared your experiences. You have contributed unique knowledge to the study. Thanks also to those involved in recruiting participants to the study.

A special thank you goes to Lisbeth Mørck. Your knowledge of the DIPS eHealth records has been crucial for the quantitative part of the study. You are always available to answer all my questions, and have been quite indispensable! Thanks also to Heidi Magnussen for your help with the registration work and focus group interviews.

Many thanks to co-author Bjørn Straume for your contribution. Tordis Sørensen Høifødt, head of the Academic Development Unit at the University Hospital of North Norway, thank you for supporting and believing in the study from beginning to end.

Karina Standahl Olsen, Marita Melhus, Katja Sharashova and Marko Lukić: statistical first aid is not always fully appreciated. What would I have done without you?! And Katja, thank you too for being the perfect roommate.

Being a PhD student in a knowledgeable environment such as the Department of Community Medicine is a privilege. There is always someone who can answer the many questions in the head of a PhD student; thank you to my colleagues for sharing your experiences and knowledge. A special thank you goes to Toril Bakken and Kristin Benjaminsen Borch for practical help in my private life when I needed it most.

A big thanks to Astrid Weber, Åshild Fause, Elisabeth C. K. Reitan, Dag Erik Hagerup and Audun Hetland for feedback on my written work and encouragement.

Thanks to the researchers at Tvangsforsk, the Norwegian Research Network on Coercion in Mental Health Care, who gave me a great boost during the network's biannual gatherings.

I would also like to thank Robert Kechter of the Mental Health and Substance Use Clinic at Helse Finnmark who arranged office space for me when I lived in Alta.

To my good colleagues at the University Hospital of North Norway who keep a grip on reality, thank you for your feedback, interest, commitment and encouragement.

Thanks to my friends and family, you know who you are!

My deepest appreciation goes to Anders. You have patiently supported me throughout this work. Thank you for all of the wonderful moments, doing the things we love in mountains and at sea. Trips with you are the best disconnection and have given me the necessary distance from work. When we are together, there is nowhere I would rather be. Last but not least, Ronja and Olve. Ronja, "*Gullsen til mamma*" for giving me the world's best smile when I come home; you put it all into perspective just because you're here. Olve, you were there the last months, kicking me to get finished. I'm really looking forward to get to know you.

Tromsø, August 2016

Henriette



## Table of Contents

Preface.....	1
Summary in English.....	9
Norsk sammendrag .....	13
Original papers.....	17
1 Introduction .....	18
1.1 Coercion in mental health care .....	19
1.2 Coercive outpatient mental health care (OC) .....	20
1.2.1 History.....	20
1.2.2 Legal basis for OC.....	23
1.2.3 Lack of official data on the practice of OC .....	24
1.2.4 Ideology, purpose and practices .....	26
1.3 International perspectives on OC.....	27
1.3.1 Different practices .....	28
1.3.2 Is OC a suitable form of treatment for people with severe mental disorders? .....	29
1.3.3 Patients' and decision makers' experiences of OC .....	31
1.3.4 Transferability to the Norwegian OC scheme.....	32
2 Purpose of the study .....	33
3 Methodology.....	36
3.1 The catchment area .....	36
3.2 Context of the study.....	37
3.3 Sub-study I: A quantitative retrospective case register study of OC.....	39
3.3.1 Participants .....	39
3.3.2 Identification of participants .....	39

3.3.3	Registration form.....	40
3.3.4	Data collection.....	41
3.3.5	Analysis.....	41
3.4	Sub-study II: Patient experiences of OC .....	42
3.4.1	Participants .....	42
3.4.2	Recruitment .....	43
3.4.3	Interview guide.....	44
3.4.4	Interviews .....	45
3.4.5	Analysis.....	49
3.5	Sub-study III: How decision makers weigh up various considerations in their OC decisions.....	51
3.5.1	Participants .....	51
3.5.2	Recruitment .....	51
3.5.3	Interview guide.....	51
3.5.4	Interviews .....	52
3.5.5	Analysis.....	54
3.6	Use of literature .....	55
4	Ethical approvals and considerations .....	58
5	Results .....	60
5.1	Sub-study I: Patients on a first ever outpatient commitment order in Norway .....	61
5.2	Sub-study II: “When coercion moves into your home” - A qualitative study of patient experiences with Outpatient Commitment in Norway.....	62
5.3	Sub-study III: Community treatment orders - what are the views of decision makers? .....	64
5.4	The three articles seen in relation to each other .....	65



6	Methodological considerations.....	66
6.1	The importance of pre-understanding - some reflections .....	66
6.2	Catchment area .....	68
6.3	Design .....	68
6.4	Participants .....	69
6.5	Data quality in Sub-study I.....	70
7	Discussion of the study results .....	72
7.1	What is the role of coercion in OC? .....	73
7.1.1	How is the use of OC justified? .....	75
7.1.2	Does OC provide better access to good health care? .....	76
7.1.3	Some legal considerations .....	77
7.2	Use of readmission as an outcome measure .....	78
7.3	How many and what kind of patients are on OC orders?.....	80
7.4	Is OC practised as a supplement or as an alternative to compulsory inpatient care? .	82
7.5	Implications for clinical practice .....	83
7.6	Need for further research on OC .....	84
7.7	Conclusion .....	85
8	References .....	86



## Summary in English

### Background, purpose and method of the study

Outpatient commitment (OC), also known as community treatment orders (CTO), is a scheme whereby mental health patients live outside a hospital, but are still subject to coercion.

According to the Norwegian Mental Health Act, the same requirements must be met for OC patients as for compulsory hospitalisation. This means that the patient must have a serious mental disorder, with either a risk that the condition will deteriorate or that the patient will represent a danger to him/herself or others without treatment. Furthermore, OC must appear to be the best solution, based on a comprehensive evaluation. The purpose of OC is to ensure that patients who are unwilling or unable to continue their treatment after hospitalisation will still receive treatment, if necessary against their will. The coercive measures authorized by the mental health act is limited to the possibility that the patients on OC can be forced to comply with their treatment appointments. OC is also a prerequisite for decisions on forced medication for outpatients who refuse voluntary medical treatment.

When the study was first designed, there was no existing research on OC based on Norwegian data. The purpose was therefore to gain basic knowledge of the extent and practice of OC, and how patients and decision makers experience the scheme. The study has a descriptive design and has employed both qualitative and quantitative methods. It included three sub-studies that provide insight into different perspectives and phenomena of OC. Sub-study I is a quantitative retrospective case register study where data was collected from electronic patient records for the period 2008-2012. The purpose of Sub-study I was to describe the extent and practice of OC in Troms and Finnmark, with a particular focus on patients placed under an OC order for the first time. In Sub-study II, patients on OC were interviewed about their experience of the scheme. In Sub-study III, decision makers were interviewed about their views on OC and the factors they emphasised when making OC decisions.

### Findings

#### **Sub-study I: *Patients on a first ever outpatient commitment order in Norway***

A total of 345 OC decisions, which applied to 286 persons, were identified in the period 2008-2012. There were between 22.1 and 33.2 new cases of OC per 100 000 population over 18 years in Norway during the study period (incidence rate 2008-2012), while there were between 59.8 and 72.1 cases of persons subject to OC per 100 000 population over 18 on 1. January each year during the same period (prevalence rate). The prevalence rate increased in the first three years of the study, but declined during the final two years. In 2012, the prevalence rate was similar to that estimated for the whole country in 2013. Of the patients included in the study, 54 were placed under their first OC order in 2008 and 2009. Of these, there were twice as many males as females, and the average age was 53 years for females and 44 years for males. Thirty-nine patients had a diagnosis in the schizophrenia spectrum and all 54 were treated with neuroleptics. Most lived alone in their own house or flat and were unemployed. These patient characteristics correspond to findings in other studies of OC. The average duration of OC for first-time OC patients in 2008-2009 was 370 days (both sexes) while the median duration was 161 for women and 211 for men. Use of depot medication and having a psychiatrist responsible for the OC decision predicted longer duration. The 54 patients placed under their first OC order in 2008-2009 were studied three years before and three years after the OC order. The duration for those with first-time OC orders in 2008-2009 was longer than for those under second or subsequent OC orders in the same period. Both the number of stays in hospital and the total number of inpatient days increased in the three years after the OC order, compared with the three years before the patient began OC. However, the average number of days per admission decreased from 26 to 15 in the three years after the first OC order compared with the three years before. Only nine of the 54 patients were not hospitalised in the three-year period after their first OC order. The records show that voluntary solutions were usually not tried or discussed before OC was implemented for the first time.

**Sub-study II: *‘When coercion moves into your home’ – A qualitative study of patient experiences with outpatient commitment in Norway.***

Patients compared their everyday life under OC with their previous experiences of coercion as inpatients. In this perspective, they experienced increased freedom of action, greater stability in treatment relationships and easier access to help, in addition to being able to live

at home. Although no patients were subjected to physical coercion under OC, they talked about the negative consequences of others deciding for them, their experiences of excessive control, and their lack of real choice in their treatment. All the patients would like to leave OC if they could.

### **Sub-study III: *Community treatment orders - what are the views of decision makers?***

Decision makers viewed OC as a useful scheme to ensure control, continuity and follow-up care in the treatment of outpatients with a history of poor treatment motivation. They had varied interest in and knowledge of the patient's life situation and how the scheme affected the patient's everyday life. Varied attention and importance were devoted to patient experiences of formal and informal coercion.

### **Conclusions of the study**

The study shows that OC has a weak potential for coercion and that decision makers do not consider the scheme to be very restrictive. On the other hand, patients find OC to be very restrictive, limiting their autonomy and freedom of expression. Through the administration of medication, complying with agreements and practical and medical help in the home, everyday life must be adapted to the structures of the health care system. The positive aspects of OC highlighted by patients were generally unrelated to coercion, but showed that help was perceived as useful if they were allowed to determine what kind of help they needed and when they needed it.

The grey zone of informal compulsion that emerges from the study is problematic. Decision makers are probably less aware of this because patients tend not to mention the problem for fear of further restrictions. This probably explains why decision makers perceive OC to be less restrictive for the patient than it actually is. In considering the use of OC, it should be assessed whether the patient's life will actually improve in a coercive care framework. This requires a focus where restrictions on the patient's freedom and the associated burden must be balanced against the treatment effect. In this consideration, the patient's perspective and perceived burdens must be emphasised.

An important aim of OC is to reduce the number of inpatient stays and days, and readmissions have until now been one of the most used outcome measures to determine whether OC is a suitable form of treatment. The study shows that first-time OC patients had more hospital days in the three years after the OC order than in the three years before. While many patients find hospitalisation to be helpful when they can decide on it themselves, the opposite will apply in the case of readmission against the patient's will. There is therefore a need to distinguish between compulsory and voluntary readmission in future studies to assess the treatment effect of OC.



## Norsk sammendrag

### Studiens bakgrunn, hensikt og metode

Tvunget psykisk helsevern uten døgnopphold (TUD) innebærer at pasienten bor utenfor sykehus, men fortsatt er underlagt tvang. I henhold til psykisk helsevernloven må de samme vilkårene oppfylles for pasienter på TUD som for pasienter som tvangsinnleggelse til døgnbehandling på institusjon. Dette innebærer at pasienten må ha en alvorlig sinnslidelse, samtidig som det enten må være fare for at pasienten vil bli sykere eller representerer en fare for seg selv eller andre dersom vedkommende ikke får behandling. Dessuten må TUD fremstå som den beste løsningen etter en helhetsvurdering. Hensikten med TUD er at pasienter som ikke vil eller evner å følge opp behandling utenfor institusjon likevel skal motta behandling, eventuelt mot sin vilje. Den konkrete tvangen er begrenset til at pasienten kan hentes og bringes til behandlingspersonalet slik at behandlingskontakten opprettholdes. TUD er en forutsetning for å kunne treffe vedtak om tvangsmedisinering utenfor institusjon, dersom pasienten ikke vil motta medikamentell behandling frivillig.

Da studien ble designet var det ikke gjennomført noen forskningsprosjekt om TUD basert på norske forhold og data. Hensikten var derfor å få grunnleggende kunnskaper om ordningens omfang og praksis, og hvordan pasienter og beslutningsfattere erfarer TUD. Studien har et deskriptivt design og er gjennomført med hjelp av kvalitativ og kvantitativ metode. I studien inngår tre delstudier som gir innsikt i ulike perspektiv og fenomener ved TUD. Delstudie I er en kvantitativ retrospektiv case register studie hvor data er samlet inn fra elektronisk pasientjournal i perioden 2008-2012. Hensikten med delstudie I er å beskrive omfang og praksis i Troms og Finnmark, med et spesielt fokus på pasienter som for første gang får et vedtak om TUD. I delstudie II er pasienter på TUD intervjuet om deres opplevelse av ordningen. I delstudie III er beslutningsfattere intervjuet om deres vurderinger av ordningen og hvilke hensyn som vektlegges når de fatter beslutninger om TUD.

### Studiens resultat

#### **Delstudie I: *Patients on a first ever outpatient commitment order in Norway***

Totalt ble 345 vedtak om TUD fordelt på 286 personer identifisert i perioden 2008-2012.

Det var mellom 22.1 og 33.2 nye tilfeller av TUD per 100 000 innbygger over 18 år i studieperioden (Insidensrate 2008-2012), mens det i alt var mellom 59.8 og 72.1 per 100 000 innbygger over 18 år som var underlagt TUD per 1 januar hvert år i samme periode (Prevalensrate). Prevalensraten økte de første tre studieårene, men ble redusert i de to siste studieårene. I 2012 ligger prevalensraten nært den samme som er estimert for hele landet i 2013. Av de inkluderte pasientene var det 54 som fikk sitt aller første TUD vedtak i årene 2008 og 2009. Av disse var det dobbelt så mange menn som kvinner, og gjennomsnittsalder var 53 år for kvinner og 44 år for menn. Trettini pasienter hadde en diagnose i schizofrenispekteret og alle 54 pasientene ble behandlet med nevroleptika. De fleste bodde alene i eget hus/leilighet og var utenfor arbeidslivet. Disse pasientkarakteristika samsvarer med funn gjort i andre studier om TUD. Gjennomsnittlig varighet av TUD for pasientene med aller første TUD vedtak i 2008-2009 var henholdsvis 370 dager (begge kjønn), mens median varighet var 161 for kvinner og 211 for menn. Bruk av depotmedikasjon og at vedtaksansvarlig for TUD vedtaket var psykiater predikerte lenger varighet. De 54 pasientene som fikk sitt aller første TUD vedtak i 2008-2009 ble fulgt opp tre år før og tre år etter TUD vedtaket. Varigheten for dem med aller første TUD vedtak i 2008-2009 var lengre enn de som ble underlagt TUD i de samme årene, men hvor TUD vedtaket ikke var det aller første. Forbruk av antall døgnopphold og dager totalt på døgnopphold økte i treårsperioden etter at TUD vedtaket ble etablert, sammenlignet med de tre årene før pasienten kom på TUD. Imidlertid gikk gjennomsnitt antall døgn per innleggelse ned fra 26 dager til 15 dager i de tre årene etter første TUD vedtaket sammenlignet med de tre årene før. Ni av de 54 pasientene hadde ikke sykehusinnleggelse i tre års perioden etter deres første TUD vedtak. Journalene inneholder i liten grad informasjon om frivillige løsninger er prøvd eller diskutert før TUD etableres for første gang.

### ***Delstudie II: 'When coercion moves into your home' – A qualitative study of patient experiences with outpatient commitment in Norway***

Pasientene sammenligner sitt hverdagsliv under TUD med tidligere erfaringer de har hatt med tvang under døgnopphold. I dette perspektivet opplever pasienter økt handlingsfrihet, bedre

stabilitet i behandlingsrelasjoner og lettere tilgang til hjelp samtidig som de bor i eget hjem. Selv om ingen ble utsatt for fysisk tvang under TUD, forteller pasientene om negative konsekvenser av at andre bestemmer over dem, at de utsettes for overdrevne kontrolltiltak, og at de ikke har reelle valgmuligheter i egen behandling. Samtlige pasienter ønsket seg ut av ordningen dersom de kunne valgt.

### **Delstudie III: *Community treatment orders - what are the views of decision makers?***

Beslutningstakerne ser på TUD som en hensiktsmessig ordning som sikrer kontroll, kontinuitet og oppfølging i behandlingen for polikliniske pasienter som har en historie med sviktende behandlingsmotivasjon. Interessen for, og kunnskapen om, pasientens livssituasjon og hvordan ordningen påvirker pasientenes dagligliv er varierende. Pasientens opplevelse av både formell og uformell tvang ble viet varierende oppmerksomhet og tillagt ulik vekt.

### **Studiens konklusjoner**

Studien viser at TUD formelt har et begrenset tvangspotensiale, og beslutningsfatterne anser ordningen som lite inngripende. Pasientene opplever på sin side TUD som svært inngripende, da de opplever at deres autonomi og ytringsfrihet innskrenkes. Gjennom administrering av medisiner, oppfølging av polikliniske avtaler, hjemmehjelp og oppfølging i hjemmet må hverdagslivet tilpasses helsevesenets strukturer. De positive sidene som pasientene trekker frem med TUD har lite med tvang å gjøre, men viser at hjelp oppleves nyttig dersom de selv får lov å bestemme både når og hvilken form for hjelp de trenger.

Den uformelle gråsonetvangen som kommer frem i studien er problematisk.

Beslutningsfatterne er trolig i mindre grad klar over denne fordi pasientene underkommuniserer belastningen, i frykt for ytterligere innskrenkninger. Dette gjør at det trolig oppstår en forståelse blant beslutningsfatterne om at TUD er mindre inngripende for pasienten enn hva som egentlig er tilfelle. Når bruken av TUD kan være aktuelt bør det vurderes om pasienten faktisk får et bedre liv ved at det etableres en tvangsramme for oppfølgingen. Dette forutsetter et fokus der innskrenkning av pasientens frihet og autonomi

må balanseres mot behandlingseffekten. I denne avveiningen må pasientens perspektiv og opplevelse av hva som faktisk oppleves som belastende vektlegges.

I norsk kontekst har TUD et mål om å redusere antall døgnopphold og totalt antall døgn under døgnomsorg, og reinnleggelser har til nå vært et av de mest brukte effektmålet for å validere om TUD er en egnet behandlingsform. Studien viser at pasientene som var under TUD for første gang hadde flere døgn i institusjon tre år etter index TUD, enn tre år før TUD ble etablert. Mens mange pasienter opplever innleggelse til døgnbehandling som god hjelp når de selv får bestemme, vil det motsatte gjelde for reinnleggelser mot pasientens ønske og vilje. Det er derfor behov for å skille mellom tvunget og frivillig reinnleggelse i fremtidige studier når behandlingseffekten av TUD skal vurderes.

## Original papers

- I** Riley H, Straume B, Høyer G. Patients on a first ever outpatient commitment order in Norway. Submitted to BMC Psychiatry 14 June 2016.
- II** Riley H, Høyer G, Lorem GF. (2014). “When coercion moves into your home” – A qualitative study of patient experiences with outpatient commitment in Norway. *Health and Social Care in the Community*, 22, 506-14.
- III** Riley H, Lorem GF, Høyer G. (2016). Community treatment orders - what are the views of decision makers? *Journal of Mental Health*.

DOI: 10.1080/09638237.2016.1207230.

# 1. Introduction

Outpatient commitment (OC) is a scheme whereby mental health patients are subject to coercion outside a hospital. The study presented in this thesis is part of a national multicentre study of OC in Norway, coordinated by Tvangsforsk, the Norwegian Research Network on Coercion in Mental Health Care. The present study is limited to data collected in Troms and Finnmark, and the thesis describes the extent and practice of the scheme, in addition to the experiences of patients and decision makers<sup>1</sup> with OC in the two counties. The study consists of three sub-studies, of which one is quantitative and two are qualitative:

Sub-study I was a quantitative retrospective case register study, in which data was collected from electronic medical records with the aim of describing practices in Troms and Finnmark, with a particular focus on patients under OC for the first time.

Sub-study II was a qualitative study where patients were interviewed about their experiences of OC.

Sub-study III was a qualitative study where decision makers were interviewed about how they weigh up various considerations in their OC decisions.

The three data sources provide insights and describe different perspectives of OC. All data were collected in 2011-2013. Interviews with patients and decision makers were conducted in parallel; the patient was interviewed first, followed by the patient's decision maker, then a new patient followed by that patient's decision maker, until all interviews were completed. Data for the case register study were collected in parallel with the interviews. After all data had been collected, each sub-study was analysed separately: first the patient interviews, then the decision maker interviews and finally the patient record study.

---

<sup>1</sup> The term "decision-makers" is used in this thesis as a collective term for psychiatrists and psychologists specialising in clinical adult psychology and at least two years' relevant practice experience, who according to the Mental Health Act may have formal responsibility for decisions on OC. See also Chapter 1.2.2.



Before the sub-studies are discussed in more detail, it is pertinent to present relevant background information on OC. The focus will mainly be on the emergence and practice of the Norwegian OC scheme, but also on international research relevant to the study. Chapters 2-4 discuss the purpose, methodology and ethical aspects of the study, while Chapters 5-7 present results and discussion of the methodology and the study findings. Presentations and descriptions of OC in the thesis are limited to Norwegian regulations and practices, unless mentioned otherwise.

## **1.1 Coercion in mental health care**

The use of coercion is common in the treatment of people with mental disorders in Norway (Høyser, 2011). In 2014, about 5600 patients were compulsorily hospitalised a total of around 8000 times (Norwegian Directorate of Health, 2016). Coercion is difficult to define, and can vary from the specific use of physical force which is easy to observe to more covert forms of coercion such as having to comply with various rules or the will of others (Wertheimer, 1993; Nytingnes & Husum, 2011). In addition, there are unclear boundaries between what may be considered as coercion, threats, pressure, persuasion and advice, which creates further problems in defining the concept. The subjective experience of coercion varies, but the violation of personal integrity and autonomy is usually closely linked to coercion, and Beauchamp and Childress (2009) state that coercion is often the outer limit of autonomy. Dilemmas arise when patients are unable to look after themselves and refuse help.

Legal use of coercion in mental health care for adults is regulated by the Act on the Establishment and Implementation of Mental Health Care (the Mental Health Act) of 2 July 1999. Coercion covers different areas and can be described from various perspectives. The Official Norwegian Report NOU 2011:9, p.86 distinguishes between three categories of coercion: 1) *formal coercion*, which refers to events or actions involving decisions on the use of coercion under the Mental Health Act, 2) *perceived coercion*, which refers to patients' own perceptions that they are subjected to coercion in mental health care, and 3) *specific coercion*, which is coercion actually used on a patient. This study concerns all these three forms of coercion.

## **1.2 Coercive outpatient mental health care (OC)**

### **1.2.1 History**

Since the introduction of the Mental Health Act of 28 April 1961, it has been possible to use coercion on patients who were discharged to what the Act described as “compulsory aftercare”. Until the 1950s, the focus in psychiatry was on long-term care in an institution, and psychiatric hospitals were under considerable pressure with an average of 25% patient overcapacity (Pedersen, 2002, p. 190). The need for more beds was considered the main problem in psychiatric care (Ministry of Social Affairs, 1955, pp. 5 and 65), while the 1950s were characterised by an increasing number of discharged patients (Pedersen, 2002, pp. 190-191). When patients were discharged from hospital, the mental health care ceased. It soon became apparent that many of the former patients were readmitted; in 1950, 1253 previously discharged patients were readmitted and as many as 625 of these were discharged in 1949 or 1950, while 1571 patients were admitted to a psychiatric hospital for the first time in the same year (Ministry of Social Affairs, 1955, p. 65). This period was also marked by treatment optimism due to the introduction of antipsychotic drugs such as chlorpromazine in 1954 (Høyer, 1986, p. 21; NOU 1988:8, p. 62).

Conditions in psychiatric hospitals began to be publicly debated, and in 1951 a committee was appointed to revise the law in force at the time, the Insanity Act of 1848 (Pedersen, 2002, p. 190). The committee delivered its report on 31 May 1955, and the result was a new law that came into force on 28 April 1961. The new law introduced outpatient services, day care centres and aftercare homes as a supplement to the institutions (Pedersen, 2002, p. 190). At the same time “compulsory aftercare” was authorized by the new law. These new elements aimed to provide psychiatric follow-up care where the patient lived and the scheme meant that patients could be discharged earlier and many readmissions were avoided. Relapses could also be detected at an early stage to enable treatment to be provided when the prospects for improvement were considered to be optimal. The way the aftercare was organised led to the scheme being described as an economically viable form of treatment. The committee’s report portrayed compulsory aftercare as a benefit which would provide support and care to patients and their families during the challenging period after hospitalisation (Ministry of

Social Affairs, 1955, p. 65). The scheme was a stage of a return to an independent life and employment, often after a long illness.

Under the Mental Health Act of 28 April 1961, decisions on compulsory aftercare were to be taken by a doctor at the patient's hospital, who was also responsible for the aftercare. The person was still formally a patient of the hospital, even though in practice he/she did not stay there. Coercive interventions were limited to readmission of the patient, if necessary with the use of force, without any new formalities (Mental Health Act of 28 April 1961). There was a perception that no other authority was needed to use coercion in treatment than that provided for in compulsory aftercare. However, in 1984 came regulations for compulsory medical treatment, which required a separate decision for the use of medication against the patient's will in compulsory psychiatric care (NOU 1988:8, pp. 62-63).

In the committee's report that resulted in the Mental Health Act of 28 April 1961, concern was expressed about the possible intrusion and restriction of the patient's freedom and autonomy in aftercare (Ministry of Social Affairs, 1955, p. 67). To ensure the patient's legal protection, the so-called Control Commission<sup>2</sup> was given responsibility for supervision of patients in compulsory aftercare and the doctor in charge had to apply to the Control Commission for an extension for the aftercare to last longer than one year (ibid., p. 114). Patients and their relatives could also appeal against the decision on compulsory aftercare to the Control Commission.

The year 1981 saw an initiative to revise the Mental Health Act, with a mandate to examine how patients' legal rights could be enhanced (NOU 1988:8, p. 9). The subsequent report raised questions about the difficulty of control in coercive treatment of outpatients and the fact that patients' fear of coercion might make them reluctant to seek help. But these challenges were not considered important enough, relative to the arguments for the use of compulsory aftercare. The committee argued that the use of compulsory aftercare was an

---

<sup>2</sup> The Control Commission was introduced under the Act of 17 August 1848 concerning the "treatment and care of lunatics" (the Insanity Act, 1848) (Høyer, 2016). Its task is to ensure the legal rights of people in contact with mental health services, and ensure that the law is applied as intended.

important factor to limit treatment in institutions where possible, because long inpatient stays could lead to passivity and have adverse effects. To treat patients as far as possible in their local community was also an argument for this form of compulsory care. From the introduction of compulsory aftercare in 1961 until the current law came into force in 1999 (the Mental Health Act of 7 February 1999), the system of compulsory aftercare remained unchanged.

In the current legislation which came into force in 2001 (the Mental Health Act of 7 February 1999), the term “compulsory aftercare” was replaced with “coercive outpatient mental health care”, here translated as “outpatient commitment” (OC). The new law made it clear that OC was to be a more appropriate option than compulsory hospitalisation. The Ministry emphasised the importance of flexibility and continuity of treatment, while “maintaining the possibility to address the patient’s needs with less restrictive measures” (Ministry of Health and Care Services, 1998, p. 73). In the preparatory work on the new Mental Health Act, the possibilities of coercive interventions for OC patients were proposed to be expanded in two areas, and these proposals were among the most controversial in the consultation round. The most controversial proposal was to allow coercive treatment to take place in the patient’s home. This proposal met with massive resistance and was not included in the Act. The second one was that the requirement of prior compulsory hospitalisation before OC, as in the 1961 Act, should no longer apply. This was because it was considered unreasonable to require prior hospitalisation, since individual patient needs vary. Although many in the consultation round felt this to be a significant expansion of the use of coercion, the proposal was approved (Ministry of Health and Care Services, 1998, Section 7.1.4.1). There were also criticisms of the OC scheme during the consultation process for being too tempting to use because it does not include any requirements for quality in follow-up care (ibid.).

The regulations for OC were further amended in 2006 (Ministry of Health and Care Services, 2006, pp. 65-67). The requirement for patients to have their own home would no longer apply. In practice, this meant that patients could stay in institutions that were not under the responsibility of the specialized psychiatric services and did not need to have a home. Although the requirement for patients to live in their own home was removed, there is still a requirement that a patient must have a place to live before OC can be implemented (Ministry

of Health and Care Services, 2006, p. 66) without any clear definition of a place to live. Another amendment was a clarification that strengthened the position of the family members in the patient's household, where it was stated that they must be informed and consulted before an OC decision is made. Apart from the changes mentioned in 2006 and 1999, OC has largely remained unaltered since its introduction in 1961.

