

A study of Norwegian service users'  
experiences with Assertive  
Community Treatment

PhD Thesis

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## Summary

**Background:** Assertive Community Treatment (ACT) is an evidence-based model for service delivery to enable persons with severe mental health challenges to live and be active in the community. This model includes moving the services from the hospital to the service users' homes by a visiting ACT team. Implementation of the model in Norway commenced in 2009 as an offer for patients with extensive treatment needs.

**Aim:** This study aims to describe and explore the service users' experiences with Assertive Community Treatment (ACT) teams in Norway.

**Material and methods:** This study is a part of the national evaluation of 12 ACT teams in Norway and includes both quantitative and qualitative data on 70 ACT service users' experiences with the ACT teams. Twenty-two women and 48 men participated in the survey "User Interview User about ACT teams". The survey questionnaire consisted of well-established instruments, customised questions and five open-ended questions. In addition, eight of the participants were recruited to four individual interviews and one focus group. To obtain complimentary knowledge and understand the ACT service users' experiences in another context, the study applied mixed methods and a transformative lens. The ACT service users' experiences were explored by analysing their satisfaction with ACT treatment, experiences of personal recovery and experiences of possible positive and negative aspects of treatment.

**Results:** The Norwegian ACT service users, especially those on Community Treatment Orders (CTO), report high satisfaction with the ACT service (paper 1). In terms of recovery, the group under CTOs also report the highest degree of personal recovery. Male participants report a higher degree of recovery than females. Flexibility of services, medication and access to a car were mentioned as important elements for a positive recovery (paper 2). Also, ACT service users have broad knowledge concerning mental health treatment. Access to treatment is an individual right, but is intertwined with paradoxes such as experiences of both normality and marginalisation, and of autonomy and limitations (paper 3).

**Conclusion:** Service users experience the ACT model as a positive and improved service that promotes recovery, especially for those under CTOs. However, there are dilemmas and areas of improvements that must be addressed, such as experiences of autonomy versus coercion. It is essential, with ongoing ethical reflections and increased user involvement, to address these dilemmas and develop practice in accordance with the service users' needs. There is ethical and

professional obligation and legal liability to continue and sustain a well-documented and effective service, and to secure the service users' rights.

## Sammendrag

**Bakgrunn:** Assertive Community Treatment (ACT) er en evidensbasert behandlingsmodell som gjør det mulig for personer med alvorlige psykisk helseutfordringer å leve et aktivt liv i lokalsamfunnet. Denne modellen tar sykehusbehandling hjem til brukerne ved at de får besøk av et oppsøkende team. I 2009 ble modellen innført som et tilbud for pasienter med ulike behov for hjelp.

**Formål:** Formålet med studien har vært å beskrive og utforske brukernes erfaringer med ACT-team i Norge.

**Data og metode:** Denne mixed methods-studien er en del av en nasjonal evaluering av tolv ACT-team i Norge. Studiet inneholder både kvantitative og kvalitative data fra 70 brukere av tolv norske ACT-team. 22 kvinner og 48 menn deltok i spørreundersøkelsen som fikk navnet «Bruker intervjuer bruker om ACT-team». Spørreskjemaet besto av godt etablerte instrumenter, egenutviklede spørsmål og fem åpne spørsmål. I tillegg ble åtte av deltakerne rekruttert til fire individuelle intervjuer og en fokusgruppe. Mixed Methods med en transformativ linse er benyttet for å få komplementær kunnskap og se ACT-brukerne i ulike sammenhenger har studien. ACT-brukernes erfaringer ble utforsket ved å undersøke deres tilfredshet med ACT-teamets tjeneste, deres erfaringer med personlig recovery (tilfriskning) og deres erfaringer med mulige positive og negative sider av behandling.

**Resultater:** De norske ACT-brukerne, og særlig de på Tvang uten døgnopphold (TUD) rapporterte høy grad av tilfredshet med de norske ACT-teamene (artikkel 1). Det er også de på TUD som rapporterer høyest grad av personlig recovery. Mannlige deltakere rapporterer om høyere grad av personlig recovery enn kvinnelige. Flexibilitet i tjenesten, mulighet for å diskutere medisineringen og tilgang til bil ble nevnt som viktige elementer for en god personlig recovery (artikkel 2). ACT-brukerne innehar en bred kunnskap om behandling i psykisk helsetjenester. Tilgang til behandling er en individuell rettighet, men det henger sammen med paradokser. Brukerne beskriver både en normalisering og en marginalisering, og autonomi og begrensninger (artikkel 3).

**Konklusjon:** ACT-brukerne erfarer modellen som en god og forbedret tjeneste som fremmer recovery, og dette gjelder særlig for de som er på TUD. Likevel finnes det dilemmaer og områder som kan forbedres må settes på agendaen, som erfaringer med autonomi i motsetning til tvang. Det er

helt nødvendig med en pågående etisk refleksjon og økt brukermedvirkning for å møte disse dilemmaene for å utvikle en god praksis i henhold til brukernes behov. Det er en etisk, en faglig og et rettslig ansvar å opprettholde en veldokumentert og effektiv tjeneste, og å sikre brukernes rettigheter.

## Abbreviations

ACT = Assertive Community Treatment

AUDIT = Alcohol Use Disorder Identification Scale

BPRS = Brief Psychiatric Rating Scale

CRPD = UN Convention on the Rights of Persons with Disabilities

CSQ-8 = Client Satisfaction Questionnaire

CTO = Community Treatment Order, in Norwegian: TUD (Tvang uten døgnopphold)

DUDIT = Drug Use Disorder Identification Scale

EADO = Anti-Discrimination Ombudsman in Norway

Erfaringskompetanse = National Centre for Knowledge through Experience in Mental Health

GAF = Global Assessment of Functioning

NAPHA = National Competence Centre for Mental Health work

NIMH = National Institute of Mental Health

PPI = Patient and public involvement

PSF = Practical Social Functioning

QPR = Questionnaire about the Process of Recovery

RCT = Randomised controlled trials

REC = The Regional Committees for Medical and Health Research Ethics

SDI = Stepwise-Deductive-Induction

TAU = Treatment as Usual

TMACT = Tool for Measurement of Assertive Community Treatment

TCL = Training in Community Living, the first version of ACT

UN = United Nations

## Contributors to the study

**Main project group** = Collaboration between the Sykehuset Innlandet Hospital Health Trust and Akershus University Hospital Health Trust (Ahus). The group consisted of six researchers and performed the national evaluation of the ACT teams.

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## List of papers

### Paper 1

Lofthus, A-M, Westerlund, H, Bjørgen, D, Lindstrøm, JC, Lauveng, A, Clausen, H, Ruud, T, Heiervang, KS (2016) Are Users Satisfied with Assertive Community Treatment in Spite of Personal Restrictions? *Community Mental Health Journal* 52(8): 891-897, DOI: 10.1111/inm.12304.

### Paper 2

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### Paper 3

Lofthus, A-M, Weimand, BM, Ruud, T, Rose, D, Heiervang, KS (2018). This is not a life anyone would want"—a qualitative study of Norwegian ACT service users' experience with mental health treatment. *Issues in Mental Health Journal*, p. 1-8, DOI: 10.1080/01612840.2017.1413459



# 1 Introduction

This thesis examines the Norwegian Assertive community treatment (ACT) service users' experiences with the service. In Norway service user involvement has been emphasised in political regulations. There has been a development regarding the rights of mental health service users' participation in their treatment, and the related services have an obligation to enable the users' leadership in their own life. At the same time, this right to decide challenges the power balance in treatment. My research aim is to examine the perspectives of Norwegian ACT service users and to describe their experiences of this, initially American, mental health service delivered in a Norwegian context.

The Assertive community treatment (ACT) model is one of the most researched and well-documented models in mental health care worldwide. Research on the ACT model and outreach treatment is characterised by a large number of randomised controlled trials (RCTs), and these studies have been summarised in two Cochrane reviews addressing outreach services (Dieterich, Irving, Park, & Marshall, 2010; Marshall & Lockwood, 2010). The reviews examine the content of the treatment and the treatment outcomes and usually describe results in clinical terms, such as treatment outcome, reduction in symptoms or improvement in functioning. RCTs are considered the "golden standard" and "the best evidence on the effectiveness of treatment and health care interventions" (Kirkwood & Sterne, 2003, p. 396). However, studies on clinical outcomes may be unable to describe the entire picture of how the ACT service users may experience the services and their influence on everyday life.

There are several studies describing the ACT model in an European context (Aagaard & Müller-Nielsen, 2011; Killaspy et al., 2006; Killaspy et al., 2009; Lambert et al., 2010; Minghella, Gauntlett, & Ford, 2002; Priebe et al., 2003; Ryan & Morgan, 2004; Williams, Firn, Wharne, & Macpherson, 2011; Williamson, 2002). These studies demonstrate a need for local adjustments of the fidelity measures, which could inform the implementation process of the ACT teams in Norway.

Internationally, the ACT literature undergoes a shift after 2010. The research incorporates recovery thinking into the studies, but the focus remains on the efficacy of the ACT model in a treatment context (Monroe-DeVita, Teague, & Moser, 2011; Morse, Glass, & Monroe-DeVita, 2015; Salyers et al., 2013). I chose to focus on literature that described the ACT service users' situation and addressed this study's research questions. A different focus implies less focus on literature aiming to describe clinical results and organisation. I excluded literature that describes Flexible ACT teams (FACT), which were not considered in this study. The specific literature related to ACT service users' experience is presented in section 2.2 important concepts.

Apart from in the current study, the ACT model in Norway is described in handbooks, articles, masters and PhD theses (Aakerholt, 2013; Clausen, 2017; Haugen, 2012; Lesjø, 2015; Meese & Ekeland, 2017; Pettersen, 2015; Pöyry, 2011; Sommer, Strand, Borg, & Ness, 2013; Stokmo, Ness, Borg, & Sommer, 2014). These sources provide an overall positive impression of the treatment model and focus on the effect of the model in a Norwegian context, both for the ACT service users and ACT professionals.

## 1.1 The development of the Assertive Community Treatment (ACT) model

The Assertive Community Treatment (ACT) model of interdisciplinary service arose because of deinstitutionalisation (Dixon, 2000; Lamb & Bachrach, 2001; Stein & Santos, 1998). Namely, the need for structural changes due to overcrowded hospitals, budget drains and civil rights forced the deinstitutionalisation process forward after the Second World War. This process included the downscaling of mental hospitals and moving treatment from institutions to local communities and enabled mental health patients to enter into society (Paulson, 2012; N. Rose, 2001; Warner, 2013). Mental health patients had been living under unsuitable conditions and treatment was criticised by those in the civil rights movement and other critical voices (Davidson, Rakfeldt, & Strauss, 2011; Goffman, 1961, 1963).

For our context, there are three important events in the development of community-based care in the United States (US). According to Davidson et al. (2011), President Truman's signing of the National Mental Health act in 1946 laid the foundation of community-based care. S. J. Johnson (2011) underpinned the importance with Congress passing the Community Mental Health Act in 1963. In addition, the introduction of Medicaid in 1965 provided financial incentives to move care from State hospitals to the communities (Stein & Santos, 1998). Although these actions aimed to improve conditions for the mental health patients, the allocated funds did not follow the patient into the community. For example, the Community Mental Health Team Act of 1963 demanded that 2000 new community mental health centres be established, but only 754 existed in 1980 (Brodwin, 2013). Overall, American society did not seem prepared to integrate a marginalised group in the decades following the Second World War and thus, the governmental attempt to compensate for fewer hospital beds in mental health treatment.

Due to the shifting times within mental health care, the ACT-model was developed. This model started at Mendota Health Institute in Madison, Wisconsin with a grant from the National Institute of Mental Health (NIMH) in 1972 (S. J. Johnson, 2011). The study's first results were presented in 1975 (Dixon, 2000; Stein, Test, & Marx, 1975). The ACT model's founders, Leonard Stein, Mary Ann Test and Arnold Marx, first named the programme "Training in Community Living" (TCL).

The founders described the programme as a way to enable mental health patients to maintain a balanced life and manage living in the community despite their mental health challenges. The founders focused on civil rights and emphasised reduced hospitalisation, increased social training, meaningful spare time activities, the team's assertiveness, and social integration as important factors for enabling persons with severe mental health challenges to live in the community. To prevent the TCL becoming a failure, the founders identified the need for research and documentation. This decision contributed to ACT becoming an evidence-based and wide-spread model (Marshall & Lockwood, 1998; Stein & Santos, 1998; Stein et al., 1975).

In 1980, the TCL model was further presented in the paper series "Alternative to mental hospital treatment: Conceptual model, treatment programme, and clinical evaluation" (Stein & Test, 1980; Test & Stein, 1980; Weisbrod, Test, & Stein, 1980). In their first paper, Stein and Test describe how ACT could be a *conceptual model*, a *treatment model* and an *evaluation of clinical practice* through the study they had conducted. Regarding the conceptual model, Stein and Test recognised that the following six criteria must be met for patients to function in society: 1. Basic needs had to be met and medication had to be adequate; 2. The patients had to have a certain level of knowledge to cope in society; 3 Help and support needs must be met; 4. "*Freedom from pathologically dependent relationships*" (dependence on family or institutions) (p. 393), i.e., dysfunctional relationships; 5. Provision of assistance and education for local people who help the patient; and 6. A support system that can help with the first five criteria. Note that the study was a randomised controlled trial (RCT). The control group received treatment as usual (TAU) and the experimental group received assistance through the TCL programme. The study's findings revealed that members of the experimental group (TCL) made significantly better progress than the TAU population. The results indicated a need for mental health patients' to be educated to become an integrated and responsible citizen.

Stein and Santos (1998) described this mental health service model as: "*the assertive community treatment (ACT) model is best conceptualized as a service delivery vehicle or system designed to furnish the latest, most effective and efficient treatments, rehabilitation, and support services conveniently as an integrated package*" (p. 2). The dissemination of the ACT treatment model in the US and globally may be due to the evidence-based practice and a governmental and organizational

will to implement the treatment in mental health services locally. According to the Center for Evidence-Based Practices, the ACT model is currently present in 13 US states and in several countries across Europe and Asia (Center for Evidence-Based Practices, 2017).

### 1.1.1 The Norwegian context

Norwegian mental health care underwent a process of deinstitutionalisation in the 1970s, and this period was characterised by interactions between changes in economy, ideology, research and professional developments (Ekeland, 2011). An important turning point was the Norwegian Escalation Plan for Mental Health 1998-2008 (Escalation Plan), which uncovered deficits in the mental health services, the need for increased resources and Norwegian society's apparent inability to integrate persons with mental health challenges (Sosial- og helsedirektoratet (Directorate of Health and Social Affairs), 1998-2008).

According to Ekeland (2011), the Escalation Plan was a political document with significant spin-off effects. He discusses how this document represented an admission that the Government had neglected the mental health field for years. After this criticism, the plan was amended to improved situation for persons with mental health challenges, and a focus on their individual wishes and needs (p. 9).

In the wake of the Escalation Plan (1998-2008), the Norwegian Parliament enacted the Coordination Reform (2009). In this White Paper, the Government acknowledged that there were two main challenges in the existing welfare system – the fragmented services and a lack of effort to reduce and prevent illness. The aim of the reform was to secure that future welfare services could respond to patient needs for coordinated services and socioeconomically challenges (Grimsmo, Kirchhoff, & Aarseth, 2015). This goal could be met through a more defined patient role, delegating more responsibility to the local community health system, and establishing economic incentives to change the services. The specialised health services intended to perform more personal help (Helse-og Omsorgsdepartementet [Norwegian Ministry of Health and Social Affairs], 2009). In a 2008 government report, estimates revealed between 5000 to 6000 patients in the mental health service were not receiving adequate treatment (Helsedirektoratet (The Norwegian Directorate of Health), 2008).

### 1.1.2 The development of ACT teams in Norway

In 2005, the District Medical Officer in Moss, Knut Michelsen, discovered the ACT model after searching the Cochrane database (NAPHA, 2017). He discovered an evidence-based model demonstrating positive results for patients with severe mental health challenges and substance abuse. Michelsen and colleagues then established the first Norwegian ACT team in the region of Moss in 2007. This team served four municipalities and the district psychiatric centre (Pöyry, 2011). Experiences from the Moss project became important for the development of assertive community treatment in Norway.

To meet the critiques outlined in the Escalation Plan, and to trial methods of cooperation between primary health care and secondary care, funding of new ACT teams was passed in the Coordination Reform (2009). In this White Paper, the ACT treatment was described as interdisciplinary and to be implemented across sectors. The paper also demanded that first-line service and secondary care be provided together: *“An ACT team is an active outreach treatment team that works across levels and sectors. They seek out the service users where they live – at home, in parks, at school, at work, or elsewhere”* (Helse- og Omsorgsdepartementet (Ministry of Health and Care Service), 2009, p. 70). The Government also argued that:

*“According to the Norwegian Directorate of Health, the establishment of an ACT team requires at least six positions with a population of 60 000, and ten professional positions with a population of 90 000–100 000. Future efforts will assess whether establishing an ACT team should be a statutory municipal task”* (Helse- og Omsorgsdepartementet (Ministry of Health and Care Service), 2009, p. 70).

In addition to the ACT team in Moss, 13 ACT projects followed in the subsequent years, resulting in 14 ACT teams in Norway in 2013. The National Competence Centre for Mental Health work (NAPHA) was assigned to coordinate the education of the ACT teams in Norway and arranged 11 seminars between 2009 and 2011 (NAPHA, 2017). NAPHA’s website provides extensive information about the development of the ACT treatment in Norway.

### 1.1.3 The ACT service users

The Norwegian ACT handbook states the following: *“The ACT model is most suitable for psychosis patients with a low functional level and extensive additional problems”* (Aakerholt, 2013, p. 11). The intention behind establishing ACT teams in Norway was to secure a service provision for people characterised as “hard to reach and hard to treat”. These were persons who, according to the Norwegian Directorate of Health, had *“a prolonged and unstable history of illness, long-term psychotic disorders/schizoaffective disorders, severe bipolar disorders, substance use/substance abuse disorders and tentative severe mental disorders, severe mental disorders and mild intellectual disability”* (Aakerholt, 2013, p. 11).

The ACT service users’ starting point was difficult. Many experienced poor living conditions and had experienced infringements and inadequate treatment from ordinary mental health services. Poor finances, medication, coercion, drug use and isolation characterised the lives of many service users. Overall, this group of service users was in need of adequate services to help them lead a meaningful life (Clausen, 2017). The national evaluation conducted by Sykehuset Innlandet Hospital Health Trust and Akershus University Hospital Health Trust included 12 of the 14 existing teams, concluded that the number of ACT service users enrolled in the 12 ACT teams was approximately 600 individuals. Accepting services from an ACT team is a voluntary decision and implies a right to receive services from the ACT staff. Importantly, an ACT service user has a legal right to withdraw from treatment.

### 1.1.4 Evaluation of Norwegian ACT teams - context of the current study

When establishing ACT teams in Norway in 2009, the national health authorities conducted a research-based evaluation of the implementation (Helse-og Omsorgsdepartementet [Norwegian Ministry of Health and Social Affairs], 2009). The Norwegian Directorate of Health commissioned this research and handed the assignment to Sykehuset Innlandet Hospital Health Trust, in collaboration with Akershus University Hospital Health Trust (Ahus). The main project group was charged with designing and conducting the evaluation, including assessment of the teams’ fidelity according to Tool for Measurement of Assertive Community Treatment (TMACT) (Monroe-DeVita et al., 2011), which measured how well the Norwegian teams followed the ACT model. The ACT team members collected clinical data regarding individual ACT service users. The final report was “Evaluation of ACT teams in Norway. What do the results show?” (Landheim A et al., 2014), and concludes with an improved situation for most of the ACT service users.

A sub study of the national evaluation concerning the ACT service users' experiences commenced in 2012 (Heiervang et al., 2014). This was a collaborative research project between Ahus and the National Centre for Knowledge through Experience in Mental Health (abbreviated Erfaringskompetanse). This evaluation was the first-ever to utilise the "Users Interview Users" methodology to collect quantitative data. The "Users Interview Users" method is a dialogue-based method of evaluation and the goal is to improve the service. This originally qualitative method originated in England in 1998 and was further developed in Norway during the 2000s (Brukererfaring.no, 2017; Rise et al., 2013).

The project group, named the Collaborative research group, consisted of two researchers from Erfaringskompetanse and three researchers from Akershus University Hospital, where, interestingly, one was a researcher and a service user. The Collaborative research group designed the study "User Ask User about ACT teams". In addition to the two collaborative researchers from Erfaringskompetanse and me, six service users were later recruited as service user researchers and visited the 12 participating ACT teams to meet the participants and document their answers to the questionnaires. From the onset, I was recruited as one of these nine service user researchers. I later received the post as PhD student and joined the Collaborative research group. This thesis includes data from the substudy "User Interview User about ACT teams".

## 1.2 Important concepts

### 1.2.1 Patient or service user?

According to official guidelines, *"a service user is a person who makes use of relevant services in some form or another"* (Helsedirektoratet [The Norwegian Directorate of Health], 2006) p. 7). According to Norwegian legislation, a patient is defined as such when they receive health care and a user when utilising social services (Pasient- og brukerrettighetsloven [Patient Rights Act], 1999). These two terms indicate a slight difference in activity.

The term 'patient' derives from the Greek word *'pati'* meaning to suffer (Caprona, 2013). This is an indication of passivity and not an active choice of the individual. 'User' indicates a more active stand and derives from German, meaning 'consume' (Caprona, 2013). The ACT model's interprofessional and holistic approach to meet all of the individual's needs may define the ACT service user both as a

patient and as a user. Inclusion by an ACT team provides status as a patient or service user, along with formal and informal rights and obligations (Pettersen, Ruud, Ravndal, Havnes, & Landheim, 2014). In the reviewed literature, ACT service users are referred to with different names, such as 'client' (Allness & Knoedler, 2003; Pettersen et al., 2014) 'outreach patient' (Priebe et al., 2003) and 'service user' (Wright, Callaghan, & Bartlett, 2011).

The term 'service user' may be in accord with the Norwegian terminology, but the term is disputed. McLaughlin (2009) has discussed the development of the concept of the 'service user' in social services and views the names as a description of power distribution between social worker and service user. McLaughlin describes a development from a more passive term 'client' to embrace the consumer term in lines of New Public Management's idea about consumerism. The term 'service user' implies various limitations and negative connotations, such as being dependent and in an inferior power position (McLaughlin). This client-service user development in social services is parallel to the development of the patient-service user concept in medical and mental health treatment.