### **1.2.2 Legal basis for OC**

In the Mental Health Act of 7 February 1999, coercion is more clearly described and defined than in the Mental Health Act of 28 April 1961. This also applies to the provisions on OC. The legal basis for using OC is regulated in Sections 3 and 4 of the Mental Health Act of 7 February 1999, and the accompanying regulations (Mental Health Regulations of 16 December 2011). These provisions are intended to ensure that OC is implemented in a responsible manner and is only used when it is the best form of care for the patient concerned. A decision on OC may only be made by a psychiatrist or psychologist specialised in clinical adult psychology with at least two years' relevant practice experience, cf. the Mental Health Act of 7 February 1999, § 1-4, and the Mental Health Regulations of 16 December 2011. In this thesis and actual papers, these are referred to as decision makers. Decision makers must work in a facility approved for the use of coercion in mental health care, cf. the Mental Health Act of 7 February 1999, § 3-5 and 3-10.

There must be a comprehensive assessment as to whether OC is the best solution in each case, and this assessment should take into account the wishes of the patient and the patient's relatives before OC is commenced (Mental Health Regulations of 16 December 2011). The patient must meet the same criteria as for compulsory admission to hospital, cf. the Mental Health Act of 7 February 1999, § 3-3. This means that the patient must have a serious mental disorder<sup>3</sup>, with either a risk that the condition will deteriorate or that the patient will represent a danger to him/herself or others without treatment. In addition, the patient must have a

---

<sup>3</sup> A mental disorder is generally understood as synonymous with psychosis or other severe mental illness with a comparable level of functional impairment.

known medical history to ensure that the decision maker has experience with the treatment the patient needs. Before OC is commenced, voluntary treatment must have been tried unless it is clearly pointless.

OC decisions are made under the Mental Health Act of 7 February 1999, § 3-3. The decision is in principle valid for one year, but there must be controls at least every three months to assess the situation, cf. the Mental Health Act of 7 February 1999, § 4-9. OC may be extended upon application to the Control Commission, which may grant an extension of one year at a time. There is no limit on the number of extensions for the same patient. Checks must still be carried out at least every three months during any extension.

An OC decision itself may only include an order to attend appointments with therapists, which usually involve talk therapy, medication or milieu therapeutic measures aimed at restoring or maintaining the patient's level of functioning (Ministry of Health and Care Services, 1998, Section 7.1.5.3). The legal physical coercion allowed for in OC is limited to bringing the patient back to hospital, either because his/her condition has considerably worsened or because the patient does not comply with orders on medication and contact with the therapists. If necessary, the patient may be brought back with the help of the police (Mental Health Regulations of 16 December 2011, § 34).

If the patient refuses medication treatment, a separate decision on treatment without consent must be made, cf. the Mental Health Act of 7 February 1999, § 4-4. A treatment decision can only be implemented with drugs used for the treatment of serious mental disorders registered in Norway in regularly used doses, and the effect should clearly outweigh the disadvantages of any side effects. Only psychiatrists may make a decision on coercive treatment. If a specialist psychologist is responsible for the OC decision, there must also be a psychiatrist responsible for the involuntary treatment decision. A treatment decision is valid for three months and may be appealed to the county governor by the patient or the patient's relatives.

### **1.2.3 Lack of official data on the practice of OC**

The Norwegian health authorities have little information on the use of coercion in mental health care, and particularly poor data for OC (Ministry of Health and Social Affairs, 2006, p.



10; NOU 2011:9, p. 93). There is no reliable data on the extent of OC under the current or the previous Act. Under current legislation, there are only a few reports on the use of OC in Norway by SINTEF Health Research (Bremnes, Hatling & Bjørngaard, 2008; Pedersen, Hatling & Bjørngaard, 2004) the Norwegian Board of Health Supervision (Helsetilsynet, 2006) and in recent annual reports from the Norwegian Directorate of Health. The reports contain estimates of the extent of OC, but these estimates are uncertain because the data are incomplete and of poor quality. The poor data quality can probably be attributed to several factors, including the quality of the reporting of activity data by the health services to the Norwegian Patient Register (NPR), on which the estimates in the report are based. An estimate based on figures from 2009 shows that 5084 people were hospitalised involuntarily, and that about 1 in 3 of these (1695 people) were discharged with an OC order (Norwegian Directorate of Health, 2010, p. 21). The next estimate was made in 2013, showing that 2364<sup>4</sup> people had an OC decision (Norwegian Directorate of Health, 2014, p. 12), which corresponds to a nationwide prevalence of 61.1 people per 100 000 population over 18 years. The latest estimate is from 2014, when 2422 people were subject to OC, but this figure is not adjusted for inadequate reporting, as the figures from 2013 were (Norwegian Directorate of Health, 2016, p.32). How long patients are on OC, how many OC decisions are made per patient, and how often OC is commenced in an outpatient-clinic setting, are all unknown factors. We also have no knowledge of how often coercive treatment decisions are made in connection with OC.

Since there is little detailed information on OC, it is difficult to know for certain who the OC patients are, but some particular characteristics of the group as a whole have been described. There are more men than women, they tend to be about 30-49 years of age, and the dominant diagnosis is schizophrenia (86%) (Pedersen, Hatling & Bjørngaard, 2004). These patient characteristics match the descriptions of OC patients from the 2013 estimate (Norwegian Directorate of Health, 2014, pp. 21-22), and also the patient material included in the present

---

<sup>4</sup> Conversation with Ragnhild Bremnes on 15.05.15. Bremnes, who is the first author of the report “The Use of Coercion in Mental Health Care for Adults in 2013” said that the figure of 2364 persons was calculated from the reported patients where a new OC decision or an extension was indicated. These were adjusted for patients subject to OC decisions in 2012 and the patients’ ID numbers.

studies.

#### **1.2.4 Ideology, purpose and practices**

OC is referred to as a less restrictive treatment option than compulsory hospitalisation (NOU 2011:9, pp. 92-93), and its purpose is to maintain or improve the patient's functioning. This understanding is based on an ideology that treatment and rehabilitation without patient consent should be given as the least intrusive option, but ensures that the patient receives what is considered to be necessary healthcare and treatment. OC is regarded as a less restrictive alternative because the coercion is limited to attending treatment appointments, and does not involve deprivation of liberty by keeping the patient in a hospital, away from everyday life and ordinary movement and freedom of action (NOU 2011:9, pp. 92-93). Patients are to receive the treatment and care necessary for their particular mental disorder. Apart from bringing patients back to hospital against their will if they do not attend treatment sessions, OC may only include measures that can be implemented without physical coercion (Mental Health Regulations of 16 December 2011).

In clinical practice, OC has two main consequences (Hatling, 2013, p. 263): 1. OC means that the patient can more easily be compulsorily (re-)hospitalised because there is no requirement for a new formal clinical assessment by an independent doctor. 2. OC is required when patients are to receive forced medication<sup>5</sup> outside a hospital setting. For patients, this means in practice that they receive compulsory outpatient treatment, medication and monitoring that they partially or completely do not want. Clinical experience shows that the scheme is usually initiated to ensure medication for patients who have been compulsorily hospitalised with a history of fluctuating treatment motivation (NOU 2011:9, p. 93). It is reasonable to assume that a large proportion of OC patients either have a decision on treatment without consent, or that they take medication "voluntarily" because they consider that they would otherwise be

---

<sup>5</sup> If the patient actively refuses medication, a separate compulsory treatment decision must also be made, cf. the Mental Health Act, § 4-4. This is elaborated in the last paragraph of Chapter 1.2.2.

subject to coercive treatment in addition to the OC order (ibid.). Ideally, OC should only maintain health care and ensure that the patient cooperates with the OC framework:

*“This form of coercion (OC) is thus intended for patients who do not need to be kept in a hospital, but who would have a better life with an order to attend treatment appointments. This scheme should not be used if there is a frequent need to use coercion to bring the patient for treatment. The assumption is therefore that the patient will comply with the order to attend for treatment.”* (Ministry of Health and Care Services, 2006, p. 66)

In other words, OC is aimed at patients who adapt and comply with its framework.

The specialist health services are responsible for patients on OC, but the primary health care are responsible for providing general public health care and contributing to the implementation of the treatment involved in OC (Mental Health Regulations of 16 December 2011). There is thus often a need for primary health care to be involved in the monitoring of OC patients to ensure that the scheme is being implemented as intended. Although the legislation stipulates collaboration between specialist and primary health care levels in accordance with individual plans, there are no guidelines for an everyday practical division of responsibility, and how interventions and care should be organised when the patient is still formally under specialist care, but living at home. At a time when health authorities are promoting decentralised services, with a decreased focus on inpatient mental health care (NOU 2011:9, p. 93), it may be assumed that OC will become a more relevant form of treatment in the future.

### **1.3 International perspectives on OC**

Various forms of outpatient commitment have been introduced in over 75 Western jurisdictions (Rugkåsa, 2016) for different reasons and with varying mandates regarding coercive interventions (Dawson, 2005; Churchill et al., 2007). Norway is not included in these reports, but as we have seen, Norway was one of the first countries to have a scheme resembling OC with the introduction of “compulsory aftercare” in 1961. The literature states that the first jurisdictions to introduce OC were the USA and Australia in the 1980s

(Churchill et al., 2007), followed somewhat later by New Zealand in the early 1990s (Dawson, 2005) and Canada from the mid-1990s (Gray & Orilet, 2005). Apart from Norway, and Israel who introduced OC in 1991 (Ajzenstadt et al., 2001), most European countries have introduced the scheme much more recently. First was Scotland in 2005 (Churchill et al., 2007), followed by Sweden and England and Wales in 2008 (Lag om psykiatrisk tvångsvård, 20 June 1991; Canvin et al., 2014), and Denmark in 2010 (Lov om anvendelse af tvang i psykiatrien, 2 December 2010).

Early research on OC is largely from the USA (Dawson, 2005), but as more jurisdictions have introduced the scheme, research articles from other countries have increased. A brief description follows of how international literature has dealt with the following topics relevant to the thesis: different practices in different jurisdictions, effects of OC and patients' and clinicians' experiences of OC. The research publications mentioned are mainly from the last ten years.

### **1.3.1 Different practices**

Reference is often made to two main forms of coercive psychiatric care for outpatients. The first is when the scheme is practised as a *less restrictive treatment option*, where the criteria for OC are the same as for compulsory hospitalisation, and the purpose is to treat an already existing disorder. In this case, the scheme could potentially be used for all patients who meet the conditions for compulsory hospitalisation (Churchill et al., 2007). An example of this form of OC is described by Scheid-Cook (1993) as the type of OC introduced in the first US states. The scheme is described as a political compromise to meet new treatment requirements and a variety of social and organisational demands that followed deinstitutionalisation in the 1980s, together with the principle of the least restrictive option for the patient. The second form involves the use of OC *to protect society*. In this approach, OC is more often used for patients who are considered as potentially dangerous (Churchill et al., 2007). In 1991, New York State introduced Kendra's Law after the young girl Kendra Webdale died from being pushed in front of a train by a man with untreated schizophrenia (Player, 2015). Kendra's Law is an example of an OC scheme primarily aimed at preventing dangerousness (Swartz et al., 2009). Most jurisdictions outside the USA use an approach

where the justification for OC is both to provide a less restrictive alternative and to protect society (Churchill et al., 2007).

In all jurisdictions, OC allows for measures to force the patient to attend outpatient treatment sessions (Churchill et al., 2007). However, what OC may involve, its coercive potential, and how it is practised vary between jurisdictions. The question of how restrictive the scheme is particularly a matter of whether it allows coercive treatment (Høyer & Ferris, 2001). For example, Australia permits the use of forced medication in OC, while several US states do not (Kisely & Campbell, 2014). In some jurisdictions, the decision to implement OC is rooted in clinical practice and involving a decision maker, while in others, a legal decision is required. There is a time limit to OC in some jurisdictions, while in others the OC decision may in practice be valid indefinitely (Churchill et al., 2007). In most jurisdictions, OC is only used after compulsory hospitalisation (Rugkåsa, 2011).

Despite differences in legislation, culture and health care practices, Churchill and colleagues (2007) found that OC is largely used with the same group of patients. They are more often men, about 40 years old on average, have a long history of mental disorder and a schizophrenia diagnosis with much hospitalisation and poor medication compliance, and they are often considered to be potentially dangerous. These patient characteristics have also been identified in recent studies from different jurisdictions (Burns et al., 2013; Kisely et al., 2014; Kisely et al., 2013; Lera-Calatayud 2014).

### **1.3.2 Is OC a suitable form of treatment for people with severe mental disorders?**

The international debate is dominated by the question of whether OC is a suitable treatment for adults with severe mental illness. The usual outcome measures used are the number of readmissions, hospital days and use of community health services (Rugkåsa, 2016).

Randomised controlled trials (RCTs) are considered the best way to measure the effect of treatment or other interventions (ibid.). Until now, three RCTs on the effect of OC have been published: two older studies from the USA (Swartz et al., 1999; Steadman et al., 2001) and the OCTET study involving 336 patients from England and Wales (Burns et al., 2013). The OCTET study found no reduction in readmissions, hospital days, global clinical outcomes (as

assessed by the Brief Psychiatric Rating Scale or the Global Assessment of Functioning) or in a number of other clinical and social outcomes (Burns et al., 2013; Rugkåsa et al., 2015). In the OCTET study, the follow-up was primarily 12 months (Burns et al., 2013), but a new follow-up study after an additional two years has shown that TUD is ineffective (Burns et al., 2015). The OCTET study confirmed the results from the first two RCTs from the USA (Swartz et al., 1999; Steadman et al., 2001). None of the RCTs have thus found evidence to back up the most common arguments used to justify OC. There is also no evidence that OC reduces the risk of serious violence (Szmukler, 2015).

Two systematic reviews of OC have been published, the most comprehensive of which was by Churchill and colleagues (2007), dealing with literature published prior to 2006. The other review is by Maughan and colleagues (2014) and includes studies from 2006 to 2013. Kisely and Campbell have also performed a Cochrane review, most recently updated in 2014, and meta-analyses have been conducted which were last updated in 2014 (Kisely & Hall, 2014). These studies also show no evidence that OC is effective in terms of consumption of health care, and Maughan and colleagues (2014) conclude that there is robust evidence that OC has no significant effect on hospitalisation or other service use outcomes.

Study design and methodological challenges in seeking to determine whether OC works are a recurrent theme. The RCTs have been criticised for their choice of design, such as the OCTET study for not comparing OC with voluntary treatment (Swanson & Swartz, 2014) and also for too few study participants in relation to the actual number of patients on OC (Szmukler, 2015). The variety of criteria for OC in the different jurisdictions means that the studies must also be seen in this light when considering generalisability.

We find a distinction between those who now believe that there is sufficient evidence that OC is ineffective and those who believe that further research is needed to draw any conclusion because of the lack of clarity in the findings (Swanson & Swartz, 2014). Advocates of OC believe that the scheme provides access to necessary care with fewer restrictions than hospital treatment, and allows the patient to be discharged earlier and receive health care in the local community (*ibid*). Opponents of OC think that it allows excessive intrusion in the patient's life, and this criticism is especially aimed at those jurisdictions where social prevention is the primary basis for OC (Swanson & Swartz 2014; Geller, 2006). The authors of OCTET found

no evidence to justify the restriction of patients' freedom with OC (Burns et al., 2013). Patients' legal protection has also been examined, and Zettberg and colleagues (2014) criticised OC in this area, finding that patients are at risk of being exposed to new kinds of coercion of an unclear nature. Between these views, there are those who are more uncertain and want clearer answers about whether OC works (Swanson & Swartz 2014). Based on current knowledge of different OC schemes, there is reason to assert that the benefits and disadvantages for patients are still unclear. As of today, there are no grounds to maintain that OC can be considered as evidence-based practice (Sjøstrøm, 2012).

### **1.3.3 Patients' and decision makers' experiences of OC**

Despite the lack of evidence of the effectiveness of OC, studies of the experiences of the various people involved portray the scheme in a more positive light (Stroud, Banks & Doughty, 2015).

Studies of the experiences and opinions of patients and clinicians have found that these groups have divergent views of OC, and that these differing viewpoints are found across jurisdictions (Rugkåsa, 2016). Clinicians often see OC as a desirable treatment option and emphasise that it helps to maintain structure and continuity of treatment after discharge from hospital (O'Reilly et al., 2006; Romans et al., 2004; Swartz et al., 2003; Manning et al., 2011). The essential purpose is often to ensure that medication treatment is maintained (Canvin et al., 2014), and OC is used for patients with a known history of poor treatment compliance, which affects their condition (O'Reilly, Dawson & Burns, 2012). In general, studies show that clinicians emphasise the positive aspects of OC (Canvin et al., 2014; Stroud, Banks & Doughty, 2015), and if they at all find OC problematic, this is connected to its possible negative influence on the therapeutic alliance (Romans et al., 2004; Stensrud et al., 2016) and the challenge of knowing the right time to terminate OC (Mullen, Dawson and Gibbs, 2006).

In studies of patients' experience, the theme is often how they view OC in general (Sjøstrøm, 2012). The usual picture is more negative than that of clinicians, but patients are often ambivalent, because parts of the scheme are perceived as helpful. The positive aspects

often cited are that OC gives them more involvement, more choice and more responsibility (Gibbs, 2010; Canvin, Bartlett & Pinfold, 2002; O'Reilly et al., 2006; Gibbs et al., 2005). It has also been shown that patients associate OC with better access to various health services and better social welfare benefits (Canvin, in press; Canvin, Bartlett & Pinfold, 2005; Schwartz et al., 2010; O'Reilly et al., 2006). Patients often compare OC to hospitalisation; they therefore prefer OC (Swartz et al., 2003) and comply with the requirements of the scheme (Sjøstrøm, 2012). Churchill and colleagues (2007) question whether the positive aspects highlighted by patients may be attributable to the improved and better adapted follow-up care they receive when on OC. Negative aspects mentioned by patients are that OC lasts too long (Gibbs et al., 2005) and that it restricts their autonomy and control over their lives (Ridley & Hunter, 2013). Existing literature on patients' perceptions of coercion in OC is largely centered on comparisons with coercion during hospitalisation, and the various possible consequences of outpatient coercion for self-determination, normal life, care, supervision and the recovery process (Canvin, in press; Rugkåsa, 2016).

#### **1.3.4 Transferability to the Norwegian OC scheme**

Foreign studies have limited relevance to the Norwegian situation. Health care is structured differently in different countries/jurisdictions, and cultural differences lead to different practices. Legislation on mental health care in general and on coercion in particular differs greatly between jurisdictions, in terms of both preconditions for OC (O'Brien & Farrell, 2005) and the degree of coercive powers. The transferability of international research to the Norwegian OC scheme must be considered in light of these reservations.



## **2 Purpose of the study**

When the study was designed, there was no research on OC based on Norwegian data. Basic knowledge of OC was therefore a stated priority area for research into the use of coercion in Norway, according to both the Ministry of Health and Social Affairs (2006, Chapter 4) and Tvangsforsk (Norwegian Research Network on Coercion in Mental Health Care, 2009, p. 11). The greatest priorities were descriptive studies to provide knowledge of basic features of OC, such as extent, duration and treatment content, and also studies of the experiences of those involved.

The overall purpose of the present study is to gain knowledge of the extent and practice of OC, and how it is experienced by patients and decision makers in Northern Norway. To achieve this, it was decided to conduct one quantitative and two qualitative sub-studies. The structure of the study is shown in Figure 1.

### **Sub-study I: *Patients on a first ever outpatient commitment order in Norway***

The purpose of the study was to:

- a) ascertain the number of new OC orders per year (incidence) and the number of people on OC at any given time (prevalence) in Troms and Finnmark
- b) gain knowledge of patients on their first ever OC: who they are, reasons for the OC decision, duration of OC, and hospitalisation in the three years before and three years after their first OC order.

### **Sub-study II: *“When coercion moves into your home” - A qualitative study of patient experiences with Outpatient Commitment in Norway***

The purpose of the study was to:

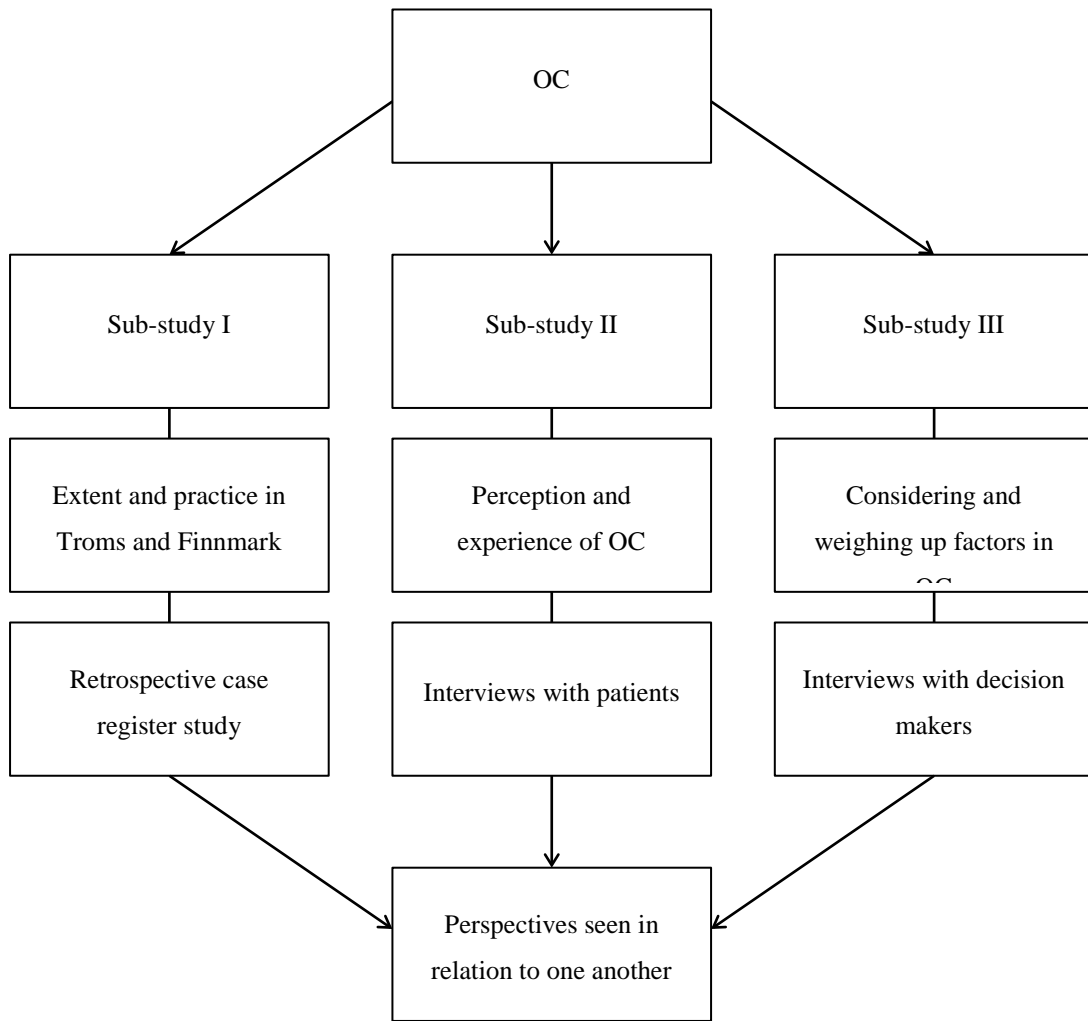
- a) explore patients' overall experience with OC
- b) examine how patients feel that OC affects their everyday life

- c) examine how patients experience the coercive framework involved in OC

**Sub-study III: *Community treatment orders - what are the views of decision makers?***

The purpose of the study was to:

- a) explore how decision makers consider and weigh up various factors when making decisions on OC.
- b) examine how decision makers view the role and importance of coercion for OC patients.



**Figure 1** Structure of the study

### 3 Methodology

This chapter first gives a brief description of the catchment area and the general context of the study, followed by separate accounts of the three sub-studies, descriptions of the mapping and use of relevant research literature, and finally ethical considerations.

#### 3.1 The catchment area

The study was conducted at the University Hospital of North Norway (UNN) and is based on data from patients in the two northernmost counties in Norway, Troms and Finnmark. Troms and Finnmark contain 43 local authorities, with a total population of 240 088<sup>6</sup> people. UNN is formally responsible for all use of coercion in mental health care in the two counties<sup>7</sup>, organised under various sections/departments in Tromsø. This means that all clinicians formally responsible for OC decisions work in Tromsø. In addition to mental health beds in Tromsø, there are various specialist health services offered by local District Psychiatric Centres (DPCs) in both counties.

Primary mental health care have everyday responsibility for the monitoring and follow-up care of a large proportion of OC patients. Troms and Finnmark are large counties, with a total area of 74 485 km<sup>2</sup> and often long distances between patients and health care providers, as well as a varied and challenging climate<sup>8</sup>. The population of the local authority areas ranges from about 1000 inhabitants to 73 000 in the largest, Tromsø. The care received by patients

---

<sup>6</sup> Troms: 163 330, Finnmark: 75 758, Statistics Norway: Population Statistics (1 January 2016), available from <https://ssb.no/befolkning/statistikker/folkemengde/aar-per-1-januar/2016-02-19?fane=tabell&sort=nummer&tabell=256001>

<sup>7</sup> Finnmark has its own health trust, Finnmark Hospital, but the Mental Health and Substance Use Clinic is not approved for the use of coercion under the Mental Health Act. The University Hospital of North Norway is therefore legally responsible for any use of coercion in Finnmark, and also serves as the central hospital for mental health services for Finnmark.

<sup>8</sup> It may be up to 800 kilometres with partly bad roads and unpredictable weather much of the year from the patient's home to the hospital responsible for the OC decision in Tromsø.

during OC will depend on the services and opportunities that exist where they live.

### **3.2 Context of the study**

In order to answer the research question, various perspectives of OC were explored: one study examined the extent and practice of OC (Sub-study I), one study dealt with patient experiences of OC (Sub-study II), and one study looked at the considerations of decision makers in making OC decisions (Sub-study III). The use of different perspectives on the same topic allows for different research foci, and is called a multilevel design (Edmonds & Kennedy, 2013). Such a design may include different methodological approaches within qualitative and quantitative traditions, with the aim of achieving an overall understanding through the findings of the different approaches. Data was first collected, analysed, and results prepared from each individual study, and finally the studies are brought together to achieve a common interpretation (Tashakkori & Teddlie, 2002). This is an eclectic form of meaning generation, and none of the sub-studies have epistemological primacy (Kvale & Brinkmann, 2009). Data collection in the sub-studies was performed in the same period, from 2011 to 2013.

#### **Sub-study I**

The aim of Sub-study I was to provide basic knowledge of how OC is practised in the catchment area, using a quantitative retrospective case register study. Such descriptive studies are often used as the initial tentative approach to researching a new phenomenon, and in clinical settings to create descriptive reports which may then generate hypotheses (Grimes & Schulz, 2002). The study started by collecting information on each patient, which was then combined and analysed to look for common features and differences (Bhopal, 2002; Grimes & Schulz, 2002). All data was collected from the DIPS patient electronic health records (hereafter referred to solely as DIPS).

#### **Sub-study II**

In order to ascertain how OC is perceived and how it affects everyday life, patients need to be asked about their experiences. We chose a narrative approach because narratives allow for enhanced understanding of social phenomena (Riessman, 2008; Frank, 2010; Georgakopoulou, 2006), and are suitable for generating knowledge of how people create identity and meaning, and how they organise and relate to past experiences (Raffard et al., 2010). Each participant has his/her unique history and the purpose is to reveal different experiences and opinions regarding how patients experience everyday life under an OC order. The use of narrative interviews aims to generate detailed descriptions instead of superficial and general statements (Riessman, 2008). The focus in the text analysis may vary (ibid.), but in order to highlight the patients' stories and opinions, the analysis focuses on what the participants relate. The stories are not only analysed with the aim of presenting personal aspects of the stories, but also with an eye for consistent similarities between the patients' experiences, with the intention of generating descriptive knowledge.

### **Sub-study III**

Here, the purpose was to gain insight into how decision makers consider and weigh up various factors when making OC decisions, and both the interviews and analysis therefore focused on the participants' interpretations and reflections on the reasons for the scheme. The data material has a completely different character than the patient stories, which are personal narratives. The data from the interviews with decision makers includes many events, but demonstrates greater analytical distance in that the decision makers talk about their interpretations and considerations and how these are grounded in clinical practice. We chose a methodological approach described by Kvale and Brinkmann (2009), which differs from the narrative approach applied to the patient experiences, where the experiential horizon is the key aspect. Although there are differences in approach, the research interest in the interviews with decision makers also lies in understanding a social phenomenon (OC decisions) from the perspective of the actor (how decision makers consider this), in seeking to understand and describe the way the world is perceived by the participants.

### **3.3 Sub-study I: A quantitative retrospective case register study of OC**

#### **3.3.1 Participants**

Sub-Study I consists of two parts, A and B. Part A is population-based and includes all patients on OC in mental health care for adults (aged 18 years or older) in the catchment area. These were either on OC when the study started, or received one or more OC orders during the study period from 01.01.08 to 31.12.12. A patient could have more than one OC decision within the study period. The data basis in Part A consists of 345 OC orders received by 286 people. This corresponds to a transfer to OC on discharge of 8.2% of all patients subject to compulsory hospitalisation (both for compulsory observation and compulsory care) during the study period.

Of the 286 persons in Part A, 54 received their first OC order during 2008 and 2009. These 54 were included in Part B, which consisted of further recording of data where these patients were studied for three years before and three years after their first OC order.

Patients living outside Troms and Finnmark, where OC was used in their home location, were excluded, as were patients on OC during admissions to a general hospital when subject to compulsory mental health inpatient care. There were about 10 such patients; they were excluded because OC was used to maintain coercion when the patient was outside mental health care for a very limited period, and they were thus not regarded as real OC patients. Patients living in reception centres for asylum seekers and receiving treatment and care from the hospital during OC were included. If a patient included in Part A died during the data collection period, the death was recorded as conclusion of the OC.

#### **3.3.2 Identification of participants**

In order to ensure that all OC patients who met the inclusion criteria for Part A were included, data from the DIPS reports D 88 and D 1341 were used. Report D 88 indicates the decisions made on a patient for a given period, grouped by ward/department and type of decision. The decision is shown in the ward where the patient was when the decision was made, and the report shows all decisions regarding the patient, and includes patients

discharged during the period. Report D 1341 lists the decisions made on a patient in a given period, grouped by ward/department and type of decision. The information on participants from the two reports was accessed on three occasions, and the reports were checked against each other. To identify patients who met the inclusion criteria for Part B, all OC orders from 2008 and 2009 were examined using a decision module for each patient to determine whether it was the patient's first OC. The patient's decision module in DIPS was also checked against the therapist's record for the patient to examine consistency between the documentation in the therapist's records and the decisions recorded in the decision module. The patients included in Part B were checked twice.

### **3.3.3 Registration form**

In designing the study, a registration form was drawn up which contained A and B sections to define which data were collected (see appendix III). The registration form contained descriptive variables (Bhopal, 2002) and descriptions of various aspects of OC. Part A contained nine variables with demographic data, index OC and concluded OC, and whether there was a forced medication decision in conjunction with the OC (here all 345 OC orders for 286 people were included). Part B had 58 variables on consumption of healthcare three years before and three years after index OC, grounds for the decision, legal procedures, diagnosis, drug use and treatment content (this information was recorded for the 54 people who received their first OC order in 2008-2009).

Some variables are open to different interpretations because they are coded from text written by different health professionals and from written documents that allow for different understandings of practice. In order to attempt to achieve similar coding for the data, we created a guide (see appendix III) containing instructions on how to record variables open to different understandings and interpretations. The registration form was tested on five patient records, which resulted in some minor corrections. These five patients were included in the study.

An important part of the registration process was to keep a diary to capture challenges and cases of doubt. One example of the usefulness of the diary was when a pattern was detected



during the registration revealing a need to add more alternative responses to variables 45 and 67 in Part B. These adjustments were then included in the registration, and corrected for relevant patients already registered.

### **3.3.4 Data collection**

Patients were assigned a serial number as a key to the patient's name, date of birth and ID number. The list of names and serial numbers was stored separately from the data collected. On the registration form, only the serial number was recorded and the data were therefore stored anonymously. Information on OC orders or subsequent care of patients not recorded in DIPS was not followed up in any other way.

Data were identified under various sections in the tabs in DIPS, the most important of which were "Mental Health Care Decisions", "Therapists' Records" and "Discharge Summaries". To identify admissions to mental health care, the general category "Admissions" was also used, and data on the Control Commission were identified under "External Correspondence" (scanned). If there was inconsistency or if information was not found in the DIPS tabs mentioned above, "Nursing/Environmental Documentation" was used. Data was collected from 20.09.2011 to 16.04.2013, and extensive quality work to review the data was performed in April 2014 and February/March 2015. The estimated time for registration in Part B was 2-6 hours per patient, plus the time needed for proof-reading and quality assurance.

### **3.3.5 Analysis**

IBM SPSS 22 (<http://www-01.ibm.com/software/analytics/spss/>) was used to record data and for the statistical analysis. The analysis included the chi-square test, t-test, and a Kolmogorov-Smirnov test. A survival analysis with two dependent variables, duration of OC and time from index OC to first hospitalisation, is presented using Kaplan-Meier curves which were tested for significance with a log-rank test. The following independent variables were considered as possible predictors of OC duration: gender, age, diagnosis, time since first contact with mental health care, consumption of inpatient care in the three years prior to OC, reason for index OC, geographical distance to UNN, living alone or not, compulsory

admissions in the three years prior to OC, use of medications (forced medication, voluntary medication and depot medication), substance use and who treats the patient on an ongoing basis. The independent variables included in the Cox regression model to predict duration of OC were the following: gender, age, place of residence, use of depot medication during OC and follow-up by a psychiatrist. Use of depot medication and follow-up by a psychiatrist significantly predicted longer duration of OC.

The following independent variables were considered as possible predictors of the time between index OC and the first subsequent hospitalisation: age, gender, substance use, forced medication, time since first hospitalisation in mental health care, number of compulsory admissions in the three years before index OC, and use of depot medication. The independent variables included in the Cox regression model to test predictors of time between index OC and the first subsequent hospitalisation were as follows: forced medication, substance use, time since first hospitalisation in mental health care, number of compulsory admissions in the three years before index OC, but none of these were significantly associated with the dependent variable.

### **3.4 Sub-study II: Patient experiences of OC**

#### **3.4.1 Participants**

To obtain empirical knowledge of how OC is perceived by people under the scheme, Sub-study II needed to give a voice to the patients. The main inclusion criterion was that the patient was under an OC order at the time of the interview<sup>9</sup>. We also wished to include participants of varying ages, living in different settings, who had been on OC for at least three months. Participants were asked to consent to the participation of their decision maker in the study (Sub-study III), and a final inclusion criterion was therefore that the patient's decision

---

<sup>9</sup> One of the participants had his OC order terminated after we had agreed on the date for an interview, but before the interview took place. I chose to include this person in the study because his experience of OC was recent.

maker had not previously been interviewed in the study<sup>10</sup>. To avoid inappropriate and unnecessary challenges and ethically problematic situations in the interviews, patients with a language barrier which required an interpreter and those whom the decision makers considered incompetent to give consent were excluded. Eleven participants were recruited, all with an ICD-10 F 20-29 diagnosis (schizophrenia, schizotypal disorder and other psychotic disorders). There were a few who also had challenges with substance abuse.

### **3.4.2 Recruitment**

For potential participants, I was given lists of names of patients placed on an OC order in the catchment area from the staff at UNN<sup>11</sup>. In an attempt to achieve variation, patients were divided into three new lists on the basis of place of residence, age, gender and decision maker. I identified the information via DIPS, without reading any other information about the patient's health or life situation. The first name from one of the lists was selected as the first person to be asked to participate. The next person was recruited from the next list and other strategic variables such as gender and age were taken into account. This continued until recruitment ended. Since the interviews were conducted over several months, some OC orders were terminated and new ones began. In order to include these changes, I received an updated list of potential participants three times during the recruitment process.

When a patient was identified who was suitable to be asked to participate in terms of the inclusion criteria, I phoned the decision maker to make sure that the patient did not come under one of the two exclusion criteria for the study. To ensure that patients were not asked to participate by the person in charge of coercion in their case, I was given contact details of a person whom the decision maker considered that the potential participant knew well. One

---

<sup>10</sup> This inclusion criterion is described in more detail under Sub-study III, 3.5.1 and 3.5.2.

<sup>11</sup> To enable the collection of complete data on incidence and prevalence in Sub-study I, the REK Nord Regional Committee for Medical and Health Research Ethics approved data collection from the medical records without patient consent (see also the description in Chapter 4, Section 2). I thus obtained access to the names of all patients on OC in the study catchment area.

purpose of this recruitment procedure was that the contact could provide the necessary information about the study tailored to the individual patient, in order to give the patient a fair opportunity to either accept or refuse to participate.

I phoned the contact and introduced the study, and asked for help to request the patient's participation. The contacts had different roles in relation to the patient; several worked in primary mental health care, some in specialist health care but with no legal responsibility for coercion, and one was the patient's lawyer. In my inquiry, I emphasised the purpose of the study and of the interview, the practicalities of the interview, and the importance of information about the study being tailored to each individual potential participant. In addition to receiving information about the study on the phone, both the decision maker and the contact were provided with information in writing by email. When a patient had agreed to participate via the contact, the interview date was agreed through the contact, or alternatively I was given permission to phone the patient myself and make an appointment.

I knew none of the study participants and wanted to arrive at the interview without being influenced by clinicians' opinions of the participant. It sometimes happened that I got information about a participant before the interview that I felt I did not need. I therefore said it was important that I received as little information as possible because I wanted to form my own idea of the patient.

We recruited seven men and four women, aged 21-60 years. All had been under an OC order for more than six months, and some had been on the scheme over several years. Twenty-seven people were asked to participate; 14 did not respond or refused, one was judged incompetent to consent by the decision maker, and in another case the local health services considered that it would be unhelpful for the patient to be approached.

### **3.4.3 Interview guide**

In planning the interviews, it was important to design an open but thematic approach. It needed to be open enough to enable participants to relate their stories and viewpoints, but also thematic, so that they could talk about various aspects of being on OC. The interview guide was developed with the help of a focus group interview with three participants who had

experience of OC and/or hospitalisation. Kvale and Brinkmann (2009, p. 162) state that focus groups are particularly suitable for exploratory research in a new field. A typical focus group interview has a non-directive interview style, where the main point is to elicit different views on the topic in focus for the group (ibid.). Unlike individual interviews where the interviewer has a more active role, the group members should be encouraged to talk to each other, ask each other questions, and comment on each other's experiences and views (Kitzinger, 1995). The users in the focus group were not included as participants in the interview study. I led the focus group interview with the help of a research assistant. The interview was taped and parts of it were later transcribed, and notes were taken during and immediately after the interview. On the basis of findings from the focus group and input from supervisors, the interview guide for patient interviews was created with five topics and associated questions (see appendix III). Table 1 shows the topics and focus areas of the interview guide.

**Table 1** Topics and focus areas for interviews with patients

<b>Topic</b>	<b>Focus area</b>
Own experiences and thoughts about being on OC	<ul style="list-style-type: none"> <li>➤ Experiences of everyday life here and now</li> <li>➤ Experience of being on OC</li> <li>➤ Establishing OC</li> <li>➤ Perceived consequences of OC</li> <li>➤ Description of 'One day in my life'</li> </ul>
Content of treatment	<ul style="list-style-type: none"> <li>➤ Treatment: frequency, therapist, alliance, medicines, relationships</li> <li>➤ Experience of taking medication</li> <li>➤ Overall experience of treatment</li> </ul>
Autonomy	<ul style="list-style-type: none"> <li>➤ Experiences of inclusion in discussions with health professionals</li> <li>➤ Autonomy in everyday life</li> <li>➤ Influence of personal/social relationships</li> <li>➤ Life without OC</li> <li>➤ Experience of legal protection</li> </ul>
Specific use of coercion	<ul style="list-style-type: none"> <li>➤ Specific use of coercion in OC</li> <li>➤ Consequences of breaking treatment appointments</li> </ul>
Insight and understanding	<ul style="list-style-type: none"> <li>➤ Views on necessity of treatment</li> <li>➤ Views on treatment needs</li> <li>➤ Best treatment for you</li> </ul>

### 3.4.4 Interviews

In an attempt to provide an open and relaxing interview atmosphere, participants were allowed to choose the interview location. Eight chose to be interviewed where they lived, and three chose to come to the university. Interviews lasted from 30 to 120 minutes and were

transcribed in their entirety. Each participant was interviewed once. To ease my workload, I had assistance in the transcription of all interviews except one (as also in Sub-study III). There were some natural breaks, such as smoking breaks or when participants needed a break to help them get back their strength. All breaks and interruptions were determined by the participants, but I also sometimes asked if they wanted or needed a break. I was therefore often with the participants considerably longer than the recordings suggest.

The interview method was inspired by a narrative approach where participants are encouraged to talk as freely as possible about their lives (Frank, 2010). In the introduction, I explained about the study and that I wanted to hear about their current life situation. I often started by asking openly what their everyday life was like, and used their stories as a basis for the further conversation. The participants could talk freely but were also encouraged to tell stories that gave the interviews a thematic focus on their reflections and feelings about the topics on OC in the interview guide. Below is an excerpt containing three sequences from the interview with Lise<sup>12</sup>, showing examples of how questions were asked and topics pursued.

*Henriette: Can you tell me what's good about your life at the moment?*

*Lisa: Good about my life? Well, it's really the fact that I'm not in the hospital, maybe. That's a good thing! It feels like things are getting better. I'm beginning to start again with my old activities and things I used to have before.*

*Henriette: You say things are beginning to get better, can you tell me a bit about that?*

*Lisa: Well, luckily I'm not in hospital and I have a very good relationship to the mental health care and the people I'm in contact with now. When I've been in hospital, there were different wards and lots of different people. Lots of different doctors, lots of different psychiatrists, psychologists, occupational therapists and nurses. The way it is now, I don't suddenly have to change doctors.*

---

<sup>12</sup> All names in the study are fictitious.

(.....)

*Lisa: I think I could have been discharged to voluntary aftercare. But it was maybe just the doctor I had who didn't agree with it. Or that I was still on forced medication and had to continue with it, then. (...) I wasn't given any special reason for it, just that it would continue like that ... that they did not feel confident that ... I don't know what ... very kind of vague, no particular explanation.*

(.....)

*Henriette: Now, when you're under coercion (OC), what impact does it have on your everyday life?*

*Lisa: Well, I suppose it's that I still have to relate to mental health care. I can't choose to walk away from it. Or carry on with my life on my own, as I'd like to. It's that I have contact with the different providers, I go to my psychiatrist once a week, talk to him, and I'm in contact with mental health services and the outpatient team. So I suppose it's all those things. The fact that I still have that contact.*

During the conversation, the interview guide was mostly used as a checklist. I chose to give priority to what the participants were interested in and wanted to relate, while I led the conversation back to any topic that was missed out or asked questions when I wanted more details from the participant about anything. For example, Knut wanted to talk a great deal about his life before he became ill, while my task was to get the conversation to swing between past, present and future. As far as I could, I avoided asking yes-no questions. In order to create a common language in the interview, I tried to use the participants' terminology and expressions. When I found I was not succeeding, I actively tried to return to the participant's way of narrating. One example is that several participants did not use the term OC, saying instead "*this coercion that I'm under*". I used phrases such as "*Can you tell me a bit about*" and "*It sounds as if you disagree with the other people's view, can you tell me more about how you feel about it?*" In this way, participants were encouraged to emphasise everyday experiences and tell their stories in their own language.

I tried hard to adapt the interview situation to each individual participant and his/her level of functioning, which was a methodological measure to encourage them to tell their stories based on their own premises and possibilities. The longest stories were about experiences some time ago when the participants were subject to formal, specific forms of coercion, usually during hospitalisation. The stories typically showed that the participants were deprived of any control over their own bodies and will and were misunderstood and subject to strong coercive interventions that could involve the police, belts and forced medication. Here is an example from the interview with Marius:

*Marius: It happened several times that I ended up strapped to the bed. And before ending up strapped to the bed, there was the usual interaction with the people who worked there, but then something had somehow gone wrong and it was a big mess (...) It can be a test of patience to lie strapped to the bed. And it can be scary, when you feel like you are getting a delusion that hell has actually arrived and you're in the bed waiting for them to come and start torturing you.*

It was a privilege to be invited into the participants' homes, and it was useful information to see how they lived. I was concerned about how I appeared and what I represented at the visit, and wanted to be a guest, which I was, after all. There were some small details which I thought about later. One example is when I visited Lars who lived in a flat in a sheltered community, and I was accompanied by two members of staff to show me the way. When we entered Lars' flat, the staff put on blue over-shoes, while I felt it was quite natural to take off my shoes in the hall.

Three participants were interviewed at the university. When the first one said he wanted to be interviewed there, my immediate thought was that I would lose important observations. That was probably true, but when I realised that it meant a lot to the three participants to go to the university, I felt reassured that it was right to let them choose the interview location. Kari was one of those interviewed at the university. When we met at the door, I recognised her because she had described her dress. It was perfect, just right for the occasion. After we had introduced ourselves, Kari walked with bowed head through the university's long corridors. There was nobody in the break room and we got ourselves some coffee. I said cautiously that people we meet here will think we are colleagues or friends. From the break room to the



interview room, Kari walked with her head high. During the interview, Kari told me that her identity as a patient was so strong that she felt everyone could tell by looking at her that she was *a psychiatric patient*. Meeting Kari made a strong impression on me, and I found that the first few minutes we were together helped to create a relaxed and open interview.

### **3.4.5 Analysis**

A thematic narrative analysis based on Riessman (2008) was used to process the interviews. This method is particularly suitable to develop theoretical arguments, and invites the reader to see more than the text reveals at first glance (Riessman, 2008). When I received the transcribed interviews, I listened to each interview and made corrections in the text where misunderstandings had arisen. In that way, I avoided errors that had occurred because I did not do all the transcriptions myself.

The analysis consisted of several stages, where my attention was focused on specific areas. I started by working my way into the material by listening to the tapes, reading the field notes and writing down my immediate impressions. My aim was to achieve a general overview and a comprehensive perspective on the stories. In this part of the analysis, my focus was on the personal aspects of the stories. In an interview context, knowledge is produced together and emanates from the social relationship between interviewer and interviewee (Riessman, 2008). Listening to the audio files gave me a clearer and more conscious idea of how I appeared in the interview and in interaction with the participant. There were parts where I should have asked for more detail and clarification, and other parts where I should have allowed the silence to continue to give the participant the opportunity to provide additional comments.

The next step consisted of creating a thematic overview; here NVivo 9 software (QSR International, Melbourne, Victoria, Australia) was used to arrange and systematise the data. Each interview was read through to find meaning units in the stories. My interest lay in what the participants related and what it meant for them. In this phase, the focus changed; consistent similarities in the stories were also sought. The meaning units were then coded to provide a general view and find common themes in the data. Each story was interpreted as a

whole, which is an important feature of the method and distinguishes it from coding in grounded theory (Riessman, 2008).

I found it challenging to identify the participants' message. I needed to change my understanding of how I had usually thought about coercion in general and OC. To get closer to their stories and see each interview in its entirety, I removed the transcribed text of my own words, without otherwise changing the text. This was a helpful approach, as it provided a clearer picture of the stories. By reading the participant's voice as a continuous text, I achieved a better understanding of what the stories of previous experiences of coercion as an inpatient meant for participants' perception of OC.

The third stage was to perform an internal validation to determine what the stories in the analysis described. This work consisted of studying confirmations and contrasts in the data by bringing concepts from the initial analysis back to the text. Finally, an external validation was performed where the findings were discussed in the light of other research. My supervisors were involved in all phases of the analysis with different approaches.

The analysis involved three main themes that provided insight into patient experiences of OC: *being hospitalized, being at home* and *obedience as a strategy*. The first theme shows how past experiences of coercion as inpatients have an effect on patients' experience of being on an OC order. This is a key finding for our understanding of the whole picture of how, and most importantly why, the OC scheme functions. The next topic shows that OC is perceived ambiguously, with both advantages and disadvantages. Finally, we find stories about why participants choose to comply with the OC treatment programme and general framework. These three themes reveal different interdependent aspects that describe how and why OC functions as it does for the study participants.

### **3.5 Sub-study III: How decision makers weigh up various considerations in their OC decisions**

#### **3.5.1 Participants**

The purpose of interviewing decision makers was to gain insight into how assessments are made and which considerations are emphasised in making decisions on OC. Sub-study III had nine participants, seven psychiatrists and two specialist psychologists, all of whom had several years of experience of OC decision making. To avoid general and superficial descriptions, we wanted the interviews to be based on a specific example of how OC was practised. This approach was possible and ethically acceptable, since patients interviewed in Sub-study II consented to their decision maker being interviewed with an exemption from confidentiality. The inclusion criterion was therefore that decision makers were responsible for the OC decision for a patient who was interviewed and that the patient gave written consent for the participation.

#### **3.5.2 Recruitment**

Before patients consented to the inclusion of their decision maker, they were given information on why we wanted to talk to the person. Patients were also assured that there would be no repetition of their own stories in interviews with decision makers. When a patient had consented to the decision maker's interview and exemption from confidentiality, I contacted the decision maker by phone or email. There were two patients who did not consent and their decision makers were therefore not asked to participate. All the other decision makers agreed to participate.

#### **3.5.3 Interview guide**

The interview guide was created at the same time as that used in patient interviews, and on the basis of the same focus group (see the description of the focus group in Chapter 3.4.3); it contained five themes with corresponding sub-questions (see appendix III). Table 2 shows

the themes and focus areas in the interviews with decision makers.

**Table 2** Topics and focus areas for interviews with decision makers

<b>Topic</b>	<b>Focus area</b>
Reasons for decision	➤ Factors considered as a basis for OC decisions
Treatment goals and content	<ul style="list-style-type: none"> <li>➤ Treatment</li> <li>➤ Quality of treatment</li> <li>➤ Alternative treatment/actions desired</li> <li>➤ Treatment goals</li> </ul>
Implementation	<ul style="list-style-type: none"> <li>➤ Implementation of controls and examinations</li> <li>➤ How OC is assessed and evaluated</li> <li>➤ Factors considered in terminating OC</li> </ul>
Autonomy	<ul style="list-style-type: none"> <li>➤ Arranging for patient to participate and be included in determining the content of the OC</li> <li>➤ Information on rights</li> <li>➤ Consideration of possible treatment on a voluntary basis</li> </ul>
Patient-clinician relationship	<ul style="list-style-type: none"> <li>➤ Significance of coercive framework for relationship</li> <li>➤ Changes in relationship as a result of OC</li> </ul>

### 3.5.4 Interviews

The interviews took place at the decision makers' place of work; this was a strategy to save time for the participants. The interviews lasted from 50-80 minutes and consisted of the participants' considerations, assessments, opinions and experiences, but also their experience of having responsibility for OC. In the introduction, the decision makers were reminded of which patient the interview was about. However, this framework was expanded to allow for expression of the decision makers' overall experience with OC with other previous or current patients, and all of them contributed in this way. These descriptions were given anonymously. Topics and questions were more structured than in the patient interviews, but without being chronological or taken word for word from the interview guide. The various topics were supplemented with supporting questions from the interview guide and spontaneous follow-up questions. There was also room for exploring spontaneous topics and aspects of OC that were not included in the interview guide.

It was important that participants felt comfortable with the interview situation and I therefore pointed out clearly that the interview was not concerned with evaluating or finding fault with

the participants' management of OC. I spent time explaining the purpose of the study before the tape recorder was turned on. In some interviews or sequences of interviews, I managed to create openness and a relaxed atmosphere, but not always. One example where I was successful was when the decision maker provided personal reflections on managing coercion:

*Participant 8: Since I have this job, I also have to take unpleasant decisions. I've learned this over time, but I find that decisions on coercion can be very painful. Outwardly I can be professional, but inside I feel pain.*

At other times, I found that participants closed up or avoided questions, and did not include personal comments. The following participant exemplifies this:

*Participant 2: Our mandate is to administer the law, and that's what I have to relate to.*

Sometimes more detailed descriptions emerged when the tape recorder was turned off. I then made an effort to write field notes or asked if I could turn on the tape recorder again.

Although I am familiar with the language used by such professionals, I tried not to make it obvious that I understood what the participants meant, and instead tried to listen and ask naïve, clarifying questions:

*Henriette: You said, "He has good functioning", is that what you said?*

*Participant 5: Yes.*

*Henriette: Can you explain what you mean by that?*

*Participant 5: Yes, he's good-humoured and has different things they do every day in the housing. He has a job he earns some extra money from, he exercises and goes on trips. One day a week he's allowed to go shopping.*

Clarifying questions were also important to enable participants to provide specific, detailed descriptions and opinions.

### 3.5.5 Analysis

The interviews were taped and transcribed in full. One patient wanted to read the interview with his decision maker; this was done as the decision maker agreed to it. The patient had no objections to the interview and no changes were made to the transcribed material.

The analysis started in the same way as with the patient interviews, by listening to the tapes, reading the field notes and writing down my immediate thoughts and questions. I quickly realised it would be necessary to change the procedure I had used with the patient interviews. The third-hand perspective of the decision makers gave the material a more descriptive approach where stories were not so important. A narrative approach where large parts of the text were aligned would therefore have been artificial in this case.

I took a step back in my analytical work and found great help in the thematic approach to analysis of Kvale and Brinkmann (2009), who seek to understand social phenomena from the actor's own perspective and describe the world as it is experienced by participants. This analysis is a combination of intuition and structured method. I first approached the data intuitively by again reading and listening to each interview separately. This provided a general overview and was useful for seeking out meanings in each interview, and is an eclectic way of making sense of the material (Kvale & Brinkmann, 2009). I formed an idea of what was most prominent in every interview and possible topics for further analysis were noted down. I discussed the prominent themes with my supervisors and these formed the basis for the systematic approach to the data.

In the structured work, I used a thematic approach where meaning units from each interview were identified. The aim was to create an overview of the topics that arose from the data. As with the patient interviews, the NVivo analysis software (QSR, Melbourne, Victoria, Australia) was used to arrange and systematise the data. The first step in the structured approach was to analyse each interview separately. After this, similarities and contrasts in the interviews that were descriptive of the material and recurrent themes were noted down. The overarching themes were further discussed with supervisors and then merged into new themes.

The analysis has three main themes and provides insight into various aspects of the factors considered when decision makers manage OC: *CTO as a treatment tool*, *a relationship in tension between coercion and voluntariness* and *recognition of patients' perceptions of burdens and restrictions as involuntary outpatients*. The first theme describes how OC is used in treatment, while the last two provide insight into dilemmas and tensions and how coercion in an outpatient setting is viewed, and finally how decision makers assess and relate to this.

### **3.6 Use of literature**

During my work on the study description and in the sub-studies, I performed a literature search in the PubMed, Ovid and Google Scholar databases I decided to use the various terms for OC and similar schemes used in different jurisdictions as key words: *outpatient commitment*, *community treatment orders*, *involuntary outpatient treatment* and *compulsory community care*, and combinations of these. The reference lists of relevant articles were also important to identify literature. Literature included in the study was assessed for relevance, focus, purpose, method and context. In order to systematise the articles, I created a table with the headings *title*, *author*, *country*, *year*, *design*, *participants*, *purpose*, *results*, and *conclusion/recommendations*. Neither inclusion and exclusion criteria nor any systematic gradation of quality were recorded. In retrospect, I realise that my work with the literature in these phases would have been more systematic if I had used checklists for the evaluation of research articles such as those published by the Knowledge Centre (<http://www.kunnskapssenteret.no/verktoy/sjekklistor-for-vurdering-av-forskningsartikler>), which are designed to evaluate the methodological quality and relevance of studies.

When I began to compile the various parts of the study, I performed a systematic literature search with the help of a senior librarian in Ovid MEDLINE (R) (1946 to April Week 1 2015), Embase Classic + Embase (1947 to 2015 April 13), and PsycINFO (1806 to April Week 1 2015). This was a broad literature search aiming at a general overview of the existing literature on OC and relevant studies that were not captured previously. This started by searching for relevant controlled search terms in the three databases using the words *outpatient commitment*, *community treatment orders* and *compulsory community care*. The

only controlled term that was suitable was *outpatient commitment* in PsycINFO. We therefore decided to perform the search as a general search in all three databases without controlled search terms. The search terms and the exact search strategy are presented in Table 3. The search found 1188 results. After deduplication, 636 hits remained.