It has been a discussion whether to name the enrolled individuals as 'patient' or 'user', as the ACT model has become a synthesis of medical clinical practice and social service. On the other hand, the traditional hierarchal structures, with medical professionals as the leading figures, may influence the development of the teams, slow the process of user involvement and hinder the service user becoming the focal point. (Brodwin, 2013; N. Rose, 2001). I prefer to describe individuals included in an ACT team as 'ACT service user' or 'service user'. Using the term 'service user' could contribute to a consciousness aimed toward user involvement.

### 1.2.2 Experience

'Experience' derives from the Latin word 'experientiri', meaning 'try' (Oxford Dictionaries, 2017). Experience is a concept with several meanings. As a noun, the term describes 'practical contact with and observation of facts and events' or 'practical experience of something'. As a verb, experience describes encounters with a phenomenon or feelings toward something (Oxford Dictionaries, 2017). The Norwegian word for experience is 'erfaring' and is borrowed from German. The word describes both receiving information, to feel and to notice, but also to 'get hold of' and 'know by traveling through' (Caprona, 2013). I have chosen to use the definition by Gadamer (2012), who defines experience both as a process and participation in a happening.

Experience in the context of this thesis may be a collection of different involvements in ‘mental health services’. ACT service users possess a broad knowledge base about treatment and treatment methods in mental health care, making it tempting to use the term “expert by experience” (McLaughlin, 2009). Kogstad, Ekeland, and Hummelvoll (2014) state that user experience and knowledge may be concealed by professional and official versions. Thus, it is important to obtain the service users’ narratives for a more complete overview of their experiences.

Challenges arise when attempting to obtain service users’ core ACT treatment experiences. Many of the participants have a long-time involvement in various mental health services prior to enrolment in an ACT team. Consequently, the ACT-specific experience could be difficult to extract. As such, the service users’ collected experiences could be defined as a process (Austgard, 2004; Gadamer, 2012). To extract user experiences with ACT teams, the researcher must, therefore, participate and listen to the users’ broad experiences of receiving mental health treatment.

In an example of first-hand experience of the ACT treatment, Estroff (1981) was the first researcher to describe the Assertive Community Treatment service users’ experiences and living conditions outside the mental hospital and their challenges of adapting to their community’s norms and demands. Her close observations as a participant in an ACT team in Madison, Wisconsin, was:

*“being a long-term psychiatric patient does not seem so awful anymore. Yet it also appears to be a self-other constructed trap. Clients have taught me and have demonstrated the benefits and rewards of this pathway. But they are also not unaware of the costs, negative consequences, and trade-offs to be made. Understanding this seeming contradiction is perhaps the most important and difficult task”* (Estroff, 1981, p. 19).

From this account, there seems to be a difference between the description in the RCTs and this eyewitness encounter in the ACT literature.

Furthermore, the literature divides the descriptions of ACT service users’ experiences into two main traditions. The first description is rooted in medical science (Dieterich, Irving, Park, & Marshall, 2010; Marshall & Lockwood, 1998; Phillips et al., 2001; Ryan & Morgan, 2004; Stein & Santos, 1998). The approach may be interpreted as the clinical practice being the main context to understand and explain the ACT service users’ experiences and knowledge. Positive experiences may provide justification for the ACT model’s existence and operation. On the other hand, it is important to map out the full scope of the service users’ experience to correct any wrongdoings in treatment.

The second description of experience, rooted in social science, is generally more critical (Brodwin, 2013; Estroff, 1981; S. J. Johnson, 2011). The critics include social and external factors influencing the ACT treatment and are more focused on describing the ACT service users' point of views. The literature includes more qualitative studies, which aim to understand the ACT model and its services from a service user's perspectives and place greater emphasis on human rights and marginalisation (Molodynski, Rugkåsa, & Burns, 2016; Sommer et al., 2013; Ye et al., 2016).

At the turn of the millennium, for example, several studies criticised prior research, which focused on clinical treatment and ignored the ACT consumers' experience with the service (Krupa et al., 2005; Lang, Davidson, Bailey, & Levine, 1999; Leiphart & Barnes, 2005; Wharne & Spilsted, 2011). These studies emphasised the importance of the ACT service users' opinion and revealed that good relations, trust, engagement and emotional support were important for improving life for service users and their gaining of positive experiences with ACT treatment. Phillips et al. (2001) emphasised that the RCT trials lacked interest in how the ACT treatment works. However, the service user perspective is more in accordance with the initial description of the ACT model, where clinical practice and social inclusion are equally positioned (Stein et al., 1975).

Experience is the personal knowledge about a phenomenon gained as both an active and a passive participant (Austgard, 2004). The concept of experience can be regarded as a process of accumulated knowledge that may include both positive and negative aspects. Service user experience is more emphasised in ACT research due to the person-centred treatment as an important treatment aspect. Calsyn, Winter, and Morse (2000) demonstrate that ACT service users who selected the ACT team from five different treatment programs were more satisfied than a group of ACT service users who were enrolled without being consulted about their treatment options. Later, Calsyn, Morse, Klinkenberg, Yonker, and Trusty (2002) found that higher intensity and frequency of contact between team and service users improved the service user's experience with the services due to social interaction and a positive helping alliance. Likewise, Krupa et al. (2005) have demonstrated that personal relationships and a flexible approach towards the individual ACT service user's needs and wishes influence their experience. Importantly, social sense of belonging and improved personal finances create more satisfaction among the service users. Thus, there seems to be a link between positive social interaction and positive service user experiences, and thereby, an improved treatment result.

Fricker (2007) introduced the term '*epistemic injustice*' to refer to different connections between power and knowledge and how these factors are dependent on communication between the speaker and the listener. Epistemic injustice explains that a speaker may be misread as a first-hand knower due to a listener's prejudice. The author argues that there are two types of epistemic injustice. '*Testimonial injustice*' refers to an individual with some kind of deficit that may be related to mental or physical illness. The speaker is misunderstood or discredited due to this deficit, which causes a bias in the listener. Fricker (2007) relates '*hermeneutical injustice*' to an overarching level. That is, the hermeneutical injustice refers to a listener's prejudice based on whether the speaker belongs to a powerless or marginalised group. Bearing this in mind, as a reader and a researcher, we must listen with an open mind and thereby, provide our readers with correct information.

The theory of 'Epistemic injustice' has also been elaborated on in the field of psychiatry. Crichton, Carel, and Kidd (2017) have described how mental health patients are more exposed to epistemic injustice compared to patients with a physical illness. The authors demonstrate how mental health patients are considered less credible than others due to the nature of the mental health challenge, unbalanced power distribution and negative stereotypes. Leblanc and Kinsella (2016) claim that the Western world has undermined mental health service users' voices and opinions. Thus, it is important to improve the credibility of mental health service users' statements and experiences.

### 1.2.3 Satisfaction

Satisfaction is a Latin word, '*satisfacere*', which means 'to content' (Oxford Dictionaries, 2017). As a noun, satisfaction describes a fulfilment of one's needs or expectations or the pleasure derived from such fulfilment. In a treatment setting, the concept of satisfaction may be used as a quality measure of the services provided (Biering, 2010; Ziguras & Stuart, 2000).

Therefore, satisfied service users can be a valuable measurement of successful clinical practice. The field of satisfaction assessments in mental health is large and may be considered in line with the efforts to improve the quality of clinical practice and management (Gerber & Prince, 1999; Lebow, 1983; Manary, Boulding, Staelin, & Glickman, 2013; Ruggeri, 1996, 2010). In addition, the service users' measured satisfaction offers an opportunity to compare their treatment with other services, both nationally and internationally (Lebow, 1982). A satisfied patient or service user may also be a valuable governing resource for the management and may provide an example of documenting good practice (Ruggeri, 1994).

Satisfaction is also connected with engagement and good therapeutic relations in an ACT context (Ben-Porath, Peterson, & Piskur, 2004; Calsyn et al., 2002; Phillips et al., 2001; Redko, Durbin, Wasylenki, & Krupa, 2004; Wharne & Spilsted, 2011). There is a consensus in these studies that the ACT service users are more satisfied than service users in ordinary services. For instance, Ben-Porath et al. (2004) report fewer days in hospital as an important factor for service user satisfaction and that relatives are reportedly more satisfied with the team than the service users are. The authors argue that the relatives may be more satisfied than the service user due to the ACT service users' directly experiencing invasions in their private life. A flexible team approach, low caseload, individual treatment and user participation seem to be important components contributing to the ACT service users' satisfaction (Killaspy et al., 2009). Therefore, the degree of satisfaction relating to the will to involve the user in treatment occurs in the wake of more focus on individual needs.

#### 1.2.4 User involvement

The service users' participation in treatment is incorporated in the legal system. Critical voices claim that it seems to be a challenge for mental health services to involve the service user in treatment in a satisfactory manner (Klausen, 2017). The involvement of the user poses questions regarding human rights. In the following subsections a discussion of the basis of user involvement and relate such involvement to recovery and coercion in a Norwegian ACT treatment setting.

#### 1.2.5 User involvement as a democratic principle of control and a human right

The concept of user involvement dates back to the United Nations' (UN) adoption of the Universal Declaration of Human Rights in 1948 (FN-sambandet (United Nations Association of Norway), 2016). This declaration establishes that everyone has a right to enjoy a good and meaningful life based on their own capabilities. Thus, user involvement implies a democratic principle of involvement with decisions that affect the individual's life.

The Pasient- og brukerrettighetsloven [Patient Rights Act] (1999) is one of several laws that enact the right of service users to be involved with their own treatment. The Act places obligation on the health care services to ensure that users play an active role in decisions concerning their own lives. Notably, Section 3-1 emphasises that:

*“Patients and service users are entitled to participate in the implementation of their health care. This includes the patients’ right to participate in choosing between available and medically sound methods of examination and treatment. The form of participation shall be adapted to the individual patient’s ability to give and receive information.”* This passage from the Patient Rights Act confirms that the service user or patient has a right to participate in their own treatment.

Johansen and Solbjør (2012) posit that user involvement is also a phenomenon and discourse found in government documents and that user involvement has changed from being a model of active citizen participation intended to secure rights to a consumer model designed to safeguard the established welfare system. I interpret this development as a suggestion that on an individual and system level, user involvement may become a way of legitimising a system that benefits the service, rather than the service user. However, critics may point out that the paper ignores the tradition of collaboration on which the Norwegian welfare state has been built, and that our democratic welfare system is based on active citizen participation (Askheim, 2012).

### 1.2.6 User involvement in mental health services

This thesis focuses on user involvement at an individual level because I want to explore the term ‘user involvement’ due to the importance of the concept in mental health legislation. The Norwegian Directorate of Health and Social Affairs discusses the ‘user involvement’ concept in their guidelines on user involvement in the mental health sector and touch on motivation and different levels and various degrees of involvement (Helsedirektoratet [The Norwegian Directorate of Health], 2006). The guidelines’ explanation of user involvement at individual level states that: *“This also means that service users must accept responsibility for their share of the work towards a better life. For this to be achieved, service users must feel that their own contributions are meaningful and that they can genuinely influence the offer of services provided”* (ibid. p. 8). The guidelines highlight a mutual responsibility for treatment, involvement and recovery. The modal verb employed is neither ‘should’ nor ‘can’, but a ‘must’.

User involvement has been on the ACT model’s agenda since the launch in 1975, albeit with different words (Stein & Test, 1980; Stein et al., 1975). The aim of the holistic treatment model was to engage and enable the ACT service users to gain a meaningful life in society through treatment. The model has been accused of paternalism, coercion and unnecessary intervention in private life and may be an example of difficulties in exercising user involvement (S. J. Johnson, 2011; Leiphart & Barnes,

2005). Thus, it seems like the ACT teams can, though in various degrees, involve the service users in treatment due to the reported higher degrees of user satisfaction compared with other mental health services (Calsyn et al., 2002; Calsyn et al., 2000; Krupa et al., 2005; Redko et al., 2004).

That said, some studies have implied that user involvement in ACT treatment may pose challenges related to the ACT service users' engagement, motivation and health. For example, Storm and Edwards (2013) present different models of user involvement and stress the importance of ACT teams as a way of avoiding hospital stays and that user involvement is crucial for successful treatment in the patient's home environment. Wharne and Spilsted (2011) place engagement in treatment and empowerment as important aspects of user involvement, and thereby encourage the service user as an active participant in his or her own life. However, it may be difficult to engage and involve persons with severe personal and mental challenges, which may be a reason some team members find it difficult to maneuver being a impactful service provider and following protocol (Chinman, Allende, Bailey, Maust, & Davidson, 1999; Lang et al., 1999). Overall, these studies state that good treatment results depend on structural conditions that favour the establishment of user involvement and sound relations between the individual team member and the ACT service user.

Norwegian ACT teams have also been studied with respect to their involvement with service users (Stokmo et al., 2014). Their paper examines how ACT workers assess the effect of model fidelity on user involvement. The study's participants, five ACT workers, highlight difficulties in user involvement regarding involuntary treatment and medication, but state that the model as a whole ensures user involvement. The ACT workers feel they are working in a humane and holistic manner and according to ACT team staff, the model facilitates active participation by service users. In addition, Landheim et al. (2014) have demonstrated that the ACT teams improved user involvement when they became aware of its importance through fidelity evaluations. Then, acceptable user involvement facilitates awareness in the teams. Therefore, it is crucial to have a continuous discussion on how to ensure user involvement in Norwegian ACT teams.

Ultimately, user involvement requires, in various degrees, effort by the service user to participate in their own treatment. User involvement is regulated by the Norwegian legislation, but practice may differ. Thus, it is important to encourage ongoing debate on defining sound and sustainable user involvement in mental health services.

### 1.2.7 Recovery

“Recovery” is a multifaceted concept that has been described in different ways. Slade (2009) splits the concept between clinical and personal recovery. Borg and Karlsson (2013) present the concept with three different dimensions: 1. clinical recovery, 2. personal recovery and 3. social recovery. Davidson et al. (2011) argue that recovery as a movement is primarily a civil rights movement for persons with experiences of mental health challenges, and secondly, a movement describing an orientation of treatment (p. 7). These authors agree that clinical recovery differs from the other dimensions of recovery, namely social and personal.

Clinical recovery is based on the treatment and refers to recovering from symptoms or an illness (Andresen, Caputi, & Oades, 2010). Slade et al. (2014) describe clinical recovery in the following terms: “*In clinical recovery, professionals diagnose and treat with the aim of curing people or reducing their symptoms*” (p. 13). A targeted and result-oriented treatment demands attentive clinicians for the recovery process to be successful. In my view, it may even be a challenge to incorporate the recovery approach in a treatment system based on measurements and goals. As researchers in the field of recovery, Borg and Karlsson (2013) do not provide details about clinical recovery due to limited interest in the development of mental health work (p. 71). Social benefits is a fundamental right in Norway. However, diagnoses and clinical treatment are intertwined with social rights. With this perspective, I find it surprising that two Norwegian researchers have not discussed clinical recovery in a wider social context.

Importantly, personal recovery is rooted in the service users’ perspectives (Davidson et al., 2011; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Slade, 2017a). Personal stories and narratives speak of the individual’s struggle to lead a good and meaningful life, with hope and the building of a new identity as key themes (Anthony, 1993; Deegan, 1992). Consequently, personal recovery places the individual at the centre and it is essential to establish a meaningful life despite mental challenges (Borg & Karlsson, 2013; Davidson, 2005; Leamy et al., 2011). Timander, Möller, and Davidson (2016) argue that personal recovery process is about “recovery in, rather than recovery from” (p. 2). This focus indicates achieving a meaningful life despite mental health challenges. The recovery process thus becomes a process of acknowledgement, and overcoming mental challenges is not necessarily the key issue. Rather, the focus is on making the best of the situation, including any mental distress, and to reach a level of personal wellbeing (Slade & Longden, 2015).

Social recovery places the personal recovery process in a wider social context and focuses on elements that influence the individual’s mental health challenges and healing (Borg & Karlsson, 2013;

Davidson, Tondora, & Ridgway, 2010; Schön, Denhov, & Topor, 2009). The social recovery perspective relates to social sciences and involves viewing the service user's recovery process in terms of social circumstances and factors (Borg, Karlsson, & Stenhammer, 2013; Schön et al., 2009; Topor, 2015).

Hope is an important aspect in the general concept of recovery (Sælør, 2016). Service users need to redefine themselves and their space, balance their mental distress, overcome stigma and regain control of their lives, while ensuring that life becomes meaningful (Davidson, 2005). This process implies that the service user must be actively engaged in the process; participation is not enough. The service users must be in control of their situation. Therefore, it is essential to highlight genuine and considerable user involvement in a recovery context.

Healthy and thriving living conditions are important for developing a meaningful recovery. Slade (2017b) combines the social and personal concept of recovery and values personal recovery as political activism. However, he does not challenge the professionals to raise the issues of marginalisation and work to improve the living conditions on a systemic and political level in his "100 ways to support recovery" (Slade, 2017a). Perhaps marginalisation is also a challenge of the recovery concept in Norway. As such, it may be difficult for both the service user and professionals to alter the living condition and framework provided in this process of personal change. Although, it may be difficult for the individual to participate in society and social life if they do not even have spare money to buy a cup of coffee (Ljungqvist, Topor, Forssell, Svensson, & Davidson, 2015).

The recovery concept has faced fierce criticism (Recovery in the Bin, 2017). The Internet based anti-recovery group, 'Recovery in the Bin' argues that the recovery concept has been '*colonised*' by the health service and thereby narrows the notion about a good and meaningful life. This group argues that human rights and social justice must be afforded prominence in the recovery debate. Notably, Harper and Speed (2012) demonstrate that recovery has led to a focal shift away from the collective to the individual at the expense of safeguarding the service users' rights. More precisely, a recovery orientated service place increased responsibility on the service user.

The ACT model revolves around the individual service user and their needs, and as such, a recovery-orientation in service has become relevant (Allness & Knoedler, 2003; Stein & Santos, 1998; Stein & Test, 1980). Therefore, user involvement and recovery prompted a belief that participation was essential for the service user to become well and achieve a successful recovery. Also note that the revised National Program Standards for ACT Teams of 2003, which was a companion document to the ACT manual, includes a focus on recovery in the ACT model (Allness & Knoedler, 2003).

The measurement scale TMACT for the assessment of an ACT team's fidelity to the model has integrated a recovery orientation (Monroe-DeVita et al., 2011). A literature review by Morse et al. (2015) concludes that the 16 studies agree that ACT teams have become recovery oriented. The Norwegian evaluation of the ACT-model confirmed that the teams improved to include recovery in treatment, from the first to the second fidelity assessment, using TMACT (Landheim et al., 2014).

User involvement and the recovery philosophy in ACT treatment is considered as two sides of the same coin (Barrett et al., 2010; Drake & Deegan, 2008). According to a study by Milbourn, McNamara, and Buchanan (2014), the main concepts in recovery, such as hope and personal responsibility, were difficult to grasp for the participants due to their challenging everyday life and occupational needs not being met. According to the authors, the study's participants experienced themselves as recipients, rather than experts, in their own lives. The passive role expressed by the participants may confirm one of the challenges of recovery orientation, which demands an active participant involved in his or her personal process.

Other studies argue for a correlation between recovery oriented practice and experienced improvement in life as an ACT service user (Barbic, Krupa, & Armstrong, 2009; Barrett et al., 2010; Williams et al., 2011). The studies explain that the ACT service users' wishes and needs are the focus. Focus on personal goals requires that an ACT service user is attentive to personal goals, which may conflict with Milbourn et al. (2014) description of ACT service users as passive recipients of services, rather than active participants in their lives. Meese and Ekeland (2017) argue that the ACT service users' goals include becoming well again and reducing symptoms. However, these goals may be challenging to reach due to chronicity and broken social relations. In addition, the ACT teams' organisational context may work against the recovery orientation that requires patience and time. Then, to become a recovery oriented service, the ACT teams must highlight personal goals and raise awareness of personal needs and wishes set by the individual service user.

Overall, the concepts of recovery and user involvement involve placing the ACT service user in the centre of the service offered by the teams. As I understand, the recovery concept describes different elements of a process from a life in chaos and distress to a life that make sense and is filled with hope. Then, user involvement may be described as rights and obligations defined by law. It appears important to maintain recovery orientation in ACT teams to secure user involvement according to the Norwegian legislation, as well as providing ACT service users with a meaningful recovery process.

### 1.2.8 Coercion and Community Treatment Orders (CTO)

The issue of coercion in the mental health sector is the subject of major debate and the scope of this thesis does not allow for a full presentation of the discussions involved. However, a brief overview is provided here.

Coercion can be defined as compelling or restraining by force, authority or intimidation (Oxford Dictionaries, 2017). Coercion, then, equates to actions carried out against one's will in forced compliance (Nyttingnes, Ruud, & Rugkåsa, 2016). Coercion may be performed by others, either as formal or informal force (Molodynski et al., 2016) and thus, coercion is a violation of an individual's autonomy.

Wertheimer (1993) poses two philosophical questions about coercion: what do we mean by coercion and how do we justify it? One of his key points refers to the question of coercive offers: "*threats coerce but offers do not*" (p. 244). As I understand Wertheimer, the key to understanding the experience of coercion is to investigate different alternatives for patients' or service users' starting points. If their starting point is bad, they are offered something perceived as clearly better, and the service user then values the alternative as not threatening even though it may be forced. Coercive measures could be considered as an improvement on the current situation and, therefore, not as a real threat. On the other hand, a starting point compared to an alternative that is valued as worse than the current situation may be viewed as threatening and thereby perceived as coercive. To follow Wertheimer's argument, it is important that the ACT service users experience the ACT team as an improved alternative in treatment, and not as a violation of one's individual and human rights.

In Norway, it has been legal since 1961 to continue the coercive treatment of non-hospitalised patients under what is referred to as a Community Treatment Order (CTO) (Molodynski et al., 2016; Nytingnes & Pedersen, 2017; Stensrud, 2016). According to Rugkåsa (2016), there are more than 75 jurisdictions worldwide that have this treatment order and Norway is one of the jurisdictions with a long tradition of this approach (Sjöström, Zetterberg, & Markström, 2011). The CTO makes it possible to treat mental health patients outside hospitals, and may have been important in deinstitutionalisation, and where long distances are an issue, such as in the rural areas of Norway (NOU 2011:9, 2011). The argument about geographical distance is in accordance with Light et al. (2017) who claim that the organisation and administration of the service becomes a justification of the use of CTO.