The 636 hits were imported into an EndNote library, and reviewed by reading the title, authors, research community, and parts of the abstract. In some articles, parts of the results and conclusion were also read. Inclusion criteria for considering a study as interesting and worthy of further reading were that it had not previously been identified and that the subject was relevant to the thesis and the Norwegian OC scheme. Excluded were studies conducted before 2000 and studies where the focus was not relevant for OC in Norway, such as homeless patients on OC. After this review, 61 of the 631 hits were considered relevant. These were then studied in more detail. The reference lists in the included articles were read to find out whether there were relevant references not captured by the systematic literature search.



**Table 3** Overview of search terms and strategy

<b>Search terms</b>	<b>Total hits</b>	<b>Ovid MEDLINE (R)</b>	<b>Embase Classic + Embase</b>	<b>PsycINFO</b>
1: Outpatient commitment.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, px, rx, an, ui, tc, id, tm]	599	149	174	276
2: Community treatment order*.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, px, rx, an, ui, tc, id, tm]	532	121	227	184
3: (Involuntary outpatient adj2 (treatment or commitment or care)).mp.	320	90	110	120
4: (compulsory community adj2 (care or treatment or commitment)).mp.	126	33	52	41
5: or/1-4 (1188)	1188	297	425	466
6: remove duplicates from 5	636	257	95	284

## 4 Ethical approvals and considerations

All research raises ethical issues, particularly when patients and sensitive issues are involved. The study was approved by the REK Nord Regional Committee for Medical and Health Research Ethics (see appendix I) and the clinical manager for the study catchment area. Even if necessary approval is obtained, the researcher is responsible for continuously reflecting on various aspects of the research (Health Research Act of 20 June 2008).

Sub-study I was a case register study with the aim of providing reliable data on the use of OC in the study catchment area. In order to achieve our goal of full registration, we successfully applied to REK Nord for a waiver of the general rule of individual patient consent for the patients in Sub-study I. This raises ethical issues, primarily with regard to balancing the value of obtaining knowledge of how OC is practised against the disadvantage of recording data about patients without obtaining their consent. This disadvantage was hopefully reduced because the data was stored in de-identified form, and because the data was later anonymised according to the normal security procedures of UNN regarding access to DIPS and storage of research data.

Participants in Sub-studies II and III gave written consent (see appendix II), and were reassured that it would be impossible to identify individuals in the final material. In the transcription of data, names of places, people or hospital wards were not used and in the presentation of the data, adjustments were made to preserve anonymity. However, this does not mean that the persons involved will not be able to recognise themselves. In the introduction to the interviews in Sub-study II, I stressed that the participants themselves could decide what they wanted to share, and that they could refuse to answer questions. The participants in Sub-studies II and III were given written and oral information that they could withdraw from the study if they wanted, as long as relevant data had not been included in the analysis, without any negative consequences (see appendix II). None chose to withdraw from the study, but one decision maker wanted the tape recording to be deleted immediately after transcription, which was granted. There was also one patient who wanted to read the transcribed interview with his decision maker; this was also granted, and the patient had no comments or requests for changes.

Patients participating in studies (as in Sub-study II) can be designated a vulnerable group according to the Declaration of Helsinki, and research therefore requires caution and facilitation (The Norwegian National Research Ethics Committees, 2010). It was important to me that information was adapted to the individual patient and that participation in the study should be a positive experience. It is conceivable that the interviews conducted in Sub-study II, where participants talked about unpleasant coercion, could reawaken difficult experiences, and that the interview itself would not be sufficient to address any reactions. The participants were therefore told that they could speak to an independent psychiatrist afterwards if they wished. There were also invited to contact me afterwards if they so desired. However, no participants responded that they needed follow-up talks due to any negative experience of being interviewed in the study. Previous Norwegian studies have shown that patients under coercion have a desire to talk about their experiences (Norvoll 2006; Wynn, 2004), and the use of a narrative approach is a useful tool to facilitate such stories (Gold, 2007). Two participants from Sub-study II whom I met by chance later told me that they found it a positive experience to take part in the study. One can therefore hope that this also applies to other participants.

## 5 Results

This chapter will summarise the results from the sub-studies. Table 4 provides an overview of the results.

**Table 4** Summary overview of results

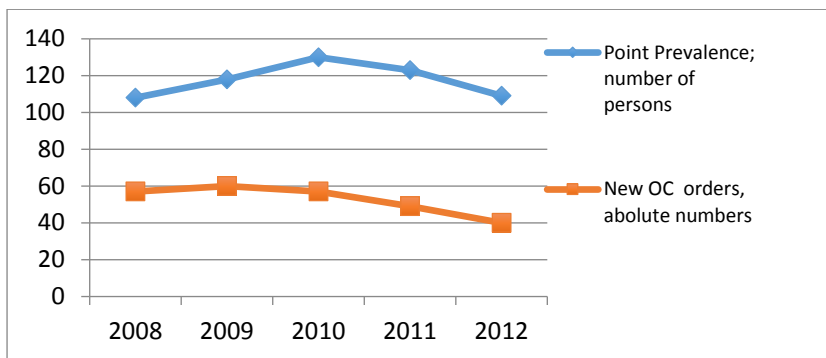
Sub-study	Theme	Summary of results
I: Patients on a first ever outpatient commitment order in Norway	To describe how OC is practised in a region in Northern Norway between 2008 and 2012, with special emphasis on people who received their first ever OC order in 2008-2009.	<p>A total of 345 OC orders applying to 286 people were identified (mean incidence rate of 29 and mean prevalence rate of 65 per 100 000 population). On average, 8.2% of all involuntary inpatient admissions were discharged to an OC order over the five years of the study.</p> <p>Fifty-four patients received their first ever OC order in 2008 and 2009. OC orders were justified by the need for treatment, specified as the need for medication. The majority of patients seemed to comply with medication without the need to make formal decisions on forced treatment. The patients had more inpatient stays and a greater mean total number of inpatient days in the three years after the order compared to the three years before, but the mean duration of stay per admission decreased from 26 days before the OC order to 15 days after.</p>
II: “When coercion moves into your home” - A qualitative study of patient experiences with Outpatient Commitment in Norway	<p>To explore how OC affects patients’ everyday lives.</p> <p>How being on an OC order affects patients’ perceived degree of freedom.</p>	<p>Participants generally complied with OC because they believed the alternative would be involuntary hospitalisation.</p> <p>Coercion was experienced as limitation of freedom of action and autonomy through excessive control and little patient influence or participation in their own treatment.</p>
III: Community treatment orders - what are the views of decision makers?	How decision makers weigh and evaluate various considerations when making decisions on OC.	<p>OC is viewed as a useful scheme to ensure control, continuity and follow-up care in the treatment of outpatients with a history of poor treatment motivation.</p> <p>Responsibility for OC was described as a tension between having control and building a good relationship with the patient. They had varied interest in and knowledge of the patient’s life situation and how the scheme affects the patient’s everyday life.</p>
	Results of the sub-studies in relation to each other.	<p>The study shows that patients and decision-makers have differing views and experiences of the coercive potential. Decision makers emphasise that OC has low coercive potential, limited to bringing a patient to a treatment appointment. Patients are concerned about the informal grey zone coercion involved in controlling everyday life that restricts their autonomy and freedom of expression.</p> <p>Patients on a first-time OC had more inpatient days in the three years after index OC than in the three years before index OC. The study also shows the usefulness of voluntary readmission desired by the patient. Readmissions as outcome measures should be divided into voluntary and involuntary readmissions.</p>

## 5.1 Sub-study I: Patients on a first ever outpatient commitment order in Norway

### Incidence and prevalence in Troms and Finnmark

During the study period, an average of 8.2% of all compulsory hospitalisations were converted to OC orders. The incidence varied between 40 and 60 new orders, representing an incidence rate of between 22.1 and 33.2 per 100 000 population over 18 years (Figure 2).

Point prevalence was measured on 1 January in the same years, and ranged from 108 to 130 persons who were on OC during the study period, corresponding to a point prevalence rate of 59.8 til 72.2 per 100 000 population over 18 years. Prevalence rates increased in the first three years of the study, but declined in the last two years (Figure 2).



**Figure 2** Incidence and prevalence in the study period

### Patients on their first OC order

There were 54 patients who had their first OC order in 2008-2009, and all of these were transferred to OC from compulsory hospitalisation. For four of the 54 patients, this was their very first experience of inpatient mental health care. The length of hospitalisation which led to OC varied from 7 to 119 days, with an average of 38.6 and a median duration of 31 days. Patients had the following characteristics: sixty-eight percent were men, and the men were significantly younger than the women with an average age of 44 for males and 53 for females. Thirty-nine patients (72.3%) had a schizophrenia diagnosis and 14 patients (all men)

had additional substance abuse problems. With regard to housing, 70.6% lived in private houses or flats, 39.4% lived with family members, spouse or friend while the majority (59.6%) lived alone. Further, 75.5% had various forms of social support as income, 74.5% had their first hospitalisation three years or more before their first OC order, 38.9% had depot medication and 57.4% had had one or more forced medication orders.

Psychiatrists were responsible for the OC order for 96% of all patients, and the decision was justified by the treatment criterion in all cases (except one case where justification-data was missing). For 51 of the patients, the need for medical treatment was specified as grounds for the decision. For seven of the patients, OC was also justified by dangerousness to themselves or others. The median duration of OC was 161 days for women and 211 days for men, while the average was the same for both genders (370 days). Patients with a first ever OC in 2008 and 2009 had significantly shorter OCs than those with a new but not first-time order in the same years ( $n = 45$ ) ( $p < 0.01$ ). Depot medication and follow up care by a psychiatrist (rather than a psychologist) predicted longer duration of OC.

Patients had significantly more hospitalisations and more inpatient days (the median was 60.5 days and the average 109.5 days) three years after index OC than three years before, and the number of days per inpatient stay decreased on average from 26 days in the three years before index OC to 15 days in the three years following index OC. The time from index OC to the first inpatient stay ranged from three to 1016 days, with an average of 145 days and a median duration of 38 days. Nine of the 54 patients had no hospitalisations three years after index OC, and five patients had still not completed index OC after three years.

## **5.2 Sub-study II: “When coercion moves into your home” - A qualitative study of patient experiences with Outpatient Commitment in Norway**

When patients talked about their experience of being on OC, their experiences of compulsory hospitalisation were their frame of reference. Powerful stories emerged of how patients had experienced various formal, specific forms of coercion such as the use of police, seclusion, mechanical restraint, forced medication and experiences marked by unpredictability and lack of autonomy. In this perspective, OC provided more freedom of action and it was preferred to

being hospitalised. The patients emphasised that OC gave them predictability, their own home, a greater degree of freedom and stable relationships with care personnel. Many had been allowed to decide for themselves when they wanted voluntary (re)hospitalisation during OC, which they found helpful. Admissions that took place on the basis of patients' own wishes were described as a great contrast to compulsory admissions. The positive factors are important in giving patients more influence and control over their lives than their experiences during compulsory hospitalisation.

However, none of the patients would have wanted to remain under OC, given the choice. A prominent feature of their stories is an institutional presence, where many familiar routines from the hospital structure have been transferred to the patient's home. Through the administration of medication, complying with agreements and practical and medical help in the home, everyday private life must be planned and adapted to the structures of the health care system. In this way, the living room becomes a hospital outside the hospital, and the home becomes a setting for the structure and implementation of the content of OC. This may be perceived as restricting social and private life. Knowing and feeling that others controlled and observed them through these structures was perceived as a burden. Patients' experiences of coercion during hospitalisation had given them a good idea of what could happen if they did not comply with the treatment regimen. Many felt unsure about whether they might suddenly be compulsorily hospitalised or medicated. Considering the fact that OC was perceived as their best option, the patients chose to comply with the scheme or appear to accept its framework.

Coercion under OC was of a different nature than during hospitalisation. The patients said that they did not experience specific coercion in OC, but were subjected to various forms of control which restricted their autonomy and freedom of expression. The lack of autonomy mainly concerned the unpleasant feeling that others decided for them and that they had no real treatment choice themselves.

### **5.3 Sub-study III: Community treatment orders - what are the views of decision makers?**

The decision makers were all responsible for a patient interviewed in Sub-study II. OC was viewed by the decision makers as an appropriate form of treatment that ensured control, continuity and follow-up care of patients with varying degrees of treatment motivation. Patients often had a history of fluctuating motivation to take medication and dramatic compulsory hospitalisations. Control of medication treatment and structure were the most important justifications for OC emphasised by decision makers. OC tended to be implemented primarily to prevent the relapse of a disorder that required inpatient treatment, and was therefore seen as a supplement to hospitalisation. One positive aspect of OC that was highlighted was that patients could more easily seek help themselves and not have to use the emergency services if they wanted readmission.

Responsibility for OC was described as a tension between having control over the patient and building a good relationship with the patient. Several decision makers found this balance between coercion and voluntariness to be challenging. There were different clinical approaches and opinions regarding the conditions for terminating OC. For some, a satisfactory treatment outcome was a basis for discontinuing OC, while for others the satisfactory treatment outcome was attributed to the coercive framework, and OC was maintained. There was variation in how decision makers themselves were affected by the management of coercion; some found the coercive aspect to be personally challenging, while others mainly focused on the fact that OC was not greatly restrictive for patients.

Decision makers thought that OC was no great burden for patients because treatment and follow-up care were organised as outpatient appointments, while patients could otherwise live their lives as they wished. The basis for determining patient burden under OC was seen to be the extent to which patients themselves mentioned dissatisfaction with the scheme and the nature of the treatment. Some of the decision makers did not consider the negative aspects of the scheme unless the patient brought up the subject. Coercion was seen in terms of the use of formal, specific coercive measures: a) the possibility to bring patients back to hospital against their will and b) the possibility to make decisions on medication treatment without consent. The decision makers found that patients largely complied with the framework and that there



was thus no need for readmission or coercive measures. Based on this understanding, the coercive potential of OC was not seen as very restrictive, while there was agreement that the coercive framework was more visible when patients had forced medication orders.

#### **5.4 The three articles seen in relation to each other**

Both patients and decision makers had mixed feelings about OC; it was perceived as having positive and negative aspects. The coercive potential was viewed differently by patients and decision makers. Decision makers (Sub-study III) considered the potential for coercion to be low because the possibility for coercive interventions was limited to bringing patients to treatment appointments, by force if necessary. Patients (Sub-study II) described an informal grey zone where they were subjected to various forms of control and a lack of autonomy which meant a great deal to them. Patients found OC to be their best option and therefore complied with treatment without much protest, which meant that decision makers were probably not aware of their burden. The present study shows that coercion in OC is realised differently from the general perception of coercion for inpatients, but this form of coercion still imposes restrictions in the lives of patients.

Sub-study I shows that patients subject to OC orders for the first time had more hospitalisations and more days in hospital three years after index OC than three years before. The patients interviewed (Sub-study II) found it helpful to be able to decide themselves when they needed admission to inpatient care. The decision makers (Sub-study III) also point out the benefit of OC patients finding it easier to seek help when needed and that their wish for inpatient treatment will be granted. The findings of the study give reason to recommend that future studies distinguish between readmissions that are voluntary and initiated by the patient and compulsory rehospitalisations, to provide a better basis for concluding whether readmission is a suitable measure for the success or otherwise of OC.

## **6 Methodological considerations**

The purpose of the study was not to provide generally applicable knowledge about the scope and practice of OC, but rather to describe in basic terms how the scheme is practised in a defined catchment area. The study used both a quantitative and qualitative approach. This chapter contains a discussion of the chosen methods.

### **6.1 The importance of pre-understanding - some reflections**

The researcher's role and pre-assumptions will affect the collection and presentation of data (Kvale & Brinkmann, 2009; Malterud, 2003). It was therefore necessary for me to be aware of the significance of my knowledge of the research field for the validity and reliability of the study. I tried to reflect on my pre-understanding and on how my experiences influenced my work throughout the research process. My interest in the theme of the study arose from my clinical experience of work with people with severe mental illness and complex challenges. My greatest curiosity and driving force to start the research lay in gaining knowledge of the patients' perspective. Through my work on the study, I saw the importance of how the various perspectives complement each other, and how they combine to create a comprehensive understanding of how OC is practised.

I worked at the Academic Development Unit for Mental Health and Substance Abuse at UNN for eighteen months before the study began, and was therefore already familiar with parts of the catchment area and the hospital when the study was designed. A pre-understanding of the hospital culture was therefore avoidable and could have meant that I unconsciously looked for particular directions in the data, or overinterpreted or overlooked elements that should have been captured. In order to determine how this may have affected the results of the study, discussions with my supervisors were an important factor. In retrospect, I consider it possible that my pre-understanding should have been more clearly reflected on and taken into account when the study was designed. For instance, the inclusion of other catchment areas with which I was unfamiliar could have diminished the implications of my pre-understanding.

My knowledge of clinical practice based on several years of work with the patient group under study had some important advantages. For example, I believe that this was useful during the interviews (Sub-studies II and III) in asking follow-up questions or following some of the stories. Familiarity with the field of practice was necessary in order to select relevant data for Sub-study I, both in terms of understanding the language of DIPS and knowing what to look for and where to find the necessary information to provide answers to the study question.

The stories of past coercion told by participants in Sub-study II often touched me. At times it was challenging to find a good way to respond to the participants when they told such stories during the interviews. I wished to be emotionally present, and it therefore felt natural to provide support for their painful experiences. An example of this was from the interview with Tone, when she told me about being forced to take a certain type of medication that she did not tolerate:

*Tone: My body was restless. They call it akathisia<sup>13</sup>, it's like you feel you have to move all the time and it's a really tiresome side effect of medication. I had a kind of paradoxical effect. I ran and jogged, got up at five o'clock ... that restlessness in my body - I remember jogging and jogging, and losing a lot of weight.*

*Henriette: That sounds terrible!*

*Tone: Yes, it was bloody awful. I was so angry. It was so hellish that I howled and roared.*

---

<sup>13</sup> Akathisia is the inability to sit still, excessive restlessness and the urge to move about, often due to unintended and undesirable changes in the functioning of the central nervous system. These changes are caused by medications and side effects. Akathisia is often induced by neuroleptics, especially so-called low-dose neuroleptics. Because of the restless behaviour, the patient often appears anxious, but the condition is not usually accompanied by a significant subjective feeling of anxiety. The condition is troublesome, but harmless. Treatment consists of reducing the dose or changing the medication (Store medisinske leksikon: <https://sml.sn�.no/akatisi>).

I did not plan well enough in advance how the participants' stories would touch me, and how these situations should be dealt with. Eventually I became more aware of my feelings and how I handled them. Non-verbal dialogue became clearer to me, and I found that this could be used more actively to respond to participants' stories. My role as interviewer developed and as the interviews progressed I felt more secure in my researcher role, and confident enough to show my feelings without letting them get the better of me. This may have made me steer the stories and lead the participants down a particular path, but my perception is that showing my emotions helped to create a secure and confidence-inspiring interview situation.

My supervisors Georg Høyer and Geir Lorem have different approaches to the research field, as a medical doctor and philosopher respectively. They both contributed actively in various phases of the study; they read the material, discussed the analysis and are co-authors of the articles (Høyer for Sub-studies I-III, Lorem for Sub-studies II and III). Together, our three perspectives were highly valuable for the implementation of the entire study, by pointing out different aspects of the research process, which has hopefully enhanced the reliability of the study.

## **6.2 Catchment area**

The study was conducted in the area of a particular health authority which includes one large town and many smaller towns and villages. It is therefore conceivable that the study captured a local practice and culture typical of this area. The catchment area is very large (74 485 km<sup>2</sup>), and other Norwegian health authorities do not have such great distances between patient and hospital. The study might have been enhanced if we had collected data in other areas with different geography.

## **6.3 Design**

The use of different perspectives on the same theme gives access to different research focuses. As mentioned in Chapter 3.2 "Context of the study", my intention has never been that the data should be used for cross-verification. However, the design does allow for two perspectives on the same case, which could have meant that I experienced conflicts in the

data (especially in Sub-studies II and III). The data for Sub-study II were analysed and finalised before Sub-study III was analysed. I did not find that either patients or decision makers claimed to be more truthful, but rather that we achieved different insights into different phenomena to help to provide understanding of why OC may involve certain challenges. One reason why the study was designed with patient and decision maker from the same case is that we wanted the interview with the decision maker to be based on a particular patient in the hope of generating specific and detailed assessments by the decision makers. I would say that we largely succeeded, although the decision makers had varying degrees of familiarity with the patient concerned.

In working with the sub-studies, I tried as best I could to listen to the material and ascertain what it conveyed and how it should be presented. There was a general emphasis on descriptive presentations. As described in Chapter 6.1 “The importance of pre-understanding - some reflections”, my pre-understanding affected my work and the focus of the three sub-studies. Other researchers with a different history and background might have emphasised and presented other aspects of the data.

#### **6.4 Participants**

The participants were selected strategically, meaning that they were chosen on the basis of certain characteristics with the aim of generating data relevant to the purpose of the study (Tong, Sainsbury & Craig, 2007). The recruitment process for Sub-study II was time-consuming because I was often unable to contact the people I wanted, and because several of these spent some time on finding a suitable occasion to request participation in the study. To prevent the data collection period from being excessively long, and because I wanted to recruit enough participants, I had two or three requests out simultaneously. Although we wanted variation, we in fact recruited participants as they became available. It was difficult to have so many people included in the recruitment process and an alternative could have been to ask decision makers to request participation of those patients they felt were suitable. In retrospect, it has occurred to me that recruitment might have been even more random if we had drawn lots. But drawing lots might have led to poorer variation in a study with a small number of participants.

Recruitment was discontinued when there were eleven participants for Sub-study II and nine for Sub-study III. Termination of inclusion took place when similar experiences and stories were repeated by the participants. But we cannot exclude the possibility that more participants would have given the study new aspects and insights.

The names of patients to be included in Sub-study I were extracted from DIPS by Lisbeth Mørch, the office manager and person responsible for quality work in DIPS at UNN. The extraction of data took place in several stages as described in Chapter 3.3.2 “Identification of participants”. Since UNN is the only institution in charge of coercion in mental health care for adults in the study catchment area, and because the patients did not consent to participate in Sub-study I, we feel confident that Sub-study I includes all OC patients in the study period.

## **6.5 Data quality in Sub-study I**

DIPS has been used in the study catchment area since 2003. The quality of data on coercion has generally been poor in DIPS, but has improved in the past five or six years. This is mainly due to an increased focus on correct recording practices for staff, and better monitoring of data with fixed procedures to verify that decisions and dates are entered correctly and that patient information is updated. This work is performed by the administrative staff of the clinic <sup>14</sup>.

From my previous clinical work, I had knowledge of navigating in DIPS, but I was given further training by office manager Lisbeth Mørch, who also helped me when questions arose during data collection. When the aim is to find specific information, it can at times be challenging and time-consuming to navigate in DIPS, because of the variation in how orderly the medical records are and the fact that different clinicians record data in different ways. It was therefore very useful to have a research assistant with good knowledge of DIPS and OC

---

<sup>14</sup> The information in this section is based on oral information from Lisbeth Mørch on 07.05.15. She is office manager and DIPS superuser in the Mental Health and Substance Use Clinic at UNN.

to help to collect data, both to ease my workload and because it was beneficial to have two people to check and assure the quality of the data.

The module for decisions in DIPS is sub-optimal and not sufficiently well adapted to practice in mental health care. This may lead to recording errors because there is no information on when an OC order is terminated or if an order has been recorded wrongly. Another aspect of the quality of the data is that there are a great many staff with varying knowledge of recording practices who keep patient records. To meet these challenges and minimise sources of error in DIPS, extracts of the patients' running, clinical record was read and compared to the formal decisions accounted in other sections of DIPS. Errors were discovered in the recording practice for about 10 patients, due to two factors: either that staff made a mistake when recording information in DIPS or that the OC order was valid for only a few hours or days when a patient was transferred to a general hospital or another health authority. These patients were excluded from the study, as mentioned previously.

In an attempt to be consistent in handling and interpreting data from ongoing descriptions of patient care, field notes and the code instructions were used actively, and it is a strength that DIPS is the primary source of the information sought by the study. When data was recorded, the information was compared from different sources in the patient record (see also Chapter 3.3.4 "Data collection") to verify that it matched. If there was disagreement between the various sources in DIPS, the information in the "Therapists' Records" or "Nursing/Environmental Documentation" describing what actually happened was assessed and recorded if it improved the data quality.

Quality assurance to minimise errors in the data consisted of ensuring that the recorded data was read by two people, and it was also proof-read after being entered in SPSS. Comparisons were also made between interconnected variables to determine whether there was agreement in the information in the SPSS file. When errors were discovered, the patient record and registration form were studied again to identify the correct information.

## 7 Discussion of the study results

Mental health care has a particular potential to exercise power and control over patients, including the use of coercion (Øye & Norvoll, 2013, p. 73). In Norway, the justifications for a coercive intervention with patients with a severe mental disorder are to ensure improvement or prevent worsening of the condition (the treatment criterion), or to prevent patients from harming themselves or others (the dangerousness criterion). Patients under an OC order live at home or in a facility not approved for coercion, but they are formally still patients in the specialist health services without the possibility to opt out of treatment and contact with health providers if they so wish. In many ways, OC seems to be as an ambiguous form of coercion where patients are on the borderline between a normal and an restricted life. On the one hand, they are in their home environment, the setting for everyday life, while on the other hand there are restrictions and treatment appointments they *must* comply with. As a consequence, the borderline between private life and treatment becomes indistinct and dilemmas associated with coercion are brought to a head: the home is not a zone of autonomy when coercion moves in. This study demonstrates this dilemma, and even patients who found OC to be beneficial expressed clearly how they experienced restrictions and reduced autonomy.

Norwegian health authorities wish to reduce the focus on hospitalisation in mental health care (NOU 2011:9, p. 93). There is now greater emphasis on decentralised care, where patients with mental disorders are increasingly treated in their local community. Since 1998, there has been a nationwide sharp reduction in the number of beds in mental health care for adults, from 17.6 per 100 000 population over 18 years in 1998 to 9.3 in 2014, which represents a decrease of 47% when adult population growth is included in the rate (Directorate of Health, 2015, pp. 137-138). A reduction in the number of beds makes it likely that the use of OC, both as a form of treatment and as an administrative structure in mental health care, will be more widespread in the future.

The overall aim of the study was to gain knowledge about the extent and practice of OC, and how patients and decision makers experience the scheme. In this chapter, the main results from the sub-studies will be discussed, followed by suggested implications for the field of practice and the need for further research.



## **7.1 What is the role of coercion in OC?**

The two key aspects of treatment and control intertwine and make it difficult to distinguish between them. Kemshall (2002) in Zettberg et al., 2014 describes how the introduction of outpatient commitment-like schemes in different jurisdictions in the 1980s led to a shift in the approach to mental health patients from a focus on treatment and rehabilitation to one of control and monitoring. In Norway, psychiatric care was mainly institutional treatment until 1961. Stays in mental hospitals were often prolonged, but compulsory aftercare opened the way to give patients help in their home environment. The care and treatment provided to the patient aimed at rehabilitation back to everyday life, and an important aspect was that the patient would be able to return to work. Just like today, compulsory aftercare was intended as a safety net to help patients at an early stage if their condition began to deteriorate. The present study points out some key factors that suggest that current practice in Norway involves various control mechanisms in follow-up care to a greater extent than was envisaged when the scheme was introduced. Patients described this control as consisting of similar types of routines to those they were familiar with from hospital. But control mechanisms in local health care are probably less visible than in hospitals. Concern has been voiced that traditional hospital coercion is gradually spreading out into local mental health care and displacing voluntary solutions through the use of OC (Bjørngen, Norvoll & Husum 2015), and clinical practice needs to be more aware of such a development.

This study provides knowledge of how patients and decision makers experience and view the use of coercion in OC. It appears that coercive interventions are limited to bringing patients to treatment appointments, by force if necessary, but the assumption is that the patient accepts certain conditions. The health authorities go so far as to say that the scheme must not be used if it is frequently necessary to fetch the patient (Ministry of Health and Care Services, 2006, p. 66). Here we already find the assumption that patients will comply with treatment and appointments, even though they do not necessarily agree with these. For OC to work, Dawson and Muller (2008) have argued that a certain degree of insight into the scheme is needed, and patients considered unlikely to cooperate are unsuitable for this type of arrangement (Mullen, Dawson & Gibbs, 2006). OC is therefore dependent on treatment compliance, with only occasional non-compliance. The argument that OC patients must have

some insight is supported in this study. Here we see that patients have a high degree of understanding of, and insight into, how mental health care functions, which encourages them to comply with treatment. As part of this phenomenon, decision makers are good at informing patients of the consequences if they do not comply with the treatment framework. The patients' knowledge of the system suggests that the decision makers provide good and necessary information about what OC implies, except that patients miss information about how long the OC will last. Patients' knowledge of OC includes awareness of the possible consequences of non-compliance. One result of this is that patients cooperate and refrain from talking about troublesome aspects of OC.