Today, the use of coercion and CTOs is regulated by the provisions of the Norwegian Mental Health Care Act (Helsedirektoratet [The Norwegian Directorate of Health], 2012). In 2014, 980 people were subject to CTOs in Norway (Helsedirektoratet [The Norwegian Directorate of Health], 2015). In a Norwegian ACT context, coercion is generally limited in practice to follow-up treatment and clinical judgement calls (Stensrud, 2016). Note that 30% of the ACT service users are under a CTO (Stuen, Rugkåsa, Landheim, & Wynn, 2015). Landheim et al. (2014) have demonstrated that 42 ACT service users in the national evaluation were under a CTO when enrolled in the ACT teams and 29 individuals remained on this treatment order two years thereafter. In addition, seven others were committed to a CTO. ACT service users on a CTO constituted approximately one-fourth of the total. Forced medication and economic administration are other kinds of coercive means related to the ACT teams. Consequently, enrolment in a team imposes major restrictions in personal life for one third of the ACT service users.

CTOs are often applied upon discharge from a hospital stay, leaving it to the ACT team and psychiatrist to follow up the treatment order. Clausen (2017) demonstrates that the ACT service users with high usage of in-hospital treatment, who are also often on a CTO, reduced their days in hospital dramatically after being enrolled in an ACT team. This finding indicates that the follow-up by the ACT teams relates to improved health and that closer follow-up and earlier interventions reduce the need for in-hospital treatment.

Coercion is a stark contrast to user involvement and voluntariness. The Norwegian government has developed strategies to reduce the use of coercion and encourage as much shared decision making in the treatment as possible. Health care personnel are implicitly authorised to make use of coercion vis-à-vis patients in the mental health sector (Helsedirektoratet [The Norwegian Directorate of Health], 2001, 2015). Despite these efforts, the reduction in coercion use does not sufficiently meet the goals set by the government (Pedersen, Hellevik, & Skui, 2016).

*According to Fabris (2011): "CTOs and similar measures are being used more and more broadly, and they are often regarded informally as therapeutic devices rather than as legal restrictions" (p. 5).*

Legal aspects may be diminished because medical staff, not a court, issue the CTOs in Norway. Namely, a medical doctor, psychiatrist or specialist psychologist grants the CTOs and directs continued treatment to be provided in the community. One practical criterion for the CTO is that the service user holds a permanent address. This requirement becomes a commitment for society to secure safe housing for an ACT service user under CTO. Thus, secure housing becomes an offer and improvement for the service user that, according to Wertheimer (1993), can make the experience of involuntary treatment less coercive.

The Norwegian ACT team's obligation to follow up an involuntary treatment order makes them a guarantor for some ACT service users to live in their own home (Riley, Høyer, & Lorem, 2014). However, there are dilemmas in ACT treatment. Namely, user involvement and recovery are tied to the service users' rights and obligations and contrast the philosophy of recovery oriented services and use of coercion. While the ACT team has obligations regarding management, clinical demands and legal and structural frameworks, makes it important to explore how the ACT service users may experience treatment and its corresponding dilemmas.

### 1.3 Study aims

The aim of this study is to describe and explore the service users' experiences with Assertive Community Treatment (ACT) teams in Norway.

As such, the research questions are:

1. Are users satisfied with the ACT treatment? (Paper I)
2. Do the ACT service users experience personal recovery? (Paper II)
3. What do the ACT service users see as possible positive and negative sides of treatment in mental health services? (Paper III)

## 2 Methods and material

### 2.1 Design

This study used a cross-sectional, descriptive and explorative design. The three papers that constitute the thesis employed different data and methods, respectively quantitative in paper 1, mixed methods in paper 2 and qualitative in paper 3. The research process consisted of four elements: the philosophical views of ontology and epistemology, or rather how we define the world and obtain our knowledge; the theoretical lens considers the researcher's standpoint; the methodology, or the study of methods; and the specific methods used. (Clark & Creswell, 2011; Crotty, 1998/2015). This thesis used a pragmatic approach, that is, a transformative lens with a mixed methods design and the use of both quantitative and qualitative methods.

#### 2.1.1 The study's philosophical ground – Pragmatism

This study is philosophically grounded in pragmatism, which is closely related to mixed methods (Clark & Creswell, 2011; Morgan, 2013). Pragmatism was developed in the United States and became dominant at the beginning of the 20th century. Charles Sanders Peirce (1839-1914), William James (1842-1910) and John Dewey (1859-1952) were central scholars in the development of pragmatism (Brinkmann, 2006; Grønkjær, 2010; Hookway, 2008; Waal, 2005). A brief presentation of the core ideas of pragmatism, and how it relates to this thesis, is included in this section.

The philosophy of pragmatism was developed to meet the dualism that dominated the contemporary ideas at the end of the 19<sup>th</sup> century. Specifically, the pragmatists tried to bridge the gap between science and religion using examples and inquiry. (Hookway, 2008). In doing so, they admitted that knowledge is constructed and connected to the context; plausible truth may prevail through thorough inquiry. The use of inquiry implies a constant evaluation of one's knowledge, and to consider different perspectives and experiences regarding the phenomenon in question (Morgan, 2013). In the current study, I relate inquiry to the ACT service users' experiences with treatment.

An ontological stand in pragmatism demands an openness for multiple realities and closeness to the object(s). Further, one's search for knowledge becomes an instrument to gain insight and understanding (Morgan, 2013). The research questions determine the methodology, that is, whether to use a quantitative or qualitative method. The purposes of this thesis is to examine and elaborate on an understanding of Norwegian ACT service users' experiences with ACT treatment. It is suitable

to use various approaches and methods to achieve such insight, and pragmatism serves as a bridge between philosophical stands when mixed methods are used.

### 2.1.2 Transformative lens

The purpose of transformative lens is to identify and explore structures and aspects that affect a specific marginalised group. (Creswell, 2009; Mertens, 2003). This may have enabled me, as a researcher, to view the ACT service in different contexts, outside and inside the ACT teams' treatment framework. This approach, as inspired by Morgan (2013), is in line with the pragmatic use of inquiry, where systematic tests and revision of ideas influence the decision. Importantly, the use of transformative lens demands an involvement of representatives from the marginalised group in the research (Barnes & Cotterell, 2012; Mertens, 2003; Sweeney, Beresford, Faulkner, Nettle, & Rose, 2009).

This study is based on "*collaborative research*" (D. Rose, 2003), which provides an accurate description of the cooperation between researchers from Akershus University Hospital and Erfaringskompetanse, as represented by research collaborators, interviewers and researchers with user knowledge. Service users' and researchers' experiences, knowledge and contributions were considered equally in the design, data collection, analyses and publishing of papers. I also present the practical use of collaborative research, in detail, where suitable. We chose to make the qualitative "*User Interview User*" method quantitative, thereby including a range of 'user relevant' questions. The equality between the researchers and collaborative researchers enabled different perspectives, both clinical and experience-based knowledge, in accordance with collaborative research and transformative lens.

### 2.1.3 Mixed methods as a methodology

Mixed methods research is defined by collecting, analysing and integrating qualitative and quantitative data in the same study (Sweetman, Badiee, & Creswell, 2010). This approach is a method, but it also implies a strategy for performing research and integrating the two methods with opposite epistemologies. According to the pragmatic paradigm, it is the research questions that determine which method is sufficient (Cherryholmes, 2000; Creswell, 2009; Morgan, 2013).

This study has a sequential design: QUANTITATIVE -> QUALITATIVE. That is, we started with quantitative data collection and analyses and added a qualitative section. The two methods are equally weighted in the study (Clark & Creswell, 2011) and mixing two different methods provided a broader understanding of the phenomenon or issue we wanted to study. In this thesis, it was important to both identify trends using quantitative methods and then more comprehensively examine these trends using qualitative methods.

The quantitative study consisted of a questionnaire survey and baseline data about a subsample of the participants in the national evaluation of ACT teams. We opted to use a survey questionnaire because this approach made it possible to reach as many ACT service users as possible, compare the results with other studies and make comparisons between teams.

The qualitative study consisted of focus group interviews, individual interviews and open-ended questions from the survey questionnaire. To answer the research questions in papers 2 and 3, we used focus groups. There are several advantages of using this type of data collection; it saves time to meet several participants in a focus group, rather than holding separate interviews with individual participants. Focus group may also foster a group dynamic that expands knowledge when people share their experience and thoughts about a phenomenon (Halkier, 2002; Malterud, 2011). Importantly, this approach is an effective way of collecting data and participants may find it less threatening to participate in a focus group. Focus groups also provide an opportunity to lead the interaction in the group to specific themes the researcher aims to explore (Tjora, 2017). However, there are also disadvantages to focus groups. Some participants may be too dominant, and other participants may not have the opportunity to contribute. The strategy, then, is to have moderators that can lower the dominant voices and raise the quiet ones.

## 2.2 Participants

One-hundred-and-seventy-eight ACT service users provided written consent to participate in the national evaluation of ACT, and 84 opted to take part in the substudy "User interview User about ACT". Due to a lack of baseline data, 14 of the 84 participants were excluded. The current study's participant sample subsequently consisted of 48 men and 22 women (N=70). Participants ranged from 21 to 56 years old when they enrolled in the ACT team, with an average age of 40 years. The eight participants in the qualitative part of this research were recruited from these 70 participants from the quantitative study.

There were challenges with recruiting for this study, both in the quantitative and qualitative parts. The ACT service users is a patient group known to be difficult to recruit to both treatment and research due to a challenging health. The participants had been through a thorough evaluation process of the teams, which included a variety of assessment instruments. The close monitoring may have contributed to a difficult recruitment process in this substudy, as these service users may have felt that they had already sufficiently contributed to the research.

Ultimately, there was between one and eleven participants from each ACT team. With a lower number of participants per team than initially expected, we could not granulate the results at team level as the groups would be too small for statistical analyses, and the participants' answers could be easily identified, which would be a breach of important ethical principles (Fields, 2013; Kirkwood & Sterne, 2003). That is why we chose to divide the participants in larger groups, such as gender and CTO.

To provide a more complete overview of the participants, this study's selected papers present different elements regarding the participants' situations. Note that 23 of the 70 participants were under a CTO when they were enrolled in the ACT team, however, I did not actively decide to include participants with CTO experience in the qualitative part, due to problems in recruitment, which will be further discussed in section 3.4. Four of the eight participants in the qualitative part mentioned experiences with coercion and CTO in the qualitative interviews.

The participant sample constitute a fairly homogeneous group and mirror the overall ACT population. Seventy-nine per cent of the participants were of Norwegian origin, with 21 per cent having other ethnicities. Another trait of homogeneity was the high proportion of people living alone; only four of 70 participants were reported to be in a relationship with a partner. Similar ethnic and cultural backgrounds made data collection easier, but for some participants with a different native language other than Norwegian, it was necessary, with some extra effort from the service user researchers, to ensure that these service users fully understood the survey questions by having them explained in more detail.

### **2.3 Data collection with the survey questionnaire**

People with service user experience were recruited for paid engagements through a web advertisement. Those recruited then gathered in April 2012 for a two-day workshop. This gathering served different purposes; the service user researchers were educated on basic research

methodology, different interview techniques and ethics. To enable the service user researcher to perform the data collection with the survey questionnaire well, they received specialised training, including a roleplay. The aim of the roleplay was to become accustomed to presenting the survey questionnaire with the role as a service user researcher. Part of the training included how to solve difficult situations that might occur during the research. In addition, possible challenges performing the data collection, including in relation to their own experiences, were discussed. Furthermore, the service user researchers contributed to the final adjustments of the survey questionnaire.

The survey questionnaire's data collection occurred between 1 October 2012 and 31 December 2013 with users of the 12 ACT teams situated throughout Norway and included teams in both urban and rural areas. Nine service user researchers performed the data collection, including two from the collaborative research team and me. I carried out 12 of the survey interviews in three different ACT teams.

The participants received the questionnaire in advance, which posed advantages and disadvantages. Considerable time was saved during the interviews because the participants were already familiar with the questions, and any ambiguities could be easily clarified. However, some of the spontaneity in the answers may have disappeared, particularly in relation to the five open-ended questions.

The service user researchers' task was to complete the answers in the questionnaire, i.e., select the numerical value on the closed-ended questions and write the answers to the open-ended questions. Some of the service user researchers wrote lengthy answers to the open-ended questions, while others provided concise answers. The open-ended questions were placed at the end of the questionnaire, and several participants reported feeling tired during the last part of the interview. In addition, many of the participants commented on the different questions and some of the service user researchers wrote down such comments for the closed-ended questions. The "User Interview User" survey questionnaire interviews lasted between 25 minutes and two hours.

Procedures were implemented to secure the process of data collection. During the data collection period, the project coordinator was available via telephone to the service user researchers, for discussion, close guidance and advice. After data collection ended, the service user researchers and the project group gathered to share knowledge and experiences. The service user researchers then received a certificate confirming their participation in the study.

## 2.4 Quantitative data

The survey questionnaire “User ask User about ACT teams” was a combination of established instruments and customised questions designed for the survey (Heiervang et al., 2014). Instruments from the survey questionnaire (Heiervang et al., 2014) used in the current study were as follows:

### Client Satisfaction Questionnaire (CSQ-8)

A Norwegian version of Client Satisfaction Questionnaire (CSQ-8) (Larsen, Attkisson, Hargreaves, & Nguyen, 1979) was used. The CSQ-8 consists of eight items, scored at four levels of intensity. This questionnaire is the most widely used questionnaire to examine patients’ satisfaction with mental health services. The psychometric properties of CSQ-8 has been found to be satisfactory (De Wilde & Hendriks, 2005).

### The Questionnaire about the Process of Recovery (QPR)

The Questionnaire about the Process of Recovery (QPR) contains 22 items (Neil et al., 2009; Neil et al., 2013). The items are scored at five levels from 1= disagree strongly to 5= Agree strongly. The Collaborative research group translated the QPR into Norwegian, translated it back to English and then verified it with the original QPR. Importantly, the development of QPR has been in collaboration with service users. According to Bird, Leamy, Le Boutillier, Williams, and Slade (2011), the psychometric properties of the QPR are satisfactory.

Different variables from baseline data from the national evaluation (Landheim et al., 2014) used in the current study. Specifically, the demographic variables used in papers 1 and 2 were gender (man/woman), Community Treatment Order (CTO) (yes/no), age, marital status, ethnical background (Norwegian/non-Norwegian) and living arrangements.

Instruments from baseline data from the national evaluation (Landheim et al., 2014) that were used in the current study are as follows:

### The Alcohol Use Disorder Identification Test (AUDIT) and Drug Use Disorder Identification Test (DUDIT)

The Alcohol Use Disorder Identification Test (AUDIT) measures problematic use of alcohol (Babor, Higgins-Biddle, Saunders, & Monteiro, 2001). The Drug Use Disorder Identification Test (DUDIT) measures problematic use of illicit drugs (Berman, Bergman, Palmstierna, & Schlyter, 2005). Both

AUDIT and DUDIT are self-reporting questionnaires. We based the use of AUDIT and DUDIT on cut off scores of 6 for men and 2 for women.

#### Global Assessment of Functioning Score (GAF)

The Global Assessment of Functioning Scale (GAF) measures a global score of the level of psychiatric symptoms and functioning level (Goldman, Skodol, & Lave, 1992). The score ranges from 1 to 100; a low score indicates low functioning and more symptoms. The total score is used in this study.

#### Brief Psychiatric Rating Scale (BPRS)

The Brief Psychiatric Rating Scale (BPRS) is a clinical-rated instrument that provides information about the frequency and severity of psychiatric symptoms (Ventura, Green, Shaner, & Liberman, 1993; J Ventura et al., 1993). Each of the 24 items is a 1-7-point scale where a low score indicates fewer symptoms. In the current study, we used the total score.

#### Practical Social Functioning (PSF)

A revised version of the Practical and Social Functioning Scale (PSF) (Rishovd Rund & Ruud, 1994) was used in this study. This scale consists of 32 items, providing eight subscales (communication, contact with social network, personal hygiene, managing economy, housekeeping, personal health care, transportation, work and activities). Higher scores indicate better functioning and every subscale comprises four items with total subscale scores ranging from 0 to 8.

## **2.5 Qualitative data**

The aim of the qualitative data collection was to answer two research questions. The first research questions addressed the ACT service users' experience of recovery, and some of the questions and results from the quantitative study were included. This approach made it possible to validate the quantitative results by the participants in the qualitative section (Clark & Creswell, 2011; Golafshani, 2003). The second research question addressed the ACT service users' views on the ethical dilemmas of the ACT team members. The interview guide is included in appendix 3.

To increase the qualitative material, the five open-ended questions from the survey questionnaire were included. These five questions covered what the service users liked best about the ACT team, what they liked least, if they would have changed anything in relation to their ACT team, if they had experienced any turning points and if there were something important we had not asked about. Three of the five questions were taken from another ACT study and tested and used here (Redko et

al., 2004). The question about a turning point was proposed by Erfaringskompetanse and the last question, if the participant had anything left to say, was posed by the one of the members in the Collaborative research group.

We planned to carry out six focus groups in four different teams and wanted three to nine participants in each focus group. The number of participants were dependant on the team's size. Thus, recruiting participants to the focus groups was a major challenge.

In the first team, I was prepared to meet six people distributed into two focus groups. Due to illness and failure to attend the appointments by four of the participants, two participants were interviewed separately. My principal supervisor participated as a moderator in the last of these two interviews.

In the second team, the ACT team argued that I would benefit more from interviewing people individually as opposed to in a focus group. I chose to dispense with two of these interviews, because of current substance abuse and the participant's health condition. I ended up with two participants from this team.

Data collection in the last two teams was also difficult. The third ACT team had recruited three participants to a focus group. However, this focus group was cancelled due to the participants' illness and vacation plans. In the last team, I planned two focus groups, but conducted one focus group with four participants in the last team. The participants contributed important views and experience about their ACT team and knowledge about mental health treatment in general.

The individual interviews and focus groups were recorded digitally. The individual interviews lasted from 25 minutes to 90 minutes and the focus group ran for 90 minutes. The data were transcribed and constituted 86 written pages. I anonymised the eight participants' accounts in the transcribed material. The qualitative data was stored according to ethical guidelines and Akershus University hospital's regulations. The transcribed files were imported into the digital analytic tool Nvivo 10 for Windows (Nvivo, 2012).

## 2.6 My own pre-understanding

My academic background and knowledge as a patient/user of mental health services opened up this avenue of study. I also have experience of a relative's role and have worked in the field as an initiator and leader of a Norwegian clubhouse; a "low-threshold" work-oriented service for persons with mental health challenges, and as a lecturer. This broad experience has given me a four-dimensional knowledge of the mental health sector. It is somewhat difficult to avoid personal experiences

influencing my research. However, by using systematic methods and active reflections on how my personal experiences may affect my work, I aimed to reduce negative effects and increase useful effects.

That said, the transformative lens may contribute to discovery of criticisable aspects of the ACT treatment that could be ignored by other researchers who do not have service user experience. As such, I want to draw upon my personal experience to produce a thesis about Norwegian service users and their encounters with Assertive Community Treatment (ACT). I used to lead a life that could easily have made me an ACT service user and this kind of service user experience has influenced me as a person and informed my choices and concerns as a researcher, as well as the choice of a transformative lens in this thesis.

Although I have been a user of mental health services, I have no personal experience of hospitalisation in a mental care institution, coercive treatment or infringements associated with psychiatric treatment. However, I have had both good and bad experiences and possess knowledge of mental health services. I have experienced service with a high threshold and had to struggle to receive treatment for 20 years. When I finally entered treatment, the help was better than I could have expected. I also have experienced the long-term consequences of medication, and I know several important factors about receiving therapy and the importance of a good relationship with the therapist. These experiences may contribute to my perspective as a researcher and can be viewed as an important addition to more traditional clinical research.

I have benefited from this broad competence, but it has also raised some unforeseen challenges, particularly my declared background as a service user. I have experienced stigma and the feeling of 'otherness' among fellow researchers and clinicians. At the same time, other service users have questioned my role and motives for conducting research in a clinical context.

There were, however, ways to overcome these obstacles. Meaningful conversations with other researchers with service user backgrounds have been critical for my stamina and ability to endure demanding situations. To be open about some of my mental health challenges, combined with the theoretical realisation I have gained as a researcher, has been helpful to acknowledge that I exist in the liminal space of being 'in between'. This experience provides me with an opportunity to explore knowledge about the paradoxical space – to be both inside and outside a community. These gained experiences are why I find it important to incorporate my competence and experiences with collaborative research in this study.

## 2.7 Data analysis

This thesis incorporates different methods. In the first paper, we applied a regression analysis to investigate satisfaction and combined the instrument CSQ-8 from the survey questionnaire and different types of baseline data, presented in section 3.4. In the second paper, we applied a mixed methods approach to explore the concept of recovery. The quantitative part consisted of a regression analysis of the QPR questions from the questionnaire and the same baseline data as in paper 1 to allow for comparison. In the third paper, we provide an account of the ACT service users' experiences with mental health treatment, an analysis of the qualitative data consisting of individual interviews, and focus group responses and answers to the open-ended questions.

### 2.7.1 Quantitative data analysis

For statistical analysis in paper 1 and paper 2, IBM SPSS Statistics for Windows (2012) version 21 was used to perform simple descriptive statistical analyses (Fields, 2013). Regression analyses were performed in the first two papers using the statistical software system R (R Core Team, 2017) and Akaike's Information Criterion (AIC) for model selection.

In the first paper, a linear regression analysis with backwards selection applying AIC identified relevant baseline predictors for the CSQ total score. We selected the following potential variables: AUDIT, DUDIT, BPRS, CTO, GAF and Practical Social Skills. In the second paper, several different approaches were used to identify variables that could predict the QPR. First, simple linear regression models were estimated individually for each predictor. The other approach was to use three different stepwise model selection methods to build a multiple linear regression model.

### 2.7.2 Qualitative data analysis

In paper 2, I was inspired by "*search for mysteries*" (Alvesson & Kärreman, 2007), which states that an abductive approach is a way of reasoning. Specifically, we move visit and revisit the literature and the data, which in the current paper is called empirical material, and this process is ongoing. I examined the empirical material and the recovery literature I had chosen for this paper with the aim of identifying any 'gaps' between them. This approach means a recognition of mysteries and solving them. According to Alvesson and Kärreman (2007), we are looking for deviations from what would have been thought as 'expected' or 'normal' in the data and what we find in the literature and then

problematize it. As the authors describe it: *“to problematize means to challenge the value of a theory and to explore its weaknesses and problems in relation to the phenomena it is supposed to explicate”* (p. 1265).