Patients' experiences in mental health care prior to OC were a factor in their decision to comply with OC. The OC framework and expectations of how patients should relate to the health care system mean that the familiar rules and routines are moved from the hospital setting to the patient's home, and in this way patients feel that they retain their patient identity. An example of this is when one patient related that if he wanted to go on holiday, his mother had to accompany him because he was not allowed responsibility for taking medicines himself. The experience of keeping patient identity under OC and of having one's life largely controlled by clinicians has also been described in another Norwegian study of patient experiences of OC (Stensrud et al., 2015).

OC works because patients appear to be satisfied because they believe that the scheme is their best option. The fact that patients find OC to be a better alternative to compulsory hospitalisation is probably an important reason why the scheme operates without any significant protests or resistance from patients, even though they would prefer not to be subject to OC. Fearing the further restrictions previously experienced, patients generally chose to comply with the framework, and decision makers did not normally need to use physical coercion. Patients undercommunicated what they felt was stressful in the scheme for fear of further restrictions, which probably means that decision makers are seldom aware that patients find certain aspects of OC to be restrictive. Examples to demonstrate this are that forced medication involving physical coercion hardly ever occurred and that a compulsory treatment order was only made for 63% of patients on their first OC. It would therefore seem that OC contains few restrictions, but the study shows that patients may consent to take

medications that they partly or completely disagree with for fear of getting a forced medication order. A further consequence of patients' and decision makers' different understandings of the coercive element of OC is that coercion in OC becomes more invisible than its actual perception by patients. For this reason, the coercive potential should be viewed from different perspectives when OC is being considered.

### **7.1.1 How is the use of OC justified?**

Sjøstrøm and colleagues (2011) have identified three arguments used to justify restricting patient autonomy under OC. Firstly, limited autonomy in the short term leads to increased autonomy in the long term. Secondly, restrictions outside hospital are preferable to restrictions in hospital. Thirdly, restrictions in everyday life constitute a potential for a general improvement in quality of life (ibid, p. 426). Sub-Study III shows that decision makers rely on all three arguments when justifying and explaining why OC is required. By controlling various aspects of the patient's life, such as medication, what the patient is doing, and compliance with treatment appointments, decision makers largely justify the need for OC by ensuring progression or maintaining stability. One challenge of this rationale is that we basically lack studies that demonstrate that coercive interventions actually help and are good treatment (Høyer, 2011). Further, there are no studies of OC that provide empirical evidence to justify the use of OC on the basis of these claims (Churchill et al., 2007; Burns et al., 2013, Maughan et al., 2014). Decision makers (Sub-study III) considered that OC had a high degree of freedom and autonomy, and that OC patients lived an almost normal life in spite of the challenges involved in their disorder. The coercive potential was therefore considered by decision makers to be low, which provides further justification for the use of coercion

Whether OC actually gives a patient a better life must be the basis for assessment. This requires clinicians to focus on balancing restrictions in the patient's freedom of action against the treatment effect. This also necessitates an emphasis on the patient's perspective and perceived burden. Patients generally find OC to be their best option and therefore adapt to the treatment programme without great protest. The fact that decision makers for their part base their view of the patient's burden on the patient's stated opposition and visible formal coercion probably leads to an understanding among decision makers that patients find OC to

be less restrictive than they actually do.

### **7.1.2 Does OC provide better access to good health care?**

The Mental Health Act and Regulations (Mental Health Act of 7 February 1999; Mental Health Regulations of 16 December 2011) lay down certain premises for the establishment of OC and stipulate that health services must undertake to provide suitably adapted outpatient care and that the patient must have a place to live. OC therefore requires various measures in both specialist and primary health care. To a greater extent than in voluntary care arrangements, the health services are obliged to find customised and effective solutions. Some decision makers (Sub-study III) found it disturbing that a coercive order was necessary to provide the treatment and social framework around the patient that all patients ought to have. The patients (Sub-study II) supported the experiences of the decision makers and confirmed that they found they received better adapted services and a more stable relationship with health care when under OC. The study suggests that OC can lead to better organised health care, which basically is good for patients, but not entirely unproblematic. The positive aspects of OC emphasised by patients are principles usually associated with good deinstitutionalised treatment (Lamb & Bachrach, 2001). For example, one of the patients (Sub-study II), who had previously lived in a sheltered community with people with substance abuse challenges, was allocated council housing in an ordinary residential area when he received the OC order. This example shows a form of systemic coercion, where patients are probably not offered adequate treatment until coercion takes place. The question of whether patients might have avoided being placed on OC if they had been offered the same health care previously is outside the scope of this study, but several of the positive aspects experienced by patients (Sub-study II) have little to do with coercion.

Bjørngen, Norvoll & Husum (2015) ask whether health services are capable of trying out voluntary care before coercion is used and how far they check whether voluntary care has actually been attempted or has obviously been pointless. The study shows that this is a relevant question in relation to OC, both when it is being considered and also in the regular controls, monitoring and care of the patient. The medical records of patients studied three years before and three years after their first OC decision (Sub-study I) show that voluntary

solutions are usually not tried or discussed. Considering that it is a legal requirement that voluntary care should be tried, unless obviously pointless, before OC is implemented (Mental Health Act of February 7, 1999), it is an unexpected finding that decision makers scarcely discussed this in the patient record. In the interviews with decision makers (Sub-study III) there were, however, more reflections on voluntariness than the few comments in the patient records.

Flexibility in health care to relate to patients on their own premises to better safeguard their wishes is seen to be necessary to obtain voluntary cooperation. Specialist health services and primary health care should, separately and together, be held responsible to a greater degree if a voluntary solution has not been adequately tried out (Bjørngen, Norvoll & Husum, 2015). A clearer description of why OC is started and later still considered necessary and what has been done to enable voluntary cooperation (or why it is obviously pointless) should be more apparent. Guidelines for the documentation of voluntariness should be more prominent and clearly explained by health authorities, and the Control Commission should have an active role, including the assessment of whether the stipulation on voluntariness has been met or not.

### **7.1.3 Some legal considerations**

The implementation of this study has provided some insight into how the legal rights of OC patients are safeguarded in clinical practice, although this was not an aim of the study. Three theoretical bases for assessing how patients' legal rights are protected in OC have been described by Zettberg & colleagues (2014): legal rules, legal monitoring of clinical practice, and how clinical practice actually relates to the patient's legal rights (p. 545). The present study (especially Sub-study II) gave an insight into how some local mental health services applied rules typical of institutionalisation. Examples of such regimes are that the patient had to present himself several times a day, either by phone or going to see the staff, and that the patient was given a cigarette once an hour. All the sub-studies revealed great variation in how decision makers performed the controls (after 3, 6, 9 and 12 months) to assess whether the conditions for OC were still present and whether OC was still the best option for the patient. Two controls were sometimes combined, such as the assessments after three and six months.

Several decision makers do not meet the patient themselves, but form an opinion on the basis of information about the patient from other medical staff on the telephone. Such examples give grounds to question whether current forms of organisation and practice adequately safeguard patients' legal rights.

## **7.2 Use of readmission as an outcome measure**

Internationally, one of the main arguments for the use of OC is that it will help to maintain adequate treatment in primary health care that reduces the risk of relapse requiring readmission (Appelbaum, 2001; Churchill et al., 2007). This corresponds with the arguments used by the Directorate of Health for the Norwegian OC scheme (NOU 2011:9 pp. 92-93). Sub-study I shows that first-time OC patients had more hospitalisations in the three years after index OC than in the three years before, but the number of days per inpatient stay was reduced from an average of 26 days in the three years before to 15 days in the three years after. However, the total number of days in inpatient care was higher in the three years after index OC than in the three years before. Readmission is one of the most widely used outcome measures to determine whether OC is an appropriate form of treatment for patients with severe mental disorders (Swartz & Swanson, 2004). The validity of this outcome measure, however, is little discussed (Maughan et al., 2014). The patients interviewed in Sub-study II said that being allowed to decide themselves when they need readmission was seen as good and useful help. Decision makers (Sub-study III) emphasised that patients on OC can more easily seek help when they have a need and desire to be hospitalised, without having to go via an independent doctor who in practice is often attached to the emergency services (Fuglseth et al., 2016). A Norwegian study that described the experience of introducing self-referral admissions<sup>15</sup> to a ward for rehabilitation of patients with schizophrenia showed that the

---

<sup>15</sup> *Self-referral admissions means here that admission and discharge take place on the patient's initiative. The purpose of the scheme was to help discharged patients get through an episode of exacerbation and reduced functioning without having to go via their own doctor or the emergency services.* (Heskestad & Tytlandsvik 2008, p. 32)

admission rate increased but that the total number of inpatient days fell by 33% and that the total time of compulsory hospitalisation was roughly halved (Heskestad & Tytlandsvik, 2008). Heskestad and Tytlandsvik (2008) conclude that when the threshold for admissions was lowered, patient autonomy increased, and this provided reassurance for patient and relatives. Another Norwegian study, where patients with an agreement on self-referral admission were interviewed, showed that this form of hospitalisation was perceived as significantly different from regular hospitalisation because patients had the power to decide and had access to services focusing on their individual needs (Olsø et al., 2016). Olsø and colleagues (2016) described how self-referral admission led to increased confidence in health care services, and patients' ability to cope with everyday life also improved.

With the aim of OC in mind, it was unexpected that the study showed that patients' total hospitalisation time increased during the three years after OC was initiated for the first time. The study shows that patients had different perceptions of how and under what conditions admission took place. A weakness of the study is that it was not possible to identify whether admissions after the OC decision were voluntary and initiated by the patient or compulsory, because all admissions were formally recorded as compulsory in DIPS. The practice of recording admissions was amended by the Directorate of Health in 2012 (Norwegian Directorate of Health, 2012, p. 47), and patients who want voluntary admission can be formally registered as voluntarily admitted without the possibility to be detained in hospital (Norwegian Directorate of Health, 2012, p. 47). This change of admission practices by the Directorate supports a form of user-controlled admission initiated by patients even when they are on OC, although such inpatient stays may be problematical in a coercion-voluntariness perspective.

In international literature, readmission is consistently used as an indicator that OC was unsuccessful. The present study suggests that readmission is too ambiguous to be used as an outcome measure and that voluntary readmission may be described as successful treatment. It would therefore be pertinent to distinguish between voluntary admission initiated by the

patient and forced admission, in order to determine whether readmissions represent failed or successful treatment.

### **7.3 How many and what kind of patients are on OC orders?**

Despite the fact that OC has in principle been used in Norway since 1961, there were no studies on the extent of OC or patient characteristics based on Norwegian data when the study was designed. In the absence of previous studies of incidence and prevalence in Norway, it is difficult to make a comparison of Troms and Finnmark with the rest of the country. National estimates are inadequate and can only give a rough idea of how representative our results are for the rest of the country. However, the prevalence rate for 2012 in Troms and Finnmark was similar to that of the rest of the country in 2013 estimated by the Norwegian Directorate of Health, 2014, (61.1 for Norway and 61.8 for Troms and Finnmark per 100 000 population over 18 years). Although there is considerable uncertainty as to the national prevalence of OC, it is stated that it is becoming more widespread as an expression of the fact that coercion is being moved from inpatient care to decentralised and outpatient services (NOU 2011:9, p. 93). However, we find no support for an increase in OC in the latter part of the study period; from 2009 the incidence decreased somewhat and from 2010 prevalence declined slightly in the study catchment area. A comparison with the incidence in other countries is in this context considered inappropriate since the structure of health services and the legal framework vary considerably between countries. In Troms and Finnmark, an average of 8.2% of all compulsory admissions (both for observation and as inpatients) were transferred to an OC order. This corresponds to about every twelfth patient compulsorily hospitalised. It is difficult to tell whether this figure is too high or too low, since admission figures are based on all hospitalisations regardless of length of stay and reason, and are thus not based on the patients who are real candidates for discharge to OC.

OC patients in Troms and Finnmark have most of the socio-demographic characteristics previously described in Norwegian reports on OC (Pedersen, Hatling and Bjørngaard, 2004; Norwegian Directorate of Health, 2014) and in the international literature (Churchill et al., 2007; Burns et al., 2013; Kisely et al., 2014; Kisely et al., 2013; Lera-Calatayud, 2014). Although the general characteristics reflect a relatively homogeneous group of patients, Sub-



studies II and III showed that OC patients vary greatly in functioning and needs. There is greatest variation in how patients live, what kind of follow-up care they receive and how often they receive it, rather than in diagnoses and other typical features of this group. Extremes ranged from patients living in small council housing units with round the clock contact with one care worker to patients who lived in their own or rented housing, with contact with care services about every fortnight. It was obvious that some of the patients in Sub-study II could not have managed alone in society. For such patients, OC appears to be a suitable care framework and a good alternative to compulsory hospitalisation.

For all patients in Sub-study II and all patients on first-time OC in Sub-study I, OC was implemented after compulsory hospitalisation. This confirms the general view that OC orders are very rarely or never implemented for outpatients without a prior admission.

Decision makers (Sub-study III) said that the purpose of establishing OC was to ensure continued medication after discharge and that the patient had no possibility to avoid outpatient care. In terms of legislation, OC was usually justified by the treatment criterion alone, with just a few exceptions where the dangerousness criterion was applied together with the treatment criterion (results in Sub-studies I and III). This was not unexpected, since it is reasonable to assume that decision makers perceive their social responsibility as helping and treating patients, rather than exercising power and control.

All the sub-studies show that antipsychotic medications are important both for the content of OC and as a justification for the scheme. The finding that medication treatment was a key factor in OC was expected, and confirms the assumptions presented in NOU 2011:9, p. 93 and results from international studies (Høyer & Ferris, 2001; Churchill et al., 2007; Dawson, 2005).

In Sub-study I, an attempt was made to identify more closely the nature of the non-medication treatment for first-time OC patients. We found that for 39 of 54 patients, another form of treatment in addition to medication was mentioned when OC was commenced. However, the quality of this data is poor because there is no clear description what these various measures actually implied, and they could not be categorised. It was also not possible to determine whether what was described was actually implemented. The patients

interviewed (Sub-study II) said that appointments with care services were often limited to depot injections or the provision of medicines, but they also describe various milieu therapeutic measures and a few also mention treatment talks with the decision maker. It is also possible that the study reveals the perspectives and responsibilities of decision makers, which mainly concern medication, while other health professionals are responsible for rehabilitation and psychosocial interventions. However, it is rather unclear what the treatment need referred to in OC decisions really implies.

#### **7.4 Is OC practised as a supplement or as an alternative to compulsory inpatient care?**

Churchill and colleagues' (2007) categorical presentation of two main forms of practice is largely based on legal texts, not on practice. The division of OC into either a less restrictive treatment or a socially protective treatment is too narrow to be applied to OC as practised in Norway. Although it has previously been claimed that Norway practises OC as the least restrictive treatment option (Sjøstrøm, Zetterberg & Markstrøm, 2011), it would be reasonable to expand the question to include how the legislation is understood and how practice is exercised. The legislation assumes that the patient has a severe mental disorder. A commonly used tool to measure a patient's psychosocial functioning is the Global Assessment of Functioning (GAF), where 1 is the lowest conceivable level of functioning and 100 is the maximum (Goldman, Skodol & Lave, 1992). RCT studies of OC have used GAF as a measure of clinical outcome and both of the studies from the USA (Swartz et al., 1999; Swanson et al., 2000) found that OC patients had scores close to 50, while Burns and colleagues (2013) found scores close to 40. Studies of hospitalised patients show a lower score, often around 30 (Poulsen, 1999; Fuglseth et al., 2016). This could suggest that patients discharged to OC have better functioning than those subject to compulsory hospitalisation.

Restrictions and coercion must be limited to what is strictly necessary, and the effect should be so beneficial that it clearly outweighs the disadvantages of the intervention (Mental Health Act of 7 February 1999, § 4-2). The present study suggests that OC is practised as a safety net to maintain stability or improve the patient's condition. It is impossible to conclude whether OC is practised as a supplement to coercive inpatient care or a less restrictive treatment

option in the study catchment area based on the study data. Several factors indicate that there is no clear distinction between OC as a supplement and OC as an alternative. An example is how decision makers consider discontinuing OC; here the study shows that they have different understandings and professional approaches. Some chose to terminate OC when they felt that the treatment outcome was satisfactory, while others largely attributed a satisfactory treatment outcome to the coercive framework, and OC was maintained. This demonstrates different understandings of how the coercive framework and legislation are interpreted and practised, and what a satisfactory treatment outcome results in. How long the patient is on OC is affected by the decision maker's individual attitudes and understanding of the scheme, and coercion may be either maintained or terminated on the basis of a satisfactory outcome. International studies have also described different understandings of OC among decision makers (Rugkåsa, 2016). A study from England and Wales showed that some decision makers had never used OC, while others had used it more than 100 times since its introduction in 2008 (DeRidder et al., 2016).

One weakness of the study is that it does not include data on patients' decision-making competence. On the basis of studies showing that patients on OC have a higher level of functioning than patients in inpatient care and that OC in itself requires the patient to be able to follow an outpatient programme that he/she may partly disagree with, it is uncertain whether OC is a viable alternative if the legislation is amended to require that patients must lack decision-making competence in order to be subjected to coercion. Nevertheless, it is reasonable to assume that OC allows patients to be discharged earlier than if OC was not a treatment option. The differences we find in the practice of OC will affect whether OC means that a patient is under coercion for longer, or whether the patient is under a less restrictive form of coercion than the alternative. Whether OC in Norway is practised as a supplement or as an alternative to inpatient care is still unclear.

## **7.5 Implications for clinical practice**

The present study indicates a need for increased awareness among clinicians of what patients experience as coercion when they are subject to OC. In order to understand patients' experiences of coercion, clinicians must realise that coercion under OC goes beyond the

understanding of coercion usually associated with compulsory hospitalisation. Although clinical assessments suggest that OC is justified, the principle of minimum harm should be taken into account to allow the patient's freedom of action to be curtailed as little as possible. Whether the patient actually has a better life under OC should be the basis for assessment. This requires clinicians to focus on balancing restrictions on the patient's freedom of action against the treatment effect.

There is also a need for clinical practice to enhance procedures for recording data in order to provide clearer answers as to the treatment effect of OC. This applies to how legal status is recorded in DIPS and also to documentation of the admission process in the patient record, in order to ascertain whether the admission was truly voluntary or not. This data must therefore be recorded in DIPS in a user-friendly manner.

## **7.6 Need for further research on OC**

As long as it is unclear what effect OC has on treatment outcome, the need for increased knowledge is clearly a priority research area. There is also a need to examine the types of measures used to determine OC treatment outcomes. Readmission as an outcome measure should distinguish between voluntary and involuntary hospitalisation. Studies of the outcome of treatment should take place over an extended period.

The present study shows different understandings of the potential and manifestations of coercion in OC and demonstrates a need for further knowledge in this area. Here, studies of informal coercion will be important, with a particular focus on practices in primary health care. In this context, studies of what prevents voluntariness, possible alternative solutions to OC and forced medication in OC will all be relevant. There is also a need for further study of whether OC is practised as a supplement or alternative to compulsory inpatient care.

Based on my general knowledge of coercion and experiences from this study, there is also a need for more knowledge about the system of legal protection for patients on OC.

## 7.7 Conclusion

This study shows that decision makers considered their possibilities to use coercion as not very restrictive, since OC in Norway has a weak coercive potential. Patients, however, found OC to be very restrictive of their autonomy and freedom of expression, as the familiar rules and routines from hospital moved into their home. Through the administration of medication, compulsory outpatient appointments and practical and medical help in the home, everyday life must be adapted to the structures of health care. The positive aspects of OC emphasised by patients have little to do with coercion, but show that help is seen to be useful if patients are allowed to decide what kind of help they need and when they need it.

The informal grey zone coercion that emerges from the study is problematic. Decision makers are probably less aware of this because patients undercommunicate their burden for fear of further restrictions. This probably gives rise to an understanding among decision makers that OC is less restrictive for patients than it actually is. In deciding whether to use OC, the basic criterion should be whether the patient will actually have a better life under OC. This requires a focus where the patient's burden and restrictions on the patient's freedom must be balanced against the treatment effect, and the patient's perspective and perceived burdens must be emphasised.

OC is intended to reduce the number of admissions and the total number of days in inpatient care, and readmissions have until now been one of the most widely used outcome measures to determine whether OC is a suitable form of treatment. This study shows that patients who were under OC for the first time had more days in inpatient care in the three years after their first OC order than in the three years before, and also that patients find admission to be useful when they can decide it themselves. There is therefore a need to distinguish between involuntary and voluntary readmission in future studies aimed at assessing the treatment effect of OC.

## 8 References

- Ajzenstadt, M., Aviram, U., Kalian, M. & Kanter, A. (2001). Involuntary outpatient commitment in Israel: Treatment or control? *International Journal of Law and Psychiatry*, 24, 637-65.
- Appelbaum, P. S. (2001) Thinking Carefully About Outpatient Commitment. *Psychiatric Services*, 53, 347-350.
- Beauchamp, T. L. & Childress, J. F. (2009). *Principles of biomedical ethics*. 6th ed. Oxford: Oxford University Press, p. 99.
- Bhopal, R. (2002). *Concepts of epidemiology: an integrated introduction to the ideas, theories, principles and methods of epidemiology*. Oxford: University Press.
- Bjørngen, D., Norvoll, R. & Husum, T. (2015). Hvordan forebygge tvang? [How to prevent coercion]. *Tidsskrift for Norsk psykologforening*, 52, 1076-1079.
- Bremnes, R., Hatling, T. & Bjørngaard, J. H. (2008). *Bruk av tvungent psykisk helsevern uten døgnomsorg i 2007. Bruk av legemidler uten samtykke utenfor institusjon i 2007* (SINTEF A8237) [The use of compulsory outpatient care in mental health in 2007. The use of medication without consent for outpatients in 2007]. Available from: <https://www.sintef.no/en/publications/publication/download/?pubId=SINTEF+A8237>
- Burns, T., Rugkåsa, J., Molodynski, A., Dawson, J., Yeeles, K., Vazquez-Montes, M., Voysey, M., Sinclair, J. & Priebe, S. (2013). Community treatment orders for patients with psychosis (OCTET): a randomised controlled trial. *Lancet*, 381, 1627-33.
- Burns, T., Yeeles, K., Koshari, C., Vazquez-Montes, M., Molodynski, A., Puntis, S., Vergunst, F., Forrest, A., Mitchell, A., Burns, K. & Rugkåsa. (2015). Effect of increased compulsion on readmission to hospital or disengagement from community services for patients with psychosis: follow-up of a cohort from the OCTET trial. *Lancet Psychiatry*, 10, 881-890
- Canvin, C., Rugkåsa, J., Sinclair, J. & Burns, T. (2014). Patient, psychiatrist and family carer experiences of community treatment orders: qualitative study. *Social Psychiatry & Psychiatric Epidemiology*, 49, 1873-82.
- Canvin, K., Bartlett, A. & Pinfold, V. (2005). Acceptability of compulsory powers in the community: the ethical considerations of mental health service users on Supervised Discharge and Guardianship. *Law, Ethics and Medicine*, 31, 457-462.
- Canvin, K. (in press). Patient experiences and perceptions of coercion: universal meaning, individual experiences?. In; A. Molodynski, J. Rugkåsa, J., T. Burns, T. (eds). *Coercion in Community Mental Health Care: International Perspectives*. Oxford: Oxford University Press.
- Canvin, C., Bartlett, A. & Pinfold, V. (2002). A 'bittersweet pill to swallow': learning from mental health service users' responses to compulsory community care in England. *Health and Social Care in the Community*, 10, 361-369.
- Churchill, R., Owen, G., Hotopf, M. & Singh, S. (2007). *International experiences of using community treatment orders*. London: Department of Health and Institute of Psychiatry, King's College London.
- Dawson J. (2005). *Community treatment orders: international comparisons*. University of Otago: Dunedin.
- Dawson, J. & Mullen, R. (2008). Insight and use of community treatment orders. *Journal of Mental Health*, 17, 3, 269-80.

- DeRidder, R., Molodynski, A., Manning, C., McCusker, P. & Rugkåsa, J. (2016). Community Treatment Orders in the UK 5 years on: a repeat national survey of psychiatrists. *The British Psychiatric Bulletin*, 40, 119-123.
- Edmonds, W. A & Kennedy, T. D (2013). *An applied Reference Guide to Research Designs. Quantitative, Qualitative and Mixed Methods*. Los Angeles: SAGE Publications.
- Forskningsetiske komiteer/Norwegian National Research Ethics Committees. (2010). *Veiledning for forskningsetisk og vitenskapelig vurdering av kvalitative forskningsprosjekter innen medisin og helsefag* [Guidelines for ethical and scientific evaluation of qualitative research projects in medicine and health sciences]. Available from: <https://www.etikkom.no/globalassets/documents/publikasjoner-som-pdf/kvalitative-forskningsprosjekt-i-medisin-og-helsefag-2010.pdf>
- Frank, A. (2010). *Letting Stories Breathe: A Socio-narratology*. Chicago: University of Chicago Press.
- Fuglseth, N. L. D., Gjerstad, R., Mellesdal, L., Hunskaar, S., Odegaard, K. J. & Johansen, I. H. (2016). Factors associated with disallowance of compulsory mental healthcare referrals. *Acta Psychiatrica Scandinavica*, 1-9, DOI: 10.1111/acps.12545.
- Geller, J. F. (2006). The evolution of outpatient commitment in the USA: From conundrum to quagmire. *International Journal of Law and Psychiatry*, 29, 234-248.
- Georgakopoulou, A. (2006). Thinking big with small stories in narrative and identity analysis. *Narrative inquiry*, 16, 122-130
- Gibbs, A. (2010). Coping with Compulsion: Women's Views of Being on a Community Treatment Order. *Australian Social Work*, 63, 223-233.
- Gibbs, A., Dawson, J., Ansley, C. & Mullen, R. (2005). How patients in New Zealand view community treatment orders. *Journal of Mental Health*, 14, 357-368
- Gold, E. (2007). From narrative wreckage to islands of clarity. Stories of recovery from psychosis. *Canadian Family Physician*, 53, 1271-1275.
- Goldman, H. H., Skodol, A. E. & Lave, T. R. (1992). Revising axis V for DSM-IV: a review of measures of social functioning. *American Journal of Psychiatry*, 149, 1148-1156.
- Gray, J. E. & O'Reilly R. L. (2005). Canadian compulsory community treatment laws: Recent reforms. *International Journal of Law and Psychiatry*, 28, 13-22.
- Grims, D. A. & Schulz, K. F. (2002). Descriptive studies: what they can and cannot do. *Lancet*, 12, 145-149.
- Hatling, T. (2013). Bruk av tvang i psykiske helsetjenester [The use of coercion in mental health care]. In R. Norvoll (ed.) *Samfunn og psykisk helse. Samfunnsvitenskaplige perspektiver* [Society and mental health. Perspectives from social science]. (pp. 243-284). Oslo: Gyldendal Akademisk.
- Helsedirektoratet/Norwegian Directorate of Health. (2015). SAMDATA spesialisthelsetjenesten 2014 [SAMDATA Specialist health services] (IS-2348). Oslo: Helsedirektoratet.
- Helsedirektoratet/Norwegian Directorate of Health. (2012). Psykisk helsevernloven og psykisk helsevernforeskriften med kommentarer [The Mental Health Act and the Mental Health Regulations with commentary] (IS-9/2012). Oslo: Helsedirektoratet.
- Helseforskningsloven/The Health Research Act (2008). Lov om medisinsk og helsefaglig forskning [The Medical and Health Research Act]. LOV-2008-06-20-44. Available from: <https://lovdata.no/dokument/NL/lov/2008-06-20-44>
- Helsetilsynet/The Norwegian Board of Health Supervision. (2006). *Bruk av tvang i psykisk helsetjeneste* (4/2006) [The use of coercion in mental health services]. Available from:

[https://helsetilsynet.no/upload/Publikasjoner/rapporter2006/helsetilsynetrapport4\\_2006.pdf](https://helsetilsynet.no/upload/Publikasjoner/rapporter2006/helsetilsynetrapport4_2006.pdf)

- Heskestad, S. & Tytlandsvik, M. (2008). Brukerstyrte kriseinnleggelser ved alvorlig psykisk lidelse [User-driven emergency admissions for serious mental illness]. *Tidsskriftet for den norske legeforening* 128, 32-35.
- Høyser, G. (2011). Hva vet vi (ikke)? [What do we (not) know?] *Impuls tidsskrift for psykologi*, 3, 8-11.
- Høyser, G. & Ferris, R. (2001). Outpatient Commitment. Some Reflections on Ideology, Practice and Implications for Research. *Journal of Mental Health Law*, 6, 56-65.
- Høyser, G. (1986). *Tvungent psykisk helsevern i Norge. Rettssikkerheten ved slikt helsevern med særlig vurdering av kontrollkommisjonsordningen* [Compulsory mental health care in Norway. Legal protection in this health care, with a particular assessment of the control commission scheme] Tromsø: Institutt for samfunnsmedisin, Universitetet i Tromsø.
- Høyser, G. (2016). Kontrollkommisjonene i psykisk helsevern: Herman Wedel Majors nyskaping [The control commissions in mental health care. Wedel Major's innovation]. *Tidsskrift for norsk legeforening*, 136, 1109-1112.
- International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10). Available from: <http://www.icd10data.com/ICD10CM/Codes/F01-F99/F20-F29/F20->
- Kemshall, H. (2002). *Risk, social policy and welfare*. Buckingham: Open University Press.
- Kisely, S., Xiano, J., Crowe, E., Paydra, A. & Jian, L. (2014). The effect of community treatment orders on outcome as assessed by the Health of the Nation Outcome Scales. *Psychiatry Research*, 215, 574-578.
- Kisely, S., Preston, N., Xiao, J., Lawrence, D., Louise, S., Crowe, E., & Segal, S. (2013). An eleven-year evaluation of the effect of community treatment orders on changes in mental health service use. *Journal of Psychiatric Research*, 47, 650-656.
- Kisely, S. & Campbell, L. A. (2014). Compulsory community and involuntary outpatient treatment for people with severe mental disorders. *Cochrane Database Systematic Review*, 12, CD004408.
- Kisely, S. & Hall, K. (2014). An updated meta-analysis of randomized controlled evidence for the effectiveness of community treatment orders. *The Canadian Journal of Psychiatry*, 59, 561-564.
- Kitzinger, J. (1995). Introducing focus groups. *BMJ*, 211, 299-302.
- Kvale, S. & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing*. London: Sage.
- Lag om psykiatrisk tvångsvård. [The Mental Health Act 1991] 20 June 1991 No. 1128 Sweden. Available from: <http://www.notisum.se/rnp/sls/lag/19911128.HTM>
- Lamb, R. H. & Bachrach, L. L. (2001). Some Perspectives on Deinstitutionalization. *Psychiatric Services* 52, 1039-1045.
- Lera-Calatayud, G., Hernandez-Viadel, M., Bellido-Rodriguez, C., Canete-Nicolas, C., Asensio-Pascual, P., Calabuig-Crespo, R. & Leal-Cercos, C. (2014) Involuntary outpatient treatment in patients with severe mental illness: A one-year follow-up study. *International Journal of Law and Psychiatry*, 37, 267-271.
- Lov om psykisk helsevern/The Mental Health Act (1961). *Lov om psykisk helsevern av 28. april 1961 nr. 2* [The Mental Health Act of 28 April 1961 No. 2]



- Lov om anvendelse af tvang i psykiatrien. [The Act on the Use of Coercion in Mental Health Care] 2 December 2010 No. 1729 Denmark. Available from: <https://www.retsinformation.dk/forms/r0710.aspx?id=174248>
- Malterud, K. (2003). *Kvalitative metoder i medisinsk forskning. En innføring* [Qualitative methods in medical research: An introduction]. (4th edition, 2008). Oslo: Universitetsforlaget.
- Manning, C., Molodynski, A., Rugkåsa, J., Dawson, J. & Burns, T. (2011). Community treatment orders in England and Wales: national survey of clinicians' views and use. *The Psychiatrist*, 35, 328-333.
- Maughan, D., Molodynski, A., Rugkåsa, J. & Burns, T. (2014). A systematic review of the effect of community treatment orders on service use. *Social Psychiatry and Psychiatric Epidemiology*, 49, 651-63.
- Ministry of Health and Care Services. (1998) *Om lov om etablering og gjennomføring av psykisk helsevern (psykiatriloven)* [Act on the Establishment and Implementation of Mental Health Care (the Mental Health Act)]. (Ot.prp. nr. 11 (1998-99)). Assessed 03 Juni 2016. <https://www.regjeringen.no/no/dokumenter/otprp-nr-11-1998-99-/id159399/?ch=1&q=>
- Ministry of Health and Care Services. (2006) *Om lov om endringer i psykisk helsevernloven og pasientrettighetsloven* [Concerning amendments to the Mental Health Act and the Patient Rights Act]. (Ot.prp. nr. 65 (2005-2006)). Available from: <https://www.regjeringen.no/no/dokumenter/otprp-nr-65-2005-2006-/id188320/?ch=1&q=>
- Mullen, R., Dawson, J. & Gibbs, A. (2006). Dilemmas for clinicians in use of Community Treatment Orders. *International Journal of Law & Psychiatry*, 29, 6, 535-50.
- Tvangsforsk (Norwegian Research Network on Coercion in Mental Health Care) (2009). *Forskning om bruk av tvang i det psykiske helsevernet 2009-2014. Prioriterte anbefalinger utarbeidet av Nettverk for forskning og kunnskapsutvikling om bruk av tvang i det psykiske helsevernet*. [Research on the use of coercion in mental health care 2009-2014. Priority recommendations prepared by the Norwegian Research Network on Coercion in Mental Health Care]. Available from: [http://www.tvangsforskning.no/filarkiv/File/Dokumenter/Prioriterte\\_anbefalinger\\_19\\_4\\_2010.pdf](http://www.tvangsforskning.no/filarkiv/File/Dokumenter/Prioriterte_anbefalinger_19_4_2010.pdf)
- Norvoll, R. (2006). *Det lukkede rom. Bruk av skjerming som behandling og kontroll i psykiatriske akuttposter* [The closed room. The use of seclusion as treatment and control in psychiatric emergency wards]. Oslo: Universitetet i Oslo.
- Norwegian Directorate of Health (2010) *Bruk av tvang i psykisk helsevern for voksne i 2009* (The use of coercion in mental health care for adults in 2009). IS-1861. <http://helsedirektoratet.no/publikasjoner/bruk-av-tvang-i-psykisk-helsevern-for-voksne-i-2009/Publikasjoner/bruk-av-tvang-i-psykisk-helsevern-for-voksne-i-2009.pdf>
- Norwegian Directorate of Health. (2014). *Bruk av tvang i psykisk helsevern for voksne i 2013* [The use of coercion in mental health care for adults in 2013]. Available from: <https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/669/Bruka-av-tvang-i-psykisk-helsevern-for-voksne-i-2013-IS-2243.pdf>
- Norwegian Directorate of Health. (2016). *Bruk av tvang i psykisk helsevern for voksne i 2014* [The use of coercion in mental health care for adults in 2014]. Available from:

<https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/1161/Rapport%20om%20Otvang%20IS-2452.pdf>

- NOU 2011:9 (2011). Økt selvbestemmelse og rettssikkerhet. Balansegangen mellom selvbestemmelsesrett og omsorgsansvar i psykisk helsevern. [Increased self-determination and legal safeguards. The balancing act between the right to self-determination and care responsibilities in mental health care] Oslo: Ministry of Health and Care Services.
- NOU: 1988: 8 (1988). Lov om psykisk helsevern uten eget samtykke [The Act on Mental Health Care without Consent]. Oslo: Ministry of Health and Care Services.
- Nytingnes, O. & Husum, T. L. (2011). Omfang, utvikling og geografisk variasjon i bruk av tvang i psykisk helsevern i Norge [The extent, development and geographical variation of the use of coercion in mental health care in Norway]. *Impuls tidsskrift for psykologi*, 3, 20-32.
- O'Brien, A-M. A. & Farrell, S. (2005). Community treatment orders: Profile of a Canadian Experience. *Canadian Journal of Psychiatry*, 50, 27-30.
- Olsø, T. M., Gudde, C. Moljord, I. E. O., Evensen, G. H., Antonsen, D. Ø. & Eriksen, L. (2016). More than just a bed: mental health service users' experiences of self-referral admission. *International Journal of Mental Health System*, 10, 11. Available from: <https://ijmhs.biomedcentral.com/articles/10.1186/s13033-016-0045-y>
- O'Reilly, R. L., Keegan, D. L., Corring, D., Shrikhande, S. & Natarajan, N. (2006). A qualitative analysis of the use of community treatment orders in Saskatchewan. *International Journal of Law and Psychiatry* 29, 516-524.
- O'Reilly, R.L., Dawson, J. & Burns, T. (2012). Best practices in the use of involuntary outpatient treatment. *Psychiatric Services*, 63, 421-423.
- Øye, C. & Norvill, R. (2013). Psykisk helsearbeid i et makt og kontrollperspektiv [Mental health care in a power and control perspective]. In R. Norvoll (ed.) *Samfunn og psykisk helse. Samfunnsvitenskaplige perspektiver* [Society and mental health. Perspectives from social science]. (p. 73-96). Oslo: Gyldendal Akademisk.
- Pedersen, P. B. (2002). Deinstitutionalisering av det psykiske helsevernet [Deinstitutionalisation of mental health care]. In R. Norvoll (ed.) *Samfunn og psykiske lidelser. Samfunnsvitenskaplige perspektiver – en introduksjon* [Society and mental health. Perspectives from social science]. (pp. 187-203). Oslo: Gyldendal Akademisk.
- Pedersen, P. B., Hatling, T. & Bjørngaard, J. H. (2004). Tvungent psykisk helsevern uten døgnopphold 2002 (STF78 A045003) [Compulsory outpatient care in mental health 2002]. Available from: [http://www.sintef.no/globalassets/upload/helse/psykisk-helse/pdf-filer/stf78\\_a045003---tvungent-psykisk-helsevern-uten-dognopphold-i-2002.pdf](http://www.sintef.no/globalassets/upload/helse/psykisk-helse/pdf-filer/stf78_a045003---tvungent-psykisk-helsevern-uten-dognopphold-i-2002.pdf)
- Player, C. T. L. (2015). Outpatient commitment and procedural due process. *International Journal of Law and Psychiatry*, 38, 100-113.
- Poulsen, H. D. (1999). Perceived coercion among committed, detained and voluntary patients. *International journal of Law and Psychiatry*, 22, 167-175.
- Psykisk helsevernforskriften/The Mental Health Regulation. FOR-2011-12-16 nr 1258. Forskrift om etablering og gjennomføring av psykisk helsevern m.m. [Regulation on the Establishment and Implementation of Mental Health Care, etc.] Available from: [https://lovdata.no/dokument/SF/forskrift/2011-12-16-1258#KAPITTEL\\_4](https://lovdata.no/dokument/SF/forskrift/2011-12-16-1258#KAPITTEL_4)
- Psykisk helsevernloven/The Mental Health Act. Lov om etablering og gjennomføring av psykisk helsevern [Act on the Establishment and Implementation of Mental Health

- Care]. 2 July 1999 No. 62 Norway. Available from:  
[http://lovdata.no/dokument/NL/lov/1999-07-02\\_62?q=psykisk+helsevern](http://lovdata.no/dokument/NL/lov/1999-07-02_62?q=psykisk+helsevern)
- Raffard, S., D'Argembeau, A., Lardu, C., Bayard, S., Beulenger, J. P. & Linden, M. V. (2010). Narrative identity in schizophrenia. *Consciousness and Cognition*, 19, 328-340.
- Ridley, J. & Hunter, S. (2013). Subjective experiences of compulsory treatment from a qualitative study of early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003. *Health and Social Care in the Community* 21, 509-518.
- Riessman, C. K. (2008). *Narrative Methods for the Human Sciences*. California: Sage Publications, Inc.
- Romans, S., Dawson, J., Mullen, R. & Gibbs, A. (2004). How mental health clinicians view community treatment orders: a national New Zealand survey. *Australian & New Zealand Journal of Psychiatry*, 38, 836-841.
- Rugkåsa, J. (2016). Effectiveness of community treatment orders: The international evidence. *The Canadian Journal of Psychiatry*, 61, 15-24.
- Rugkåsa, J. (2011). Compulsion in the community. An overview of legal regimes and current evidence. *Impuls tidsskrift for psykologi*, 3, 56-63.
- Rugkåsa, J., Molodynski, A., Yeeles, K., Vazquez Montes, M., Visser, C. & Burns, T. (2015). Community treatment orders: clinical and social outcomes, and a subgroup analysis from the OCTET RCT. *Acta Psychiatrica Scandinavica*, 131, 321-329.
- Rugkåsa, J., Dawson, J. & Burns, T. (2014) CTOs: what is the state of the evidence? *Social Psychiatry and Psychiatric Epidemiology*, 49, 1861-1871.
- Scheid-Cook, T. L. (1993). Controllers and controlled: an analysis of participant constructions of outpatient commitment. *Sociology of Health & Illness*, 15, 179-198.
- Schwartz, K., O'Brien, A-M., Morel, V., Armstrong, M., Fleming, C. & Moore, P. (2010). Community Treatment Orders: The Service User Speaks Exploring the Lived Experience of Community Treatment Orders. *The International Journal of Psychosocial Rehabilitation*, 15, 39-50.
- Sjøstrøm, S. (2012). Det diffusa tvånget. Patienters opplevelser av åpen tvångsvård [Diffuse coercion. Patient experiences of open coercive care]. *Socialstyrelsen* 2012-1-35. Available from: <http://www.socialstyrelsen.se/publikationer2012/2012-1-35>
- Sjøstrøm, S., Zetterberg, L. & Markstrom, U. (2011). Why community compulsion became the solution — Reforming mental health law in Sweden. *International Journal of Law and Psychiatry*, 34, 419-428.
- Sosialdepartementet/Ministry of Social Affairs. (1955). Innstilling fra komiteen til revisjon av sinnssykelovgivningen. Avgitt 31. mars 1955 [Report from the committee for revision of the Insanity Act. Delivered 31 March 1955] Oslo: 1955.
- Sosial- og helsedirektoratet/Ministry of Health and Social Affairs. (2006). Tiltaksplan for redusert og kvalitetssikret bruk av tvang [Action plan for the reduction and quality assurance of the use of coercion] (IS-1370). Oslo: Sosial- og helsedirektoratet.
- Steadman, H. J., Gounis, K., Dennis, D., Hopper, K., Roche, B., Swartz, M. & Robbins, P. C. (2001). Assessing the New York City Involuntary Outpatient Commitment Pilot Program. *Psychiatric Services*, 52, 330-336.
- Stensrud, B., Høyer, G., Granerud, A. & Landheim, A. S. (2015). "Life on Hold": A Qualitative Study of Patient Experiences with Outpatient Commitment in Two Norwegian Counties. *Issues in Mental Health Nursing*, 36, 209-216.

- Stensrud, B., Høyer, G., Granerud, A. & Landheim, A. S. (2016). “Care or control?”: a qualitative study of staff experiences with outpatient commitment orders. *Social Psychiatry and Psychiatric Epidemiology*, DOI 10.1007/s00127-016-1193-8.
- Stroud, J., Banks, L. & Doughty, L. (2015). Community treatment orders: learning from experiences of service users, practitioners and nearest relatives. *Journal of Mental Health*, 24, 88-92.
- Swanson, J. W. & Swartz, M. S. (2014). Why the Evidence for Outpatient Commitment Is Good Enough. *Psychiatric Services*, 65, 808-811.
- Swartz, M. S., Swanson, J. W., Steadman, H. J., & Monahan, J. (2009). *New York State Assisted Outpatient Treatment Program Evaluation*. Available from: [https://www.omh.ny.gov/omhweb/resources/publications/aot\\_program\\_evaluation/report.pdf](https://www.omh.ny.gov/omhweb/resources/publications/aot_program_evaluation/report.pdf)
- Swartz, M., Swanson, J. D., Wagner, H., Burns, B., Hiday, V. & Borum, R. (1999). Can involuntary outpatient commitment reduce hospital recidivism? Findings from a randomized trial with severely mentally ill individuals. *American Journal of Psychiatry*, 156, 1968-1975.
- Swartz, M. S., Swanson, J. W., Wagner, H. R., Hannon, M. J., Burns, B. J. & Shumway, M. (2003). Assessment of Four Stakeholder Groups’ Preferences Concerning Outpatient Commitment for Persons With Schizophrenia. *American Journal of Psychiatry*, 160, 1139-1146.
- Swartz, M. & Swanson, J. (2004). Involuntary outpatient commitment, community treatment orders, and assisted out-patient treatment: what’s in the data? *Canadian Journal of Psychiatry*, 49, 585–591.
- Szmukler, G. (2015). Is there a place for community treatment orders after the OCTET study? *Acta Psychiatrica Scandinavica*, 131, 330-332.
- Tashakkori, A. & Teddlie, C. B. (2002). *Mixed methodology: combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage
- Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349–357.
- Wertheimer, A. (1993). A philosophical examination of coercion for mental health issues. *Behavioral Sciences and the Law*, 11, 239-258.
- Wynn, R. (2004). Psychiatric inpatients' experiences with restraint. *Journal of Forensic Psychiatry & Psychology*, 15, 124-144.
- Zettberg, L., Sjöström, S. & Markström, U. (2014). The compliant court — Procedural fairness and social control in compulsory community care. *International Journal of Law and Psychiatry*, 37, 543–550.

# Appendices

- **Paper I**
- **Paper II**
- **Paper III**
- **Appendix I Documentation of approval**
  - REK approval
  - Approval by clinical manager
- **Appendix II Information about the research project**
  - Information letter, etc. for qualitative part of study
  - Declaration of consent
  - Information about the study for decision makers (email)
- **Appendix III Registration form with guidelines and interview guides**
  - Interview guides
  - Registration form and guidelines



# Appendix I

## Documentation of Approval





---

<b>Region:</b>	<b>Saksbehandler:</b>	<b>Telefon:</b>	<b>Vår dato:</b>	<b>Vår referanse:</b>
REK nord	Monika Rydland Gaare	77620756	13.05.2011	2010/2268/REK nord
			<b>Deres dato:</b>	<b>Deres referanse:</b>
			12.05.2011	

Vår referanse må oppgis ved alle henvendelser

Georg Høyer  
ISM, Universitetet i Tromsø

## 2010/2268 - TVUNGEN T PSYKISK HELSEVERN UTEN DØGNOPPHOLD

Vi viser til komiteens vedtak av 04.05.2011 vedrørende søknad om dispensasjon fra taushetsplikt og prosjektleders tilbakemelding av 12.05.2011.

Etter fullmakt har komiteens leder fattet slikt

### vedtak:

*Med hjemmel i helseforskningsloven § 10 og forskningsetikkloven § 4 godkjennes prosjektet. Med hjemmel i helseforskningsloven § 35 gis det dispensasjon fra taushetsplikt for innhenting av data fra journal, som nevnt i søknad. Den person det gis dispensasjon for er Henriette Riley.*

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Dersom prosjektleder ønsker å foreta vesentlige endringer i forskningsprosjektets formål, metode, tidsløp eller organisering i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK. Vi gjør oppmerksom på at hvis endringene av prosjektet er så store at det må anses å være et helt nytt prosjekt, må prosjektleder sende ny søknad, eller REK kan pålegge at det sendes ny søknad.

Det forutsettes at forskningsdata oppbevares forskriftsmessig.

Godkjenningen gjelder til 31.12.2013

Prosjektleder skal sende sluttmelding i henhold til helseforskningsloven § 12.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. forvaltningsloven § 28 flg. Eventuell klage sendes til REK Nord. Klagefristen er tre uker fra mottak av dette brevet.

Vi ber om at alle henvendelser sendes inn via vår saksportal: <http://helseforskning.etikkom.no> eller på e-post til: [post@helseforskning.etikkom.no](mailto:post@helseforskning.etikkom.no)

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

May Britt Rossvoll  
sekretariatsleder

Monika Rydland Gaare  
Førstekonsulent

**Kopi til:** [tordis.sorensen.hoifodt@unn.no](mailto:tordis.sorensen.hoifodt@unn.no),

# Appendix II

Information about the study



# Forespørsel om deltakelse i forskningsprosjektet

## Tvunget psykisk helsevern uten døgnopphold (TUD)

**Vi vil med dette spørre deg om du kunne tenke deg å delta i et forskningsprosjekt om hvordan det er å være på tvunget psykisk helsevern uten døgnopphold. Nedenfor vil du finne informasjon om hva prosjektet går ut på og hva det innebærer for deg om du deltar.**

### **Bakgrunn og hensikt**

Formålet med studien er å få fram pasienter og helsepersonell sine erfaringer og meninger om tvunget psykisk helsevern uten døgnopphold (TUD). Vi ønsker å finne ut hvordan pasienter og behandlere oppfatter formålet med, innholdet i, og berettigelsen av TUD. Studien er et samarbeid mellom Allmennpsykiatrisk klinikk, Rus og spesialpsykiatrisk klinikk, Universitetspsykehuset i Nord-Norge (UNN) og Institutt for samfunnsmedisin ved Universitetet i Tromsø (UIT).

### **Hva innebærer studien?**

I prosjektet vil vi intervju 10 pasienter som er under tvunget psykisk helsevern uten døgnopphold. For deg vil det å delta innebære at du stiller opp til et intervju som vil vare fra 1-2 timer, alt etter hvor mye du ønsker å fortelle. I intervjuet ønsker vi at du deler dine erfaringer om hvordan du opplever å være på TUD og hvilke tanker du har om det å være på TUD. Vi er også interessert i å høre om din vurdering av egen helse og i hvilken grad du opplever å være i stand til selv å fatte beslutninger om din egen behandling. Du bestemmer selv hvor intervjuene skal gjennomføres dersom du vil delta. Det kan enten skje hjemme hos deg, på UNN i Tromsø eller et annet sted du foretrekker. Alle utgifter til reise, mat og lignende vil bli dekket.

Vi ønsker også å intervju den legen eller psykologen som er ansvarlig for ditt TUD vedtak, men bare om du gir tillatelse til at vi kan gjøre det. I så fall vil den som fattet ditt TUD vedtak få forespørsel om å delta i studien på lik linje med deg.

Intervjuene vil bli tatt opp på lydbånd. Bare forskeren som intervjuer deg og veileder vil ha adgang til lydbåndene. Lydbåndene vil bli ødelagt når prosjektet er fullført (01.04.2014).

En stund etter hovedintervjuet vil du bli innkalt til et nytt kortvarig intervju (ca 30 til 45 minutter) om hvordan du har det med den psykiske helsa, og i hvilken grad du klarer å fatte beslutninger om din egen behandling. Denne vurderingen vil bli foretatt av en psykiater og er en annen person enn den som først intervjuer deg.

Etter at forskeren har analysert intervjuene ønsker vi å se på sammenhengen mellom det som er sagt i intervjuene og det som står i journalen om TUD. Vi vil særlig se på hva som står i vedtaket om TUD og om det er laget en individuell plan for behandlingen du får.

Omtrent 4-5 dager etter at du har fått dette brevet vil du bli kontaktet av den forskeren som vil intervju deg for å høre om du vil være med eller ikke. Om du er i tvil eller ønsker mer informasjon, kan du enten vente lenger før du bestemmer deg, eller du kan få møte forskeren som senere eventuelt intervjuer deg, for å snakke om prosjektet før du bestemmer deg.

### **Mulige fordeler og ulemper**

Mulige fordeler med å delta i studien er at du vil kunne bidra til å øke kunnskapen om forhold som vedrører TUD. Det er ikke gjort noen studier i Norge om pasienter sine opplevelse av å være på TUD,

og vi ønsker derfor å få mer kunnskap om hva som er dårlig, hva som er bra og hva som kan bli gjort bedre for pasienter på TUD.

Det er ingen sikre ulemper med å delta i studien, men du som har erfaring med å være på TUD vil bli spurt om en del personlige spørsmål som kan gjøre at du har behov for å snakke med din behandler eller noen andre etterpå. Du vil derfor få tilbud om rask kontakt med din behandler eller en uavhengig psykiater i etterkant av intervjuet dersom du skulle ha behov for det.

### **Personvern. Hva skjer med informasjonen om deg?**

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste som oppbevares nedlåst og som er skilt fra alle opplysninger om deg selv. Det er kun forskeren som intervjuer deg som har adgang til navnelisten og som kan finne tilbake til deg. Forskere og forskningsveiledere tilknyttet prosjektet har lovpålagt taushetsplikt. All informasjon om deg vil bli slettet når studien er fullført. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Selv om det er et lavt antall pasienter som blir bedt om å være med (10 stykker) vil det ikke la seg gjøre å gjenkjenne deg på noen måte. Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede data og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

### **Økonomi**

Studien er finansiert fra Helse Nord sine midler for medisinsk og helsefaglig forskning, under Forskningsprogram for psykiatri og rus. Som deltaker i studien vil du ikke ha noen former for økonomiske utgifter.

### **Informasjon om utfallet av studien.**

Resultatene fra studien vil bli offentliggjort i form av vitenskapelig artikler. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dem som har deltatt som pasienter eller behandlere. Som deltaker vil du få tilsendt artiklene dersom du ønsker dette sammen med et enkelt sammendrag av hva vi finner ut.

### **Frivillig deltakelse**

Deltakelse i studien er frivillig. Om du ikke vil svare på enkelte spørsmål eller deler av intervjuet er det også helt i orden. Du kan også avbryte intervjuet når du vil dersom du ikke ønsker å fortsette. Du kan også velge å si ja til bare intervjuene og nei til vurderingene av en psykiater, eller omvendt.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling.

Dersom du har spørsmål til studien, kan du kontakte forsker Henriette Riley på tlf 776 44883/ 934 27 012, eller prosjektleder professor dr. med. Georg Høyner på tlf 776 44829, begge ved Institutt for Samfunnsmedisin ved Universitetet i Tromsø.

# Samtykke til deltakelse i studien. Sett et kryss for hver enkelt del du er villig til å delta i

Undertegnede har fått både muntlig og skriftlig informasjon om studien ”Tvungent psykisk helsevern uten døgnopphold”

**Jeg er villig til å delta i intervjustudien (hovedintervjuet)**

**Jeg er villig til at den som har fattet vedtaket om TUD i mitt tilfelle kan spørres om å delta i undersøkelsen**

**Jeg er villig til å la meg intervju av en psykiater for å vurdere min psykiske helse og beslutningsevne**

Dato

Navn (blokkbokstaver):

-----  
(Signatur)

**Dersom du har spørsmål til studien, kan du kontakte**

**Forsker Henriette Riley, tlf 776 44883/ 934 27 012**

**eller**

**Prosjektleder professor dr. med. Georg Høyer, tlf 776 44829**

**Adresse for begge: Institutt for Samfunnsmedisin ved Universitetet i Tromsø., 9037 Tromsø**





# Forespørsel om deltakelse i forskningsprosjektet

## Tvunget psykisk helsevern uten døgnopphold

**Vi vil med dette spørre deg om du kunne tenke deg å delta i et forskningsprosjekt om tvunget psykisk helsevern uten døgnopphold. Nedenfor vil du finne informasjon om hva prosjektet går ut på og hva det innebærer for deg om du deltar.**

### **Bakgrunn og hensikt**

Formålet med studien er å få frem pasienter og helsepersonell sine erfaringer og meninger om tvunget psykisk helsevern uten døgnopphold (TUD). Vi ønsker å finne ut hvordan pasienter og behandlere oppfatter formålet med, innholdet i, og berettigelsen av TUD. Studien er et samarbeid mellom Allmenpsykiatrisk klinikk, Rus og spesialpsykiatrisk klinikk, Universitetssykehuset i Nord-Norge (UNN) og Institutt for samfunnsmedisin ved Universitetet i Tromsø (UIT).

### **Hva innebærer studien?**

I prosjektet vil vi intervju 10 pasienter som er under tvunget psykisk helsevern uten døgnopphold og den legen eller psykologen som er ansvarlig for TUD vedtaket for den enkelte pasienten. Du forespørres om å delta i egenskap av at du har fattet vedtak om TUD for en av pasientene som er inkludert i studien. For ditt vedkommende håper vi at du i denne sammenhengen er villig til å stille opp i et intervju som vil vare ca 1 time. Det er snakk om et kvalitativt intervju der hovedfokus vil være hvordan du har vurdert behovet for at den aktuelle pasienten er underlagt TUD. Det understrekes at pasienten er informert om hensikten med å intervju deg, og at pasienten har samtykket i at vi spør deg om å delta.