For me, to read abductively meant to avoid categorisation of the empirical material, but rather search for themes that seemed to be omitted from the recovery literature. This task was difficult, but I focused on the participants’ statements and my own problematisation as described by Alvesson and Kârreman (2007). We read and reread using inquiry into the literature. I combined the empirical material with my notes I had written when performing the interviews and focus group and the open-ended questions.

To demonstrate the process of ‘search for mysteries’, I include some of the results and discussion from the open-ended questions, focus group and interviews. The ‘dialogue’ between the empirical material and literature highlighted three themes: the importance of flexibility in treatment, medication and access to a car. The reason I considered these as mysteries was multifaceted. The flexibility in treatment related to opening hours in discord with the model fidelity. According to the model an ACT team is a 24/7 service, but the Norwegian team practice merely opening hours from 8 am to 5 pm. In addition, opening hours is mentioned briefly in the recovery literature, regarding both clinical recovery and personal recovery. Importantly, the ACT service users mention access to the service as important to stay well.

Medication and access to a car greatly puzzled me. The QPR does not mention or measure attitudes to medication, even though it was developed in collaboration with service user researchers in England. In evidence-based treatment, medication seems important, but I found it poorly described in the personal recovery literature, which discusses recovery as a personal process. My own experiences as a service user have made me aware of medication side-effects and how it had a deteriorating impact on my own life. Personal experiences related to living far from a city centre without a car and limited other transport made me aware of this aspect of isolation and disintegration from the community. Lack of access to a car was also often mentioned by the participants due to their living situations far from the city centre. Thus, the way I understood the participants’ statements, a car is not only as a mean of convenience, but also as a symbol of freedom and normalcy.

My main goal for using the ‘search for mysteries’ method was not to develop a theory, but rather to use a different way to analyse the data. I commenced with a literature search and identified relevant literature together with one of my supervisors, who has a thorough insight into the recovery concept.

I then went back and forth between literature and empirical data due to my choice to split the literature between personal, social and clinical recovery, inspired by Borg et al. (2013).

I aimed to obtain a critical view on the concept of recovery used my experience as a service user to problematise the empirical materials and chosen recovery literature. This approach is accordance with collaborative research and use of the pragmatism's inquiry. At the same time, I was obliged to be true to the empirical material and literature that was inconclusive. Discussions with co-authors were also helpful to plot out a course in the study. The analysis process of the empirical material in paper 2 provided three themes and it was important to highlight these themes in the discussion of the recovery concept.

In my third paper, I used qualitative data, including individual interviews and focus groups that included eight participants. To raise the number of participants and explore the rich data in full, the open-ended questions were included in the analyses. A challenge in the analysis process was that the participants answered a research question based on the ACT team members' ethical dilemmas, as detailed in the interview guide. After an evaluation of the data, we deemed the information rich and important to analyse.

To obtain an overall impression of the data, I read the interviews and open-ended questions on paper and omitted the empirical material, or data used in previous paper. I imported the rest of the data into the qualitative analysing programme Nvivo (2012), version 10.

As in paper 2, I mixed different types of data. On a positive note, this mixing provided a rich data set with different perspectives and the possibility to more comprehensively investigate the phenomenon in question; personal recovery. In addition, I gained a broader understanding of the phenomenon by including more participants (Clark & Creswell, 2011; B. Johnson & Turner, 2003). Using answers from open-ended questions resulted in some limitations and thus, we were careful about how the answers were used on questions and what they addressed. The answers' concise natures were also problematic, due to the short answers (Clark & Creswell, 2011; Malterud, 2011).

I was inspired to used Stepwise Deductive Induction method (SDI) (Tjora, 2017), which is a working method that moves from raw data to concepts and theories. In SDI, we move upwards (inductive process) and top-down (deductive process). I also cultivated the 'empirical close coding'. This method implies the use of nodes (what Nvivo term as codes) describing the data rather than placing the codes in categories. Fragments of sentences were used as nodes. For example, a statement by Tom (55): "You have to adjust. The life, included in an ACT team, becomes so different." became the node "adjustments to another way of life with ACT" and the node group became "Limitation

and coercion". I paired nodes from the answers with possible node groups. I used inquiry to test and evaluate the node groups (Morgan, 2013). For me, SDI became a logical way to work with data. Thus, the SDI method simplifies the process of remembering.

As illustrated in the paragraph above, I divided statements into nodes, used word fragments of the statement to define the node, and then combine the nodes to node groups. I cross-checked this information with the data I had printed on paper and isolated answers relating to the participants' experienced dilemmas and paradoxes in treatment. These paradoxes were explored together with the open-ended questions. The analyses performed with Nvivo and manually contributed to the discovery of paradoxes in treatment.

## 2.8 Ethical considerations

The Regional Committees for Medical and Health Research Ethics approved the main project and PhD project (reference 2010/1196). Informed consent in this study was covered in the national evaluation and participants could withdraw at any time. The ACT team recruited participants for this study.

Although it might be demanding or tiring to answer all the 84 questions in the survey questionnaire, the Regional Ethical Committee approved the study because it was important to understand the participants' experiences. This consideration outweighed the possible negative consequences of participating.

A member of the ACT team was always available in case a participant became upset or uncomfortable and needed a talk or help minimising reactions that may have occurred after the interview. Our overall impression was that the participants, first and foremost, expressed that they appreciated being heard.

Several procedures were used to secure confidentiality. We did not inform the teams about what the individual participants had said in the interviews and I used various measures to secure the participants' identities. Namely, the names of the participants were changed in the transcripts and no affiliations to team, geography or other issues were recorded. The data were securely stored, as required by law.

## 3 Summary of papers

### 3.1 Paper 1 – Are Users Satisfied with Assertive Community Treatment in Spite of Personal Restrictions?

#### **Are users satisfied with Assertive Community Treatment in Spite of Personal Restrictions?**

Lofthus, AM., Westerlund, H., Bjørgen, D., Lindstrøm JC., Lauveng, A., Clausen, H., Ruud, T., Heiervang, KS

Community mental health journal, 2016, Vol.52 (8), p.891-897, DOI: 10.1111/inm.12304

**Background:** In the evaluation of ACT team in Norway, it is important to investigate ACT service users' satisfaction with the service. The aim of this paper is to explore satisfaction with the ACT teams' services and investigate if personal restrictions due to treatment or other factors influence user satisfaction.

**Methods:** This is an explorative study of 70 participants of twelve ACT teams in Norway. The instrument Client Satisfaction Questionnaire (CSQ-8) was used to measure participant satisfaction. Other variables were gender, age group, Community Treatment Order (CTO), Global Assessment of Functioning Scales (GAF), Alcohol Use Identification Test (AUDIT), Drug Use Disorder Identification Test (DUDIT) and Brief Psychiatric Rating Scale (BPRS).

**Results:** Compared with other international studies using CSQ-8, the 70 users of Norwegian ACT team services scored high on satisfaction with the treatment offered. The mean score ranged from 11 to 32. There was no gender disparity in satisfaction, but older service users were more positive towards the ACT teams than younger service users were. The most satisfied appeared to be the group with CTOs, with a mean total score of 27.17 (SD=3.82). The least satisfied were those with substantial alcohol-related problems.

**Conclusion:** The Norwegian ACT service users report high satisfaction with their service. The ACT teams' holistic approach to the service users' life situations, the outreach element and user involvement may be reasons for the high degree of satisfaction, despite personal restrictions due to CTOs and the treatment context.

### 3.2 Paper 2 - The Recovery concept in a Norwegian setting to be examined by the Assertive Community Treatment (ACT) model and mixed methods

#### **The Recovery concept in a Norwegian setting to be examined by the Assertive Community Treatment (ACT) model and mixed methods.**

Lofthus, AM., Westerlund, H., Bjørgen D., Lindstrøm JC., Lauveng, A., Rose, D., Ruud T., Heiervang, KS  
International Journal of Mental Health Nursing, 27 (1), p. 147-157, DOI: 10.1111/inm.12304

**Background:** The research of recovery is divided into categories of personal, social and clinical recovery, and there has been increased emphasis on recovery in treatment, including in the ACT teams. As such, the purpose of this study was to explore the experience of recovery in light of assertive community treatment (ACT) in Norway. The study has a mixed methods design with a pragmatic approach.

**Methods:** This quantitative part of this sequential mixed methods study included 70 participants and used the Questionnaire about the Process of Recovery (QPR), which consists of 22 items. Eight of the 70 participants then took part in qualitative interviews. The qualitative material consisted of the 70 participants' answers to the open-ended questions from the questionnaire, individual interviews and focus group.

**Results:** The participants under CTO reported the highest degree of personal recovery, and males a higher degree than females. In the qualitative material, the participants highlighted three important factors for their recovery: a flexible treatment to fulfil their needs, discussion related to medication and access to a car for convenience and therapy.

**Conclusions:** The participants' experiences indicate an emphasis on securing basic needs, such as secure housing, sounder finances and access to the normal benefits offered by society to experience a meaningful recovery process.

### 3.3 Paper 3 - “This is not a life anyone would want”—a qualitative study of Norwegian ACT service users’ experience with mental health treatment

#### **“This is not a life anyone would want” – a qualitative study of Norwegian ACT service users’ experience with mental health treatment**

Lofthus, AM., Weimand, B, Rose, D., Ruud T., Heiervang, KS (2018)

Issues in Mental Health Journal, p. 1-8, DOI: 10.1080/01612840.2017.1413459

**Background:** This paper examines challenges related to the ACT service users’ inclusions in an ACT team generating both possibilities and limitations. Are the ACT service users experiencing ‘community inclusion’ or ‘community integration’?

**Method:** This explorative study used a collaborative research approach in combination with Stepwise-Deductive-Induction and the analysis consisted of data from 70 participants’ open-ended questions and from qualitative interviews with eight participants individually or in a focus group.

**Results:** Two main paradoxes emerged. The first was normalcy versus marginalisation, which addressed the participants’ perceptions of being normal and a consciousness of being out of the ordinary or rather marginalised. The second paradox addressed autonomy and freedom of choice in contrast to limitation and coercion, which may imply involuntary medication, upon receiving help from the ACT teams.

**Conclusion:** The ACT service users have broad experiences of being in treatment. Even though the individuals under CTO report a high level of satisfaction with the services, they experience paradoxes and dilemmas about being in treatment. Therefore, it is of great importance that the service providers and staff, together with service users, reflect on the contradictions that appear in a treatment setting.

## 4 Discussion

### 4.1 Paper 1 – Satisfaction

Findings indicate that Norwegian ACT service users are highly satisfied with the ACT service. Specifically, results reveal that the CSQ-8 mean score was 3.26 of 4 and a mean total score of 26.04 (SD=4.21) of 32 as maximum. Other ACT studies using CSQ-8 report mean scores between 2.2 and 3.2 (Aagaard & Müller-Nielsen, 2011; Chue, Tibbo, Wright, & Van Ens, 2004; Killaspy et al., 2006; Lafave, de Souza, & Gerber, 1996; Lambert et al., 2010; Wolff et al., 1997). Other ACT studies with different measures for satisfaction also report a high degree of satisfaction with the services (Gerber & Prince, 1999; Minghella et al., 2002; Pope & Harris, 2014; Redko et al., 2004).