Om du samtykker til å delta vil intervjuer (Ph:D student Henriette Riley) kontakte deg for avtale om tid og sted for intervjuet. Intervjuet vil bli tatt opp på lydbånd, som oppbevares til prosjektet er gjennomført (senest 1. april 2014). Båndet vil oppbevares nedlåst og vil ved prosjektslutt bli destruert. Bare forskeren som intervjuer deg og veileder vil ha adgang til lydbåndene.

Omtrent 4-5 dager etter at du har fått denne henvendelsen vil du bli kontaktet av den forskeren som skal intervju deg for å høre om du vil være med eller ikke. Om du ønsker mer informasjon, kan du be om et møte (enten personlig eller per telefon) med forskeren som senere eventuelt intervjuer deg, for å diskutere prosjektet før du bestemmer deg.

### **Mulige fordeler og ulemper**

Mulige fordeler med å delta i studien er at du vil kunne bidra til å øke kunnskapen om forhold som vedrører TUD. Det er ikke gjort noen studier i Norge om pasienter sine opplevelse av å være på TUD, og vi ønsker derfor å få mer kunnskap om hva som er dårlig, hva som er bra og hva som kan bli gjort bedre.

Det er ingen sikre ulemper med å delta i studien for deg som behandler.

### **Personvern. Hva skjer med informasjonen om deg?**

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenner opplysninger. Det er ikke knyttet personopplysninger til behandlerne som intervjues annet enn profesjon, stilling, alder, kjønn og antall år i klinisk praksis. En kode knytter deg til dine opplysninger gjennom en navneliste som oppbevares nedlåst og som er skilt fra alle opplysninger om deg selv. Det er kun forskeren som intervjuer deg som har adgang til navnelisten og som kan finne tilbake til deg.

Både forskere og forskningsveiledere tilknyttet prosjektet har lovpålagt taushetsplikt. All informasjon om deg vil bli slettet når studien er fullført. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede data og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

### **Økonomi**

Studien er finansiert fra Helse Nord sine midler for medisinsk og helsefaglig forskning, under Forskningsprogram for psykiatri og rus. Som deltaker i studien vil du ikke ha noen former for økonomiske utgifter.

### **Informasjon om utfallet av studien.**

Resultatene fra studien vil bli offentliggjort i form av vitenskapelig artikler. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dem som har deltatt som pasienter eller behandlere. Som deltaker vil du få tilsendt artiklene dersom du ønsker dette.

### **Frivillig deltakelse**

Deltakelse i studien er frivillig. Om du ikke vil svare på enkelte spørsmål eller deler av intervjuet er det også helt i orden. Du kan også avbryte intervjuet når du vil dersom du ikke ønsker å fortsette

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke.

Dersom du har spørsmål til studien, kan du kontakte forsker Henriette Riley på tlf 776 44883/ 934 27 012, eller prosjektleder professor dr. med. Georg Høyner på tlf 776 44829, begge ved Institutt for Samfunnsmedisin ved Universitetet i Tromsø.

# Samtykke til deltakelse i studien

Undertegnede har fått både muntlig og skriftlig informasjon om studien ”Tvungent psykisk helsevern uten døgnopphold”

**Jeg er villig til å delta i intervjustudien**

Dato:

Navn (Blokkbokstaver)

-----  
(Signatur)

**Dersom du har spørsmål til studien, kan du kontakte**

**Forsker Henriette Riley, tlf 776 44883/ 934 27 012**

**eller**

**Prosjektleder professor dr. med. Georg Høyer, tlf 776 44829**

**Adresse for begge: Institutt for Samfunnsmedisin ved Universitetet i Tromsø., 9037 Tromsø**



# Informasjonsskriv til kontaktperson for forskningsprosjekt om TUD

---

## Formål og bakgrunn

Formålet med studien er å få frem pasienter og helsepersonell sine erfaringer og meninger om tvungent psykisk helsevern uten døgnopphold (TUD). Vi ønsker å finne ut hvordan pasienter og behandlere oppfatter formålet, innholdet, og berettigelsen av TUD. Studien er et samarbeid mellom Allmennpsykiatrisk klinikk, Rus og spesialpsykiatrisk klinikk, Universitetssykehuset i Nord-Norge (UNN) og Institutt for samfunnsmedisin ved Universitetet i Tromsø (UIT).

Du er blitt spurt om å kontakte en mulig informant til studien for å spørre om vedkommende kan tenke seg å delta i studien. Du ble kontaktet fordi vedtaksansvarlig for den mulige informanten har oppgitt deg som kontaktperson for han/henne. Når du forespør den aktuelle informanten om deltakelse i studien ønsker vi at dere sammen går gjennom informasjonsskrivet og forsikrer at informanten forstår innholdet. Dersom noe er uklart er du/dere velkommen til å kontakte forsker eller prosjektleder for utdypninger eller spørsmål. Det er mulig å avtale et personlig møte med forsker før han/hun bestemmer seg. Dersom vedkommende er i tvil om hun/ han ønsker å delta kan du gjerne oppfordre til å diskutere en eventuell deltakelse med familie eller andre. Det er fint om forsker kan få tilbakemelding om deltakelse innen en uke.

## Praktisk informasjon

- Informanten blir intervjuet av forsker/ Ph.D – student Henriette Riley. Varigheten er avhengig av hvor mye vedkommende har å fortelle, men ca 1-2 timer.
- Intervjuet blir tatt opp på lydbånd og transkribert.
- Intervjuet kan finne sted hvor informanten måtte ønske det, enten det er i hjemmet eller på et nøytralt sted. Forsker kan enten komme hjem eller til hjemstedet til informanten, eller informanten kan komme til Tromsø.
- Informanten vil bli spurt om forhold som har med hvordan det oppleves å være på TUD og hvilke meninger de har om behandlingen. Det er selvsagt lov å la være å svare på enkeltspørsmål dersom de ønsker det.
- Det vil ikke foreligge noen økonomiske utgifter for deltakelse. Dersom informanten bor et annet sted en Tromsø men ønsker at intervjuet skal gjennomføres her, vil økonomiske utgifter bli dekket.
- Den som er vedtaksansvarlig for informanten vil også bli spurt om å delta i studien i form av et intervju. Dette gjøres for at vi ønsker å belyse TUD fra de ulike perspektiver.
- Resultatene fra studien vil bli offentliggjort i form av vitenskapelig artikler, foredrag og undervisning. I disse presentasjonene vil det ikke være mulig å gjenkjenne noen av dem som har deltatt. Som deltaker vil du få tilsendt artiklene dersom du ønsker dette.

Det er viktig at du presiseres at det er frivillig å delta i studien. Behandlingen vil ikke påvirkes ved deltakelse, heller ikke dersom deltaker takker nei.

Vennlig hilsen

Henriette Riley  
Forsker/Ph.D student  
UNN Allmennpsykiatrisk klinikk/  
UIT Institutt for Samfunnsmedisin  
776 44883/ 93427012

Georg Høyer  
Prosjektleder professor dr. med  
UIT Institutt for Samfunnsmedisin  
776 44829

## Til faglig ansvarlig for vedtak om tvunget psykisk helsevern uten døgnoophold

Det pågår for tiden et forskningsprosjekt om tvunget psykisk helsevern uten døgnoophold (TUD) i Allmennpsykiatrisk klinikk og Rus og spesialpsykiatrisk klinikk i samarbeid med UIT, Institutt for samfunnsmedisin. Dette er en del av arbeidet med redusert og riktig bruk av tvang i psykisk helsevern i Helse Nord. Prosjektet består av to deler:

1. En registerstudie som inkluderer alle pasienter med vedtak om TUD truffet ved UNN HF i perioden 1. jan. 2008- 31. des. 2012. Registreringen omfatter omfang, varighet, vedtaksprosedyrer, diagnoser, anker og tentativt innhold i behandlingen samt individuell plan, bruk av psykisk helsevern og demografiske data. All data i denne delen hentes fra pasientjournalene.
2. En kvalitativ intervjustudie av pasienter underlagt TUD.

For hver pasient som intervjues ønsker vi også at den faglig ansvarlige for vedtak om TUD skal intervjues om den konkrete pasienten. Intensjonen med intervjustudien er å beskrive pasienters og helsepersonells erfaringer med TUD. Vi søker å få frem informantenes opplevelse, vurderinger, behov og kompetanse, med hensikt om å gi økt forståelse og kunnskap om hvordan TUD fungerer i praksis. Ved å intervjuer både pasienter og helsepersonell ønsker vi å sikre rike data som bringer inn ulike nyanser, perspektiv og synspunkter på hvert enkelt tilfelle.

Du kontaktes via denne e-posten fordi du er vedtaksansvarlig for pasienter på TUD og er således en viktig bidragsyter for å rekruttere informanter og bidra i studien. Mulige informanter er identifisert av undertegnede via DIPS i registerstudien. Ut fra et tilfeldig utvalg basert på inklusjonskriterier for studien vil du bli kontaktet om noen dager med forespørsel om du kan formidle kontakt mellom undertegnede og den kontaktpersonen som er i daglig kontakt med pasienten vi ønsker å intervjuer. Hensikten er at undertegnede videre kan kontakte denne personen som igjen forespør pasienten om han/hun ønsker å delta i studien.

Studien er finansiert av forskningsmidler fra Helse Nord og er godkjent av Regional etisk komité (REK). Fungerende klinikkssjef Tordis Sørensen Høifødt og Klinikksjef Grete Furu har gitt sin støtte til prosjektet. Prosjektleder er professor dr. med Georg Høyer, UIT Institutt for Samfunnsmedisin. Det er vedlagt informasjonsskriv om studien i e-posten dersom du ønsker mer utfyllende informasjon før du blir kontaktet. Dersom noe er uklart, ta gjerne kontakt med undertegnede på telefon eller e-post.

Med vennlig hilsen

Henriette Riley  
Forsker/Ph.D student  
UNN Allmennpsykiatrisk klinikk/  
UIT Institutt for Samfunnsmedisin  
776 44883/ 93427012





## **Informasjon om deltakelse i fokusgruppe til studien om Tvunget psykisk helsevern uten døgnopphold**

### **Innledning**

Dette er en forespørsel til deg i forbindelse med en forskningsstudie om tvunget psykisk helsevern uten døgnopphold (TUD). I studien skal vi blant annet intervju 10 pasienter som er på TUD. Vi ønsker å spørre deg om du vil delta i en fokusgruppe for å diskutere og kvalitetssikre hvordan innholdet i disse intervjuene (intervjuguiden) skal være. I tillegg vil en til to av dere bli spurt i etterkant om å være med i en pilotundersøkelse hvor intervjuguiden blir testet. Hensikten med pilotundersøkelsen er at vi gjennomfører et prøveintervju for å se hvordan intervjuguiden fungerer. Dette vil gi oss mulighet for ytterligere justeringer av intervjuguiden.

### **Formålet med studien**

I Norge har vi hatt hjemler for TUD siden 1961 og vi var et av de første land i verden som lovfestet en slik ordning. Det er per i dag ikke gjennomført forskningsprosjekt om hvordan TUD oppleves eller praktiseres i Norge. Formålet med studien er å få frem pasienter og helsepersonell sine erfaringer og meninger om TUD. Vi ønsker å finne ut av hvordan pasienter og helsepersonell oppfatter formålet med, innholdet i, og berettigelsen av TUD. Denne studien blir gjort for å øke kunnskapen om TUD, og resultatene vil forhåpentligvis bidra til å bedre gjennomføringen av behandlingen for pasienter under TUD

Studien er et samarbeid mellom Allmennpsykiatrisk klinikk, Universitetssykehuset i Nord-Norge (UNN) og Institutt for samfunnsmedisin ved Universitetet i Tromsø (UIT). Resultatene fra studien vil bli publisert i vitenskaplige artikler som skal inngå i en doktorgradsavhandling. Muntlig formidling av resultatene vil bli gjort i undervisning, seminarer og konferanser.

### **Hva innebærer en fokusgruppe**

Et fokusgruppeintervju er et gruppeintervju ledet av en til to personer med 4-6 deltakere. Gjennom gruppediskusjon ønsker vi at dere skal utveksle meninger om hva som er av betydning for pasienter og behandlere når noen blir underlagt TUD. Meninger og synspunkter som kommer fram i diskusjonen vil kunne bidra til at intervjuguiden i studien om TUD blir mer relevant. Dette er en viktig del i forskningsprosjektet for å kvalitetssikre spørsmålene som skal brukes under intervjuene. Vi vil på forhånd ha formulert noen spørsmål, men ønsker og at dere skal komme med egne tema som er viktige.

### **Mulige fordeler og ulemper**

Mulige fordeler med å delta i fokusgruppen er at du vil kunne bidra til å øke kunnskapen om forhold som vedrører TUD. Det er ikke gjort noen studier i Norge om pasienter sine

opplevelse av å være på TUD og vi ønsker derfor å få mer kunnskap om hva som er bra og hva som kan bli gjort bedre.

Det er ingen sikre ulemper med å delta i fokusgruppen.

### **Konfidensialitet**

Et grunnprinsipp ved all forskning av denne typen er at du som er deltakerne har krav på at det som blir sagt ikke skal gjengis slik at det er mulig å vite hvem som har sagt det. Dette vil si at *all* informasjon som fremkommer i fokusgruppen vil bli behandlet konfidensielt. Det betyr at alt du sier er fortrolig og det vil ikke bli brakt opplysninger videre til andre som kan knyttes til deg. I gruppen vil det være en gjensidig taushetsplikt som gjør at dere ikke kan snakke om hva andre i fokusgruppen har sagt. Det vil ikke bli registrert navn eller andre personlige kjennetegn om deg som deltaker i fokusgruppen.

### **Organisering**

Fokusgruppen vil vare rundt 1- 2 timer alt etter hvor mye gruppen har å formidle og vil bli tatt opp på lydbånd og senere slettet når intervjuguiden er ferdig. Fokusgruppen vil bli gjennomført 10. mai kl 12.00 på speil rommet hos Akutt teamet på Åsgård, bygg 7. Det vil være fire til seks deltakere. Fokusgruppen vil bli ledet av sosionom Heidi Magnussen og forsker Henriette Riley.

### **Frivillig deltakelse**

Det er frivillig å delta i fokusgruppen. Du kan når som helst og uten å oppgi noen grunn trekke deg fra å delta. Dersom du under fokusgruppen ønsker å trekke deg fra deltakelse kan du forlate gruppen uten at du trenger å oppgi noen grunn.

Om du har spørsmål til studien, kan du kontakte forsker Henriette Riley på tlf 776 44883/ 934 27 012. Alternativt kan du kontakte prosjektleder Georg Høyen på tlf 776 44 829.

### **Samtykkeerklæring**

Jeg er blitt informert om hva deltakelse i en fokusgruppe knyttet til prosjektet tvungent psykisk helsevern uten døgnopphold (TUD-prosjektet) innebærer, og samtykker med dette til å delta i fokusgruppen

Dato:

Underskrift:

# Appendix III

Registration form and interview guide



# Registrerings skjema, TUD Kjernestudien

ID-Slipp (Oppbevares separat etter punching)

1. Løpenummer:                      Navn:                                      Fødselsdato: DDMMYYYY

---

## A. Innsidens og prevalens av TUD 1.1. 2008 – 31.12 2012

1 A. Løpenummer ID:

1 B. Løpenummer Vedtak:

1 C. Sted: 1. Tromsø 2. Innlandet 3. Sørlandet 4. Oslo 5. Bergen

2. Utfylt dato: DD.MM.YYYY

3. Kjønn: 1.M 2.K

4. Fødselsår: YYYY

5. Bostedskommune: Kommunenummer (fire siffer)

6. Index TUD vedtak: DD.MM.YYYY

7. Er pasienten fortsatt på TUD per 1.1.2013? 1. Ja 2. Nei

8. Hvis NEI, når ble index TUD avsluttet? DD.MM.YYYY

9. Er det parallelt vedtak om tvangsbehandling under index TUD?

1. Ja under hele index TUD

2. Ja, men ikke under hele index TUD

3. Nei

---

---

## B. Første TUD vedtak 1.1.2008-31.12.2009

10. Dato første gangs TUD vedtak: DD.MM.YYYY

11. Ble første gangs TUD-vedtak fattet i forlengelsen av døgnopphold? 1. Ja 2. Nei

**12. Hvis JA på spm. 11, når ble vedtak om TO/TPH fattet? DD.MM.YYYY**

**13. Hvis JA på spm. 11, hvor var pasienten innlagt?**

1. UNN, Allmennpsykiatrisk avdeling Sør
2. UNN, Allmennpsykiatrisk avdeling Nord
3. UNN, Psykiatrisk senter for Tromsø og omegn
4. UNN, Spesialpsykiatrisk avd. Rus
5. UNN, Spesialpsykiatrisk avd. Psykogeriatr
6. UNN, Spesialpsykiatrisk avd. Sikkerhetspost
7. Helse Finnmark, DPS Vest-Finnmark
8. Helse Finnmark, DPS Øst-Finnmark
9. Helse Finnmark, DPS Midt-Finnmark
10. Avdeling utenfor Troms/Finnmark

**14. Hvis NEI på spm. 11, ved hvilken institusjon ble første TUD vedtak fattet?**

1. UNN, Allmennpsykiatrisk avdeling Sør
2. UNN, Allmennpsykiatrisk avdeling Nord
3. UNN, Psykiatrisk senter for Tromsø og omegn
4. UNN, Spesialpsykiatrisk avd. Rus
5. UNN, Spesialpsykiatrisk avd. Psykogeriatr
6. UNN, Spesialpsykiatrisk avd. Sikkerhetspost
7. Helse Finnmark, DPS Vest-Finnmark
8. Helse Finnmark, DPS Øst-Finnmark
9. Helse Finnmark, DPS Midt-Finnmark
10. Avdeling utenfor Troms/Finnmark

**15. Hvem fattet første TUD vedtak?**

1. Overlege
2. Psykologspesialist
3. Andre: (Spesifiser): \_\_\_\_\_
4. Tre måneders vurderinger mangler/ikke dokumentert

**16. Vedtaksfatters institusjonstilknytning, første TUD vedtak:**

1. UNN, Allmennpsykiatrisk avdeling Sør
2. UNN, Allmennpsykiatrisk avdeling Nord
3. UNN, Psykiatrisk senter for Tromsø og omegn
4. UNN, Spesialpsykiatrisk avd. Rus
5. UNN, Spesialpsykiatrisk avd. Psykogeriatr
6. UNN, Spesialpsykiatrisk avd. Sikkerhetspost
7. Helse Finnmark, DPS Vest-Finnmark
8. Helse Finnmark, DPS Øst-Finnmark
9. Helse Finnmark, DPS Midt-Finnmark
10. Avdeling utenfor Troms/Finnmark

**17. Varighet første TUD episode (Når ble første TUD opphevet?): DD.MM.YYYY**

**18. Hvordan ble første TUD episode avsluttet?**

1. Ved vedtak fattet innenfor gjeldende TUD periode
2. Det ble ikke søkt om forlengelse
3. Dødsfall
4. Index TUD ikke opphevet treår etter start av index TUD
5. Annet, spesifiser: \_\_\_\_\_

**19. Er pasienten i løpet av tre år etter index TUD ble vedtatt, satt på nye TUD episoder etter at index TUD ble avsluttet? 1. Ja 2. Nei**

**20. Hvis JA på spm 19, når startet og sluttet disse nye TUD periodene?**

- 20.1 Start 2. TUD periode: DD.MM.YYYY
- 20.2 Start 3. TUD periode: DD.MM.YYYY
- 20.3 Start 4. TUD periode: DD.MM.YYYY
- 20.4 Avslutning 2: TUD periode: DD.MM.YYYY
- 20.5 Avslutning 3. TUD periode: DD.MM.YYYY
- 20.6 Avslutning 4. TUD periode: DD.MM.YYYY

**21. Suicid i løpet av index TUD perioden? 1. Ja 2. Nei**

**22. Bosted:**

1. Egen/leid hus/leilighet/hybel
2. Kommunal bolig, ubemannet/delvis bemannet/tilsyn
3. Kommunal bolig, døgnbemannet
4. På institusjon
5. Uten fast bopel
6. Annet (Spesifiser): \_\_\_\_\_
7. Privat omsorgsinstitusjon

**23. Bor sammen med:**

1. Samboer, ektefelle, venn(er)
2. Familie (foreldre, besteforeldre, søsken, barn)
3. Alene
4. Uten fast bopel
5. Annet (Spesifiser): \_\_\_\_\_

**24. Arbeid/yrke/økonomisk livsgrunnlag:**

1. Lønnet arbeid
2. Kvalifisering stønad
3. Arbeidsavklaringspenger (AAP)
4. Uførepensjon
5. Økonomisk stønad
6. Sykepenger
7. Uten inntekt

**Første innleggelse i psykisk helsevern**

**25. Dato første døgnopphold i psykiske helsevern for voksne:**

1. Mindre enn et år siden
2. 1-2 år siden
3. 3-4 år siden
4. 5-10 år siden
5. Mer enn 10 år siden

**26. Legal status ved første døgnopphold:**

1. Frivillig
2. Tvang
3. Ikke funnet

**Døgnopphold tre år før og tre år etter første TUD vedtak**

**27. Første døgnopphold i treårsperioden før første TUD vedtak: DD.MM.YYYY**

**28. Siste døgnopphold i treårsperioden før første TUD vedtak: DD.MM.YYYY**

**29. Antall døgnopphold totalt i treårsperioden før første TUD vedtak: \_\_\_\_\_**

**30. A: Antall døgnopphold etter § 3-2 eller 3-3 i psykisk helsevernloven i treårsperioden før første TUD vedtak: \_\_\_\_\_**

**30. B: Hvor mange av døgnopphold etter 3-2/3-3 var reelt sett frivillig: \_\_\_\_\_**

**31. Samlet antall liggedøgn tre år før første TUD vedtak: \_\_\_\_\_**

**32. Samlet antall døgn på tvang tre år før første TUD vedtak: \_\_\_\_\_**

**33. Første døgnopphold i treårsperioden etter første TUD vedtak: DD.MM.YYYY**

**34. Siste døgnopphold i treårsperioden etter første TUD vedtak: DD.MM.YYYY**

**35. Antall døgnopphold totalt i treårsperioden etter første TUD vedtak: \_\_\_\_\_**

**36. A: Antall døgnopphold etter § 3-2 eller 3-3 i psykisk helsevernloven i treårsperioden etter første TUD vedtak: \_\_\_\_\_**

**36. B: Hvor mange av døgnopphold etter 3-2/3-3 var reelt sett frivillig: \_\_\_\_\_**

**37. Samlet antall liggedøgn tre år etter første TUD vedtak: \_\_\_\_\_**

**38. Samlet antall døgn etter § 3-2 eller § 3-3 etter første TUD vedtak: \_\_\_\_\_**



**39. Har pasienten hatt "Åpen retur" avtale i en eller flere perioder fra 3 år før til tre år etter første TUD vedtak? 1. Ja 2. Nei**

**40. Hvis JA på spm 39, når var første avtale om "Åpen retur"? DD.MM.YYYY**

**41. Hvis JA på spm 39, når ble avtale om "Åpen retur" avsluttet? (innenfor tre år etter første TUD vedtak ble tatt) DD.MM.YYYY (31.12.2020 = ikke avsluttet)**

### **Innhold i TUD Vedtak**

#### **42. Begrunnelse, første TUD vedtak (Index TUD):**

1. Farekriteriet 2. Behandlingskriteriet 3. Både fare og behandlingskriteriet 4. Ikke dokumentert

42.1. Fare for seg selv 1.Ja 2.Nei 3.Ikke nevnt/omtalt

42.2. Fare for andre 1.Ja 2.Nei 3.Ikke nevnt/omtalt

42.3. Behov for medikamentell behandling 1. Ja 2.Nei 3.Ikke nevnt/omtalt

42.4. Behov for annen behandling 1.Ja 2.Nei 3.Ikke nevnt/omtalt

42.5. Manglende compliance 1.Ja 2.Nei 3.Ikke nevnt/omtalt

42.6. Rusmisbruk uten TUD 1.Ja 2.Nei 3.Ikke nevnt/omtalt

42.7. Frivillighet prøvd, men nytteløst 1.Ja 2.Nei 3.Ikke nevnt/omtalt

42.8. Annet (Spesifiser): \_\_\_\_\_

#### **43. Begrunnelse siste TUD vurdering/vedtak:**

1. Farekriteriet 2. Behandlingskriteriet 3. Både fare og behandlingskriteriet 4. Ikke dokumentert

43.1. Fare for seg selv 1.Ja 2.Nei 3.Ikke nevnt/omtalt

43.2. Fare for andre 1.Ja 2.Nei 3.Ikke nevnt/omtalt

43.3. Behov for medikamentell behandling 1. Ja 2.Nei 3.Ikke nevnt/omtalt

43.4. Behov for annen behandling 1.Ja 2.Nei 3.Ikke nevnt/omtalt

43.5. Manglende compliance 1.Ja 2. Nei 3.Ikke nevnt/omtalt

43.6. Rusmisbruk uten TUD 1. Ja 2.Nei 3.Ikke nevnt/omtalt

43.7. Frivillighet prøvd, men nytteløst 1.Ja 2.Nei 3.Ikke nevnt/omtalt

43.8. Annet (Spesifiser): \_\_\_\_\_

**44. Er det laget Individuell plan for pasienten under døgnoophold som har gått over i index TUD perioden eller i løpet av index TUD perioden?**

1.Ja

2. Nei

3. Ja, men finnes ikke i journal

#### **45. Hvis NEI på spm 44:**

45.1 Pasienten motsetter seg IP 1.Ja 2.Nei

45.2 Det er likevel laget oppfølgingsplan/behandlingsplan 1.Ja 2.Nei

45.3 Det foreligger en kriseplan, alene eller som en del av oppfølgingsplan 1.Ja 2.Nei

**46. Er det oppnevnt navngitt kontaktperson ved etablering av index TUD perioden? 1.Ja 2.Nei**

**47. Får pasienten medikamentell behandling (psykofarmaka)?**

1. Ja, hele TUD perioden
2. Ja, men bare deler av TUD perioden
3. Nei, ingen medikamentell behandling under TUD perioden

**48. Står pasienten på depotmedikasjon under TUD perioden? 1.Ja 2.Nei**

**49. Vedtak om tvangsbehandling i tilknytning til TUD vedtak: 1. Ja 2 Nei**

49.1 Første vedtak, startdato: DD.MM.YYYY

49.2 Første vedtak, sluttdato: DD.MM.YYYY

49.3 Andre vedtak startdato: DD.MM.YYYY

49.4 Andre vedtak, sluttdato: DD.MM.YYYY

OSV.

**50. Avtale om behandlingskontakt (hyppighet) under TUD perioden:**

1. Oftere enn hver 14 dag
2. Hver 14 dag
3. Sjeldnere enn hver 14 dag
4. Ikke spesifisert

**51. Annet innhold i behandlingen enn medikamentell behandling i TUD perioden?**

1. Ja (spesifiser): \_\_\_\_\_
2. Nei

**52. Hvem har den løpende behandlingskontakt med pasienten i TUD perioden?**

52.1. Den ansvarlige for vedtak om TUD 1.Ja 2.Nei

52.2. Kontaktperson 1.Ja 2.Nei

52.3. Annen ansatt ved døgnavdeling 1.Ja 2.Nei

52.4. Ansatt i psykisk helsevern, men på annen institusjon enn der vedtaket er fattet  
1.Ja 2.Nei

52.5. Fastlege 1.Ja 2.Nei

52.6. Kommunalt Psykisk. helse team 1.Ja 2.Nei

52.7. Annen kommunalt ansatt helsearbeider, (spesifiser): \_\_\_\_\_

52.8. Ulike personer veksler med å ha løpende behandlingskontakt i perioden 1.Ja 2.Nei

52.9. Ikke definert 1 Ja 2. Nei

**53. Hvem utfører reelt sett tre måneders vurderingene?**

- 53.1. Den ansvarlige for vedtak om TUD 1.Ja 2.Nei
- 53.2. Kontaktperson 1.Ja 2.Nei
- 53.3. Annen ansatt ved døgnavdeling 1.Ja 2.Nei
- 53.4. Ansatt i psykisk helsevern, annen institusjon enn der vedtaket er fattet 1.Ja 2.Nei
- 53.5. Fastlege 1.Ja 2.Nei
- 53.6. Kommunalt psykisk helseteam 1.Ja 2.Nei
- 53.7. Annen kommunalt ansatt helsearbeider, (spesifiser):\_\_\_\_\_
- 53.8. Tre måneders vurderinger mangler/ikke dokumentert, en eller flere ganger  
1.Ja. 2. Nei

**54. Hvem står formelt som ansvarlig for tre måneders vurderingene**

- 1. Overlege
- 2. Psykologspesialist
- 3. Andre, spesifiser:\_\_\_\_\_
- 4. Tre måneders vurderinger mangler/ikke dokumentert

**Hvordan har tre måneders undersøkelser vært gjennomført?**

**55. Ved personlig undersøkelse på sykehus/institusjon.**

- 1.Ja, alltid 2.Nei, aldri 3.De fleste gangene 4.De færreste gangene

**56. Ved personlig undersøkelse der pasienten bor/oppholder seg.**

- 1. Ja, alltid 2.Nei, aldri 3.De fleste gangene 4.De færreste gangene

**57. Videokonferanse**

- 1. Ja, alltid 2.Nei, aldri 3.De fleste gangene 4.De færreste gangene

**58. Via Telefon:**

- 1. Ja, alltid 2.Nei, aldri 3.De fleste gangene 4.De færreste gangene

**59. Hvis via telefon, omfatter dette som regel**

- 1. Fastlege eller annen lokal lege
- 2. Lokalt behandlingspersonell
- 3. Pasienten
- 4. Både pasient og behandlingspersonell

**60. Via E-post**

- 1. Ja, alltid 2.Nei, aldri 3.De fleste gangene 4.De færreste gangene

**61. Annet (Spesifiser).\_\_\_\_\_**

## **Forlengelsesvedtak**

### **62. Kontrollkomisjonenes behandling av søknad om forlengelse avTUD:**

1. Forlenget av KK etter ett år
2. Avslag på forlengelse etter ett år
3. Forlenget av KK etter to år
4. Avslag på forlengelse etter to år
5. Ikke søkt forlengelse

### **63. Ble søknad om forlengelse sendt til kontrollkomisjonen innen tidsfristen (3 uker før utløp)?**

1. Ja
2. Nei, forlengelse sendt for sent
3. Forlengelse ikke sent

### **64. Hvis søknad om forlengelse ble sendt for sent, hvor lang tid etter fristen ble forlengessøknaden sendt? DDD (Antall dager)**

### **65. Hvis søknad om forlengelse ble sendt etter tidsfristen, ble søknaden behandlet av kontrollkomisjonen: 1.Ja 2.Nei**

### **66. Diagnose (Hoveddiagnose ICD nummer ved start av index TUD periode)**

Direkte koding: Kun tre verdier (F+ tosfret diagnosekategori)

1. F06
2. F20
3. F22
4. F25
5. F31
6. F21
7. F33
8. F19
9. F23
10. Annet (Spesifiser) \_\_\_\_\_

### **67. Er rusadferd en del av pasientens problemer?**

1. Ja, i vesentlig grad
2. Ja, men ikke i vesentlig grad
3. Nei
4. Usikkert





# **Kodeveiledning: TUD Kjernestudien**

## **Innledning**

Veiledningen gir instruksjoner om hvorledes de ulike spørsmålene skal forstås og kodes der det kan oppstå tvil om dette. På denne bakgrunn er ikke alle variablene kommentert. Parallelt med registreringen skal det skrives dagbok for å fange opp eventuelle problemer som oppstår og hvordan man har valgt å kode i tvilstilfeller.

### **Registrering av ikke aktuelt:**

Dersom data på en numerisk eller en string variabel ikke er aktuell, skal det kodes 99. Dersom data for en datovariabler ikke er aktuell, kodes 09.09.9999. Det er viktig at dette brukes konsekvent der informasjonen ikke er aktuell for løpenummeret, slik at det ikke blir feil missing verdier. På variablene 29 – 32, 35 – 38, og 64 kodes 0 dersom det ikke har forkommet døgnopphold eller dersom forlengelsessøknad ble sendt etter fristen.

### **Registrering av missing data:**

Missing data vil si at det ikke er mulig å finne informasjonen for variabelen i DIPS. Her skal det ikke kodes inn noe som helst, altså: Cellen/Feltet i SPSS filen skal være tom.

### **Definisjon TUD vedtak:**

I juridisk forstand er det bare to typer vedtak som ligger til grunn for TUD. Det første er vedtak om å sette noen på TUD. Slike vedtak fattes av vedtaksansvarlig (og vedtakskompetent) ved døgninstitusjon. Et slikt vedtak fattes i henhold til psykisk helsevernloven § 3-3, og er prinsipielt gyldig i ett år, men det kreves at vilkårene vurderes hver tredje måned gjennom såkalte "Kontrollundersøkelser" jf psykisk helsevernloven § 4-9. Kontrollundersøkelser er formelt ikke TUD vedtak.

Det andre grunnlaget for TUD er et forlengelsesvedtak som fattes av kontrollkommissjonen etter ett år, og har gyldighet ett år framover. Fortsatt må det gjøres kontrollundersøkelser hver tredje måned.

### **Eksklusjonskriterier:**

Når en pasient ikke tilhører opptaksområdet overføres til hjemsted og TUD etableres under «transport», regnes det ikke med som en «reell» TUD pasient, og skal ikke inngå i studien. Det samme gjelder når TUD etableres i en kort sekvens for å opprettholde tvang for en pasient innlagt på TPH som har behov for behandling ved somatisk sykehus.

## **A. Insidens og prevalens av TUD 1.1. 2008 – 31.12 2012**

### **1B. Løpenummer vedtak:**

Noen kan ha flere TUD episoder innenfor registreringsperioden. Om samme pasient har flere TUD episoder i løpet av perioden kodes andre opphold med samme løpenummer ID som første, men med tillegg av bokstaven B. Ved tredje legges bokstaven C til, osv. For at det skal være en ny TUD episode, skal pasienten ha vært uten vedtak om tvang (både TPH og TUD), som vil si at de legalt sett skal ha vært frivillig. Dersom vedtaket ikke er søkt forlenget etter 1 år, opphører vedtaket. Dersom vedtaksansvarlig glemmer å søke forlengelse etter 1 år, og det søkes forlenget etter fristen for eksempel etter 13 måneder, og det godkjennes av kontrollkommissjonen, anses pasienten ikke å ha vært legalt sett frivillig og forlengelsesvedtaket regnes ikke som en ny TUD. Se og avsnitt over: *Definisjon TUD vedtak*. Pasienter som er på TUD og bor på sykehjem eller annen institusjon godkjent for tvang skal inkluderes.

## **5. Bostedskommune**

Her kodes den kommunen som er registrert under «personalia» i DIPS på registreringstidspunktet.

## **6. Index TUD vedtak**

Med index vedtak menes det TUD vedtaket som startet TUD perioden for pasienter under TUD per 1.1.2008 og alle nye TUD vedtak fra 1.1.2008 til og med 31.12.2012.

Merk at samme pasient kan ha flere "Index TUD" i perioden 1.1.2008 – 31.12.2012. Dersom TUD etableres ved utskrivelse fra et døgnopphold, er den reelle utskrivingsdatoen index TUD. Det skal fylles ut et nytt skjema for hvert TUD vedtak i perioden som fattes på nytt. Det vil si enten etter en periode uten tvungent psykisk helsevern eller etter en ny periode med tvungent psykisk helsevern med døgnopphold og påfølgende nytt TUD vedtak. TUD og tvunget ettervern etter gammel lovgivning er sidestilt. Det vil si at dersom pasientens index TUD er etablert under gammel lovgivning er dette dato index TUD.

## **7. Er pasienten fortsatt på dette TUD vedtaket per 01.01.2013?**

Her skal svaret knyttes til TUD-episoden som registreres i det aktuelle skjemaet. Dersom en pasient har flere vedtak om TUD skal hvert vedtak ha en ny registrering og informasjonen skal være knyttet til det enkelte vedtaket. Det vil si at en pasient som har tre vedtak vil kunne få ulike svar.

## **8. Index TUD avsluttet/opphevet/utløpt:**

Om TUD vedtaket fortsatt er i kraft per 31.12.2012 skal datofeltet kodes 31.12.2012.

## **9. Er det parallelt vedtak om tvangsbehandling under index TUD?**

Her inkluderes både tvangsbehandlingsvedtak som er truffet før utskrivning fra døgnopphold, forutsatt at det fortsatt gjelder ved utskrivning til TUD, tvangsbehandlingsvedtak som fattes ved utskrivning fra døgnopphold til TUD og tvangsbehandlingsvedtak som treffes etter at på index TUD er trått i kraft, men før index TUD avsluttes. Et tvangsmedisineringsvedtak som påklages fylkeslegen og det gis medhold, er ikke et tvangsmedisineringsvedtak. Dersom det ikke er nevnt avslutningsdato, regnes tvangsbehandlingsperioden avsluttet tre måneder etter etablering.

## **B. Første TUD vedtak 1.1.2008-31.12.2009**

### **Første gangs TUD vedtak gjelder kun den aller første gangen pasienten er på TUD**

#### **10. Dato første gangs TUD vedtak:**

Dette er dato for pasientens første TUD vedtak, Jf inklusjonskriterier for B-delen. Denne datoen er lik som variabel 6.

#### **12. Vedtak om TO eller tvungent psykisk helsevern forut for TUDvedtaket**

Vedtaket om Tvungen observasjon (TO) eller Tvungent psykisk helsevern det spørres om her, dreier seg om vedtaket som ligger til grunn for døgnoppholdet som gikk forut for vedtaket om TUD.

#### **13. Hvis Ja på spm. 11, hvor var pasienten innlagt?**

Ved opphold på flere avdelinger kodes den avdelingen pasienten ble utskrevet fra. Hvert studie sted tilpasser denne variabelen etter lokale forhold.

#### **14. Hvis NEI på spm. 11, ved hvilken institusjon ble første TUD vedtak fattet?**

Slike vedtak kan treffes på poliklinikker eller av vedtaksansvarlige tilknyttet sengeposter som kjenner pasienten selv om pasienten ikke er innlagt forut for TUD vedtaket.



### **15. Hvem fatter det første TUD vedtaket**

Her kodes den som formelt er vedtaksfatter. Om noen er konstituert i stilling som er krevet for å fatte vedtak, kodes stillingen som vedkommende er konstituert i. For eksempel kodes konstituert overlege som overlege. Dersom det kodes 3. «Andre (spesifiser)», skriv teksten inn i string (tekst) variabelen for 15 i SPSS.

### **17. Varighet første TUD episode (Når ble første TUD opphevet?)**

TUD vedtak kan opphøre ved at det ikke blir forlenget eller ved at det fattes vedtak om opphør, inkludert at kontrollkommisjonene opphever tvungent psykisk helsevern enten gjennom klage eller søknad om forlengelse ut over ett år (jf spm. 19). Merk at døgnopphold i en TUD periode, enten døgnoppholdet er frivillig eller tvungent, ikke innebærer opphør/avslutning av en TUD periode. Om pasienten utskrives fra døgnopphold uten TUD (Jf evt. overføringsvedtak) skal dato for innleggelse til døgnopphold være avslutning av TUD. Dersom pasienten fortsatt er på index TUD tre år etter dato for start av index TUD, kodes datoen for treårsdagen etter start index TUD.

For TUD vedtak som "renner ut i sanden" ved f.eks at tre måneders kontrollundersøkelser uteblir, at man mister kontakt med pasienten eller lignende, settes avslutningsdato ett år etter siste formelle TUD vedtak. Om 3 mndrs vedtak fattet av Kontrollkommisjonen mangler settes tid til 3 mndr. (Det kan være forvirrende at det her snakkes om «vedtak» da lovteksten ikke bruker dette begrepet. KK har plikt til av eget initiativ «vurdere om det er behov for tvungent vern jf. §3-8 i psykisk helsevernloven og Fellesforskriften § 58 der det står at KK skal treffe vedtak ved denne 3 mndrs vurderingen)

### **18. Avslutning første TUD**

Dersom det kodes 5. «Annet (spesifiser)», skriv teksten inn i string (tekst) variabelen for 18 i SPSS.

### **20. Nye TUD episoder**

Dersom en TUD episode varer ut over tre år etter data for index TUD, kodes avslutningsdato selv om dette er senere enn tre år etter index TUD. Dersom TUD løper ved studiens slutt kodes 31.12.2012.

### **21. Suicid?**

Gjelder suicid i perioden under index TUD. Samtidig skal da dato for suicid samsvare med dato for opphør av TUD

### **22. Bosted:**

Med institusjon regnes her kommunale institusjoner eller institusjoner innenfor spesialisthelsetjenesten utenfor det psykiske helsevernet, samt frivillig opphold i institusjoner i det psykiske helsevernet som ikke er godkjent for tvungent psykisk helsevern. Fengsel kodes også som institusjon. Om pasienten bor hos familie eller venn(er) regnes dette som egen bolig. Dersom det kodes 6. «Annet (spesifiser)», skriv teksten inn i string (tekst) variabelen for 22 i SPSS. Dersom pasienten er uten fast bopel, skriv gjerne hva som er pasientens tentative bopel i loggen.

### **23. Bor sammen med:**

Dersom det kodes 5. «Annet (spesifiser)», skriv teksten inn i string (tekst) variabelen for 23 i SPSS.

#### **24. Arbeid/yrke/økonomisk livsgrunnlag:**

Her kodes hovedinntektskilden. Prostitusjon eller annen uformelt eller ulovlig arbeid telles ikke.

24.2: Kvalifiserings stønad. Dette er en stønadsform som er hjemlet i Sosialtjenesteloven (2009) § 29. 24.4 «Økonomisk stønad» er ytelse etter sosialtjenesteloven (økonomisk sosialhjelp).

#### **Første innleggelse i psykisk helsevern**

#### **25. Dato første døgnopphold i psykiske helsevern for voksne:**

Her skal man gå tilbake til den aller første innleggelsen i psykisk helsevern uavhengig om den var med tvang eller ikke. Registreringen er begrenset til opphold i voksenpsykiatrien. Om første innleggelse ligger forut for registreringene i elektronisk pasientjournal, skal det sjekkes om det finnes tidligere papirjournal og om tidspunktet kan finnes der. Tiden regnes fra dato for index TUD.

#### **Døgnopphold tre år før og tre år etter første TUD vedtak**

#### **Innledning til variabler 27-38:**

Et døgnopphold skal inneholde overnatting. Dersom en pasient kommer inn på natten, og skrives ut på formiddagen regnes dette som en innleggelse.

Dersom en pasient flytter ut av opptaksområdet eller dør, før det er gått tre år kodes de data som er i DIPS og det registreres under variabel 18, årsak til opphør av TUD. Dersom det tydelig kommer frem, av journalen at pasienten har flyttet til opptaksområdet senere enn tre år før index TUD, kodes de døgnopphold som finnes i DIPS og i dagbok noteres det at pasienten er tilflytter.

Om pasienten overføres fra en avdeling til en annen (inklusive DPS døgnavdeling) uten at han/hun er hjemme regnes dette som det samme sykehusoppholdet eller innleggelse

#### **27-38 Døgnopphold tre år før og etter index TUD:**

I første omgang registreres kun opphold i psykiatrisk sykehus i opptaksområdet. Ved mistanke eller indikasjon på at pasienten har hatt døgnopphold på en eller flere DPS og disse oppholdene ikke er registrert i DIPS ved registreringsstedet, tas det kontakt ved utløp av 3 års oppfølgingstid for å få med evt døgnopphold ved DPS. Innleggelsen umiddelbart forut for index TUD regnes ikke med. Dersom pasienten ikke har hatt døgnopphold, kodes 0 på variablene 29-32 og 35-38.

#### **29-30 Døgnopphold totalt og døgnopphold tvang**

Her skal innleggelsen umiddelbart forut for index TUD regnes med.

#### **30. B og 36 B: Hvor mange av døgnopphold etter 3-2/3-3 var reelt sett frivillig**

Her er vi ute etter å fange opp eventuell «feilregistrering» av døgnopphold under en TUD periode. «Frivillighet» er derfor her uavhengig av hvilken paragraf pasienten formelt er på. For at et døgnopphold her skal kodes som frivillig, må det ikke fremgå av journalen at pasienten motsetter seg, muntlig eller fysisk. Der det er tvil, tas ikke det aktuelle døgnopphold med i antall reelt frivillige.

### **32. Samlet antall døgn på tvang**

Her skal bare reelle døgn på tvang regnes med, dvs at det er mulig at bare deler av det som regnes som en tvungen innleggelse i variabel 26 regnes med.

### **33. Første døgnopphold etter TUD**

Dersom pasienten får vedtak om TUD og overføres til døgnopphold på DPS som ikke er godkjent for tvang, regnes døgnoppholdet ved DPS som første døgnopphold etter første TUD vedtak selv om dette skjer på samme dag.

### **39. Åpen retur:**

Med åpen retur menes at pasienten alene eller i samarbeid med lokalt helsepersonell kan komme til døgnopphold etter eget ønske og uten søknad. Det anbefales å se etter opplysninger om dette i epikrise etter utskrivning fra døgnopphold. Med åpen retur forstås en generell avtale som fremgår av DIPS om at pasienten selv kan bestemme om døgnopphold.

### **41. Åpen retur avsluttet**

Dersom «Åpen retur» ikke er avsluttet, kodes 31.12.2020.

## **Innhold i TUD Vedtak**

### **43. Begrunnelse for siste TUD vurdering/vedtak:**

Her menes begrunnelsen for TUD i den siste (ferskeste) av kontrollundersøkelsene, eller søknaden til kontrollkommisjonen om forlengelse av vedtak dersom denne er «ferskest», innenfor tre år etter index TUD. Dersom pasienten er på TUD lengre en datoen tre år etter index TUD, skal den siste av kontrollundersøkelsene, eller søknaden til kontrollkommisjonen innenfor treårs perioden legges til grunn. For de pasientene som har flere TUD vedtak i tre års perioden etter index TUD, brukes den siste vurderingen før dato tre år etter index TUD utløper.

### **46. Er det oppnevnt kontaktperson?**

Med kontaktperson menes den personen som etter TUD forskriftene skal oppnevnes som kontaktperson. Kilde blir her det opprinnelige TUD vedtaket og/eller utskrivningsnotat/epikrise. For å svare ja kreves at en navngitt person som arbeider i spesialisthelsetjenesten er oppgitt som kontaktperson

### **47. Medikamentell behandling:**

Her skal bare psykofarmaka registreres.

### **48. Depotmedikasjon:**

Det skal fremgå av DIPS at de mottar injeksjonsbehandling

### **49. Tvangsbehandlingsvedtak:**

Her registreres alle tvangsbehandlingsvedtak under index TUD perioden og tre år senere etter index TUD startet. Dersom det ikke er nevnt avslutningsdato, kodes dato tre måneder etter siste tvangsbehandlingsperiode. Også tvangsbehandlingsperioder under senere døgnopphold innenfor tre år etter index TUD registreres.

### **50. Avtale om behandlingskontakt under TUD:**

I denne variabelen er vi ute etter hva som er planlagt oppfølging ved etablering av index TUD. Her skal hyppigheten av enhver planlagt kontakt tas med, uavhengig av hvor møtet finner sted (på kontorer, hjemme hos pasienten eller andre steder). Kontakten gjelder både med personell fra spesialisthelsetjenesten og annet helse- eller sosialpersonell. Kilde: TUD

vedtaket og andre journalnotat/ epikriser som journalføres i forbindelse med utskrivning/etablering av TUD.

### **51. Annet innhold i behandlingen**

Her skal det bare registreres tiltak med behandlingsintensjon og innhold. Som f.eks individuell eller gruppeterapi/psykoterapi, sosiale treningsprogram, rusmestringsprogram. Kognitiv terapi osv. Tiltak som rusforbud, strukturert dagligliv osv faller utenfor. Dersom det kodes 1. «Ja (spesifiser)», skriv teksten inn i string (tekst) variabelen for 51 i SPSS.

### **52. Løpende behandlingskontakt under TUD**

I denne variabelen er hensikten å fange opp hvem som faktisk har løpende behandlingskontakt med pasienten under index TUD. Dersom pasienten er på index TUD over 1 år, skal registreringen ta utgangspunkt i det første året pasienten er på TUD. Det må brukes et overordnet skjønn for hva som regnes som løpende kontakt. Som en slags indikator kan man tenke at "løpende" omfatter alt fra daglig kontakt til hver tredje til fjerde uke, men for fastlege kan det aksepteres noe sjeldnere kontakt (ca hver annen måned?). Dersom det ikke lar seg gjøre å finne tilstrekkelig pålitelige data, kodes Missing. Kilde vil primært være siste tre måneders vurdering innenfor et år etter index TUD vedtaket.

### **53. Hvem utfører tre måneders vurderingen**

Den som faktisk ser pasienten ved vurderingen skal registreres.

### **54. Ansvarlig tremåneders vurderinger**

Dersom det kodes 3. «Andre (spesifiser)», skriv teksten inn i string (tekst) variabelen for 54 i SPSS.

### **Hvordan har tre måneders undersøkelser vært gjennomført?**

#### **55. 56, 57, 58 og 60 Gjennomføring av tre måneders vurdering**

De fleste gangene er mer enn halvparten, og de færreste gangene tilsvarende mindre enn halvparten.

#### **59. Dersom telefon benyttes**

Dersom fastlege (eller annen lokal lege) regelmessig blir kontaktet via telefon i tillegg til lokalt behandlingspersonell kodes 12. Om lege og pasienten regelmessig kontaktes via telefon kodes 13. Om lege, lokalt behandlingspersonell og pasienten regelmessig kontaktes via telefon kodes 123. Regelmessighet må bygge på skjønn, men det bør være slik at det omfatter det som ser ut til å være mest vanlig.

### **Forlengelsesvedtak**

#### **64. Fristbrudd for forlengessøknad til kontrollkommisjonen**

Her skal antall dager telles. Om det ikke er aktuelt kodes 0

#### **66. Diagnoser**

Her kodes hoveddiagnosen. Dersom det skulle fremkomme andre diagnoser enn mulige alternativ i registreringsskjema, kodes 10. «Annet (spesifiser)». Den nye diagnose skrives inn med F + tosifret tall i string (tekst) variabelen for 66 i SPSS.

**67. Rusadferd**

Her må det bygges på journalopplysninger i DIPS. Hva som er vesentlig grad og ikke må bygge på skjønn ut fra beskrivelser i journalen.

**VEDLEGG:**

Varighet ulike døgnopphold, TUD perioder og tvangsbehandling, fylles bare ut for de som inngår i B-delen, dvs at index TUD er fattet i perioden 1.1.2008 – 31.12.2009. IndexTUD dato er derfor samme dato som i variabel nr. 10.



# Intervjuguide

---

## Innledning

Takk for at jeg får lov til å intervju deg. Intervjuet handler om hvordan det er å være på TUD og dine meninger om denne behandlingen. Jeg ønsker at du deler dine erfaringer og synspunkter om hvordan du synes TUD er og hvilke innvirkning det har for ditt liv. Du må gjerne fortelle om spesielle hendelser som du har opplevd om du ønsker det. Dersom du bruker andre sine navn kan det være lurt at du anonymiserer dem.

Dersom jeg spør deg om noen spørsmål som du ikke ønsker å svare på er det helt greit. Skulle du ønske en pause eller av en eller annen grunn ønsker å avbryte intervjuet er det bare å si i fra om dette.

Har du noen spørsmål før vi begynner?

Tema	Spørsmål/ subbtema
1. Egne opplevelser og tanker om å være på TUD	<ul style="list-style-type: none"><li>➤ Kan du fortelle om hva du opplever som er mest bra og hva er mest dårlig i livet ditt akkurat nå?</li><li>➤ Kan du fortelle om hvordan det er for deg å være underlagt TUD?</li><li>➤ Kan du fortelle om hvordan det var for deg når det ble fattet vedtak om TUD?</li><li>➤ Kan du fortelle om hvilke konsekvenser det har for deg at du er på TUD? (Økonomi, helse, sosialt, bolig)</li><li>➤ Kan du fortelle om en dag i livet ditt?</li></ul>

<b>Tema</b>	<b>Spørsmål/Subbtema</b>
2. Innholdet i behandlingen	<ul style="list-style-type: none"> <li>➤ Kan du fortelle om hvordan behandlingstilbud du har i dag? (Hyppighet, hvem, allianse, medisiner)</li> <li>➤ Hvordan opplever du å ta medisiner?</li> <li>➤ Hva tenker du om den behandlingen du får?</li> <li>➤ Kan du fortelle om din relasjon til behandler og behandlingsapparatet?</li> </ul>

<b>Tema</b>	<b>Spørsmål/Subbspørsmål</b>
3. Selvbestemmelse	<ul style="list-style-type: none"> <li>➤ Kan du fortelle om hvordan du ble inkludert i diskusjonen om det skulle fattes et vedtak om TUD eller ikke? (Overtalelse, press)</li> <li>➤ Føler du at du får gjort det som du vil i livet ditt?</li> <li>➤ Føler du at du får omgås med de menneskene som du vil?</li> <li>➤ Hvordan opplever du å bli inkludert i beslutninger om din behandling og helse?</li> <li>➤ Hvordan ville ditt liv sett ut dersom du ikke hadde vært på TUD? (vekt på relasjoner)</li> <li>➤ Hvordan opplever du at dine rettigheter blir ivaretatt når du er på TUD? (KK)</li> </ul>



<b>Tema</b>	<b>Spørsmål/Subbetema</b>
4. Bruk av konkret tvang	<ul style="list-style-type: none"> <li>➤ Har du noen gang opplevd konkret bruk av tvang under TUD, kan du fortelle om dette?</li> <li>➤ Hva tror du vil skje dersom du ikke møter til en behandlingsavtale?</li> </ul>
5. Innsikt og forståelse	<ul style="list-style-type: none"> <li>➤ Kan du fortelle om dine synspunkter på om behandlingen du mottar er nødvendig?</li> <li>➤ Hva slags tanker har du om hva slags behov du har, både behandlingsbehov og generelle behov?</li> <li>➤ Hva vil etter ditt syn være den beste behandlingen for deg nå?</li> </ul>

<b>Tema</b>	<b>Spørsmål/Subbetema</b>
6. Avslutning / Oppsummering	<ul style="list-style-type: none"> <li>➤ Er det noe mer du kan tenke deg å fortelle som ikke er kommet frem i intervjuet?</li> </ul>



# Intervjuguide vedtaksansvarlig

---

## Innledning

Intensjonen med denne studien er å få frem pasienter og helsepersonell sine erfaringer og meninger om TUD. Du er blitt forespurt om å la deg intervjuet fordi du er vedtaksansvarlig for en pasient som er blitt intervjuet. Hovedfokuset for intervjuet vil være hvordan du har vurdert behovet for TUD for den aktuelle pasienten. Pasienten er informert om at du intervjuer og hensikten med at du og blir intervjuet.

Tema	Spørsmål/Subbtema
1. Begrunnelse for vedtak	<ul style="list-style-type: none"><li>➤ Kan du fortelle om hvilke hensyn du la til grunn når du vurderte vedtak om TUD? (Var det tvil, alternativer)</li></ul>
2. Behandlingsmål og innhold i TUD	<ul style="list-style-type: none"><li>➤ Kan du fortelle om behandlingstilbud som pasienten har nå?</li><li>➤ Hva er din vurdering av kvaliteten på tilbudet?</li><li>➤ Hvilke behandlingstiltak eller andre sosiale/økonomiske/ generelle tiltak hadde vært ønskelig i tillegg?</li><li>➤ Hvilke behandlingsmål tror du er realistisk for pasienten?</li></ul>

<b>Tema</b>	<b>Spørsmål</b>
-------------	-----------------

Tema	Spørsmål/Subbtema
3. Gjennomføring	<ul style="list-style-type: none"> <li>➤ Hvordan foretas kontroll undersøkelsene og hvordan vurderes og evalueres TUD underveis?</li> <li>➤ Hvilke hensyn legger du vil grunn når du vurderer å oppheve TUD?</li> </ul>
4. Medbestemmelse	<ul style="list-style-type: none"> <li>➤ Hvordan inkluderes og tilrettelegges det for at pasienten får mulighet til å delta i utformingen av innholdet om TUD?</li> <li>➤ Hvordan tilrettelegges det for informasjon til pasienten om han/hennes rettigheter?</li> <li>➤ Hvordan ser du på muligheten for behandling på frivillig grunnlag?</li> </ul>

Tema	Spørsmål/Subbtema
5. Relasjon	<ul style="list-style-type: none"> <li>➤ Kan du fortelle om betydningen selve tvangsrammen har for behandling av pasienten?</li> <li>➤ Har behandlingsrelasjonen blitt påvirket av at det er fattet vedtak om TUD?</li> </ul>
6. Avslutning	<ul style="list-style-type: none"> <li>➤ Er det noe mer du kan tenke deg og fortelle eller føye til avslutningsvis?</li> </ul>