Age also seems to be related to a higher degree of satisfaction. This study's participants and the participants in a Danish study were older than the aforementioned studies, with a mean age above 40 years (Aagaard & Müller-Nielsen, 2011); the average age was below 38 years in the other studies (Killaspy et al., 2006; Lafave et al., 1996; Lambert et al., 2010; Wolff et al., 1997). Older ACT service users have a broader basis of comparison than their younger counterparts and former experience could be a contributing factor affecting the individual ACT service user's expectations to treatment, and influencing their level of satisfaction.

Could personal restrictions imposed by treatment affect the participants' satisfaction? We identified four variables as relevant baseline indicators: higher alcohol use (AUDIT), more severe psychiatric symptoms (BPRS), lower functioning (GAF) and CTO. The first three variables had a negative influence on CSQ-8. In contrast, participants under CTO (N=23) reported a higher degree of satisfaction, with a mean total score of 27.17 (SD=3.82).

It was somewhat surprising that the CTO participants in the study were the most satisfied group of the ACT service users. Mental health treatment may be experienced in both positive and negative knowledge, and this includes CTO, use of force and coercion (Bonnington & Rose, 2014; Clausen, 2017; Helsedirektoratet [The Norwegian Directorate of Health], 2016; Molodynski et al., 2016; Moser, 2007). Our presumption was that restrictions, such as involuntary medication and CTO, would correlate with dissatisfaction. This presumption was rejected as CTO participants reported the highest degree of satisfaction.

Wertheimer (1993) has demonstrated how former experiences influence the degree of satisfaction. Following Wertheimer's (1993) arguments, the ACT teams' services were perceived as offers to the ACT service users, not threats. Inclusion in an ACT team is voluntary and at the same time, the CTOs

assume treatment compliance (Molodynski et al., 2016). This factor places the question of voluntary participation in a different context, as the service user may have to accept an attachment to the ACT team and their execution of the CTO to be discharged from inpatient treatment.

A combination of the ACT model's flexible approach and a broader focus on user involvement could also indicate why users under CTO reported a high degree of satisfaction. Publications by Stuen et al. (2015) and Stensrud, Høyer, Granerud, and Landheim (2015) make it possible to compare persons under a CTO in two different Norwegian treatment settings. Stuen et al. (2015) explored the ACT service users' experiences, while Stensrud et al. (2015) studied CTO in an ordinary outpatient treatment. Stuen et al. (2015) highlight the ACT team's flexibility and supportive relations as contributing factors for a more positive experience with CTO for the ACT service users. Stensrud et al. (2015) find that the service users in ordinary treatment describe CTO as "putting their life on hold". These service users reported that they experienced a lack of information and no control or influence regarding what was happening. The CTO maintained the service user in a patient role and made it more challenging to lead a normal life. Conversely, the ACT service users received more information and the possibility to take a more active part in their own treatment even though the treatment was involuntary.

In this study, the least satisfied ACT service users were those with challenging alcohol abuse, as measured using AUDIT. These participants reported lower satisfaction with the ACT services, which could be related to this group generally experiencing a lower quality of life (Clausen, 2017). This acknowledgement led to the ACT model's integration of an integrated dual diagnoses approach with treatment of both severe mental illness and substance misuse concurrently and by the same team (p. 78). Unfortunately, the national evaluation proved treatment of dual diagnoses to be a weak point within the ACT-teams (Landheim et al 2014), as the teams' fidelity scores on dual diagnosis treatment were generally low.

It may be argued that persons with substance misuse, in general, are demanding to work with due to their "double trouble" challenges, as Davidson et al. (2008) name problematic substance use combined with mental health challenges. To make changes in a lifestyle requires clear personal goals, motivation and effort, both by the individual and the support network (Davidson et al., 2008; Pilgrim, 2009). As Williams et al. (2011) highlight, there is a mismatch between offers in traditional treatment and the needs of the individual with substance misuse issues. These opposing interests may create ethical problems and dilemmas regarding what is 'normal' and acceptable behaviour for a service user enrolled in an ACT team.

To be enrolled in an ACT team implies a close follow-up, which places the ACT service user's life on display. The question of whether the ACT service users experience the team's close follow up as a kind of monitoring, or as a moral stand against their way of living is raised. One challenge the team might experience is that alcohol is a legal stimulant, and it may be more difficult to advocate for moderate consume in contrast to illicit drugs.

A challenging life situation may imply a lower degree of satisfaction. According to Clausen (2017), the Norwegian ACT service users with substance abuse experience a lower quality of life and more burdens in life. Overall, they seem to be less satisfied. The national evaluation revealed that the teams scored lower on treatment regarding substance misuse (Landheim et al., 2014). Being less able to meet the ACT service users with both mental health problems and substance use could also contribute to less satisfaction (Davidson et al., 2008). A lower quality of life and services less able to meet the patients' difficulties could be additional contributing factors for the reported low satisfaction among participants with substance use.

Pettersen (2015) recruited participants from the same ACT population as this study and his findings supported the traditional self-medication hypotheses and revealed that this group experienced a positive effect on well-being and mental health experiences of substance use. In addition, several of his participants reported substance use as a way of gaining more energy and reducing the adverse side effects of medication (p. 37). Based on this researcher's findings, there are reasons to claim that the positive experiences with substance abuse, especially regarding alcohol, may outweigh the ACT team's advice for lower consumption and thus, these participants report lower satisfaction with the team.

Overall, participants in paper 1 reported a high degree of satisfaction with the ACT team. There were no significant differences for gender, but the ACT service users under CTO reported the highest degree of satisfaction, while those with higher alcohol consumption were less satisfied.

## 4.2 Paper 2 - Recovery

ACT service users reported a high degree of recovery related to the ACT treatment; the mean total score was 3.69 of 5 using the QPR. ACT service users under CTO reported the highest degree of recovery, as they did on satisfaction, and QPR correlated with CSQ-8. Males reported a higher degree of recovery than females, with a mean score of 3.73 compared to 3.60 for the latter group. The

participants under CTO (N=23) had a mean score of 3.85, which was higher than for the other participating groups. In the qualitative part of this study, the participants talked explicitly about obtaining basic needs, such as secure housing and economic security, that they had access to a car as a means of mobility, participation in social relations, recreation and relaxation. In addition, the ACT service users emphasised the importance of control of their everyday life, including in user involvement and medication.

This study investigated what recovery may imply for a Norwegian ACT service user in their everyday life. This concept includes theoretical notions, such as hope, sense of coherence, improved life and personal development. Leamy et al. (2011) presented a theoretical framework for recovery built on connectedness, hope and optimism about the future. Identity, meaning of life and empowerment, which is abbreviated as CHIME. This concept is also framed in the QPR (Neil et al., 2009). However, a challenge with a theoretical model is operationalising the framework in everyday life experiences. In this study we focused on everyday life events and challenges expressed by the participants.

One such activity of everyday life was access to a car and this theme constitutes a surprisingly large part of the qualitative material in the current study. The number of comments related to access to a car in both the open-ended questions and the interviews and focus group provides an indication of a car's importance to the ACT service users. The participants mentioned car rides as convenient when shopping and participating in social activities, but also as a means for recreation and therapy. Therefore, access to a car may represent a symbol of freedom and normal life.

In this study, recovery in an ACT treatment context refers to tangible and personal actions, such as implementing order in a chaotic everyday life, improved social relations, and a more predictable life. According to the quantitative material obtained, represented by the QPR, participants reported a sense of recovery. The findings in the qualitative material the participants' narratives concentrated on conditions for a better life inside and outside an ACT treatment setting. Findings indicate that basic needs, a holistic treatment approach and flexibility in service were factors that could promote a positive recovery process for the ACT service users.

A recovery oriented service refers to meeting the service user's needs and wishes as the centre of attention and in action (Borg & Karlsson, 2013; Monroe-DeVita et al., 2011). Recovery may be a demanding task considering the existing framework provided, such as legislation, funding, organisation and staff. Barrett et al. (2010) demonstrated a correlation between recovery oriented service, satisfaction and empowerment, and concluded that positive relations and support for a

meaningful life is essential to personal recovery. According to Leamy et al. (2016), the notion of recovery orientation may vary among different stakeholders in the mental health services and that a high degree of recovery orientation promotes personal recovery.

Landheim et al. (2014) demonstrated that an increased focus on user involvement in the service is needed to succeed in fidelity assessments, i.e. how well the individual team performed the ACT model. This finding was complimented by Stokmo et al. (2014), who implied that fidelity and user involvement are intertwined. As such, a conscious and continuous debate of what the notion of user involvement contains and how to implement it, is a crucial contribution in the development of personal recovery in an ACT team. A recovery oriented service implies, or rather demands, comprehensive involvement of the service user.

User involvement is an important element of the recovery process and is incorporated in law to promote motivation, compliance and active patient or user participation in treatment (Helsedirektoratet [The Norwegian Directorate of Health], 2018). However, a challenge may be that the ACT service users' everyday life is filled with demanding tasks and therefore, it may be difficult to focus on personal wants and needs. The ACT service users have typically been in treatment for many years and may be accustomed to allowing the professionals make decisions about their important personal issues (Milbourn et al., 2014). That said, Norwegian ACT service users report positive experience with user involvement and recovery (Heiervang et al., 2014; Stokmo et al., 2014). Nevertheless, the participants in the current study reveal different views on how the Norwegian ACT teams practice user involvement, and some statements may not be in line with recovery oriented services, e.g. coercion and various means that breach with the individual's autonomy.

The use of CTO in treatment is disputed (Molodynski et al., 2016). Moreover, it should be asked how a CTO may be compatible with recovery when it may conflict with a service user's ability to control their own lives. The paper by Stuen et al. (2015) explains this contradiction and a carefully positive attitude towards CTO in an ACT context. The participants described a different, and more positive, experience of being under a CTO in an ACT team, compared to ordinary services, which Stensrud et al. (2015) define as "putting the life on hold". Stuen et al. (2015) describe teams with a will and ability to solve some of the ACT service user's individual challenges, but there were frictions regarding involuntary treatment, the individual's sense of control and discussion about medication. These elements are important in a person's autonomy and could be seen as a breach of both recovery and user involvement.

Wertheimer (1993) argued that threats coerce, but offers do not, and this idea may be relevant in understanding CTO and recovery. Many of the ACT service users experience CTO as a condition for a life outside the hospital and in that sense, may perceive the CTO as a threat. However, enrolment in an ACT team may be experienced as a good offer compared to ordinary services. A flexible approach, openness for discussions related to medication and respect for the individual could be contributing factors for accepting a CTO in an ACT treatment (Heiervang et al., 2014; Pettersen, 2015; Stuen et al., 2015). This study's participants elaborated their views on CTO, but the participants did not agree whether this was meant in treatment-promoted recovery.

A question to raise in the discussion of paper 2 is whether recovery is a new paradigm, or 'new words on old expressions'. Davidson, O'Connell, Tondora, Lawless, and Evans (2005) demonstrated how personal recovery relates to a meaningful life, not necessarily without symptoms and illness. The authors also emphasise the importance of thriving environments, such as overcoming the feeling of being a mental health patient, strengthening social rights, worthy living conditions and reducing negative personal relations. This finding is in line with the founding ideas in the ACT model presented by Stein and Test (1980). Moving the mental health treatment from the hospital to the service user's home could create a new obstacle to shed the label of mental health patient. Therefore, it may be timely to ask whether the new paradigm sustains existing structures and power relations.

I am ambivalent to the concepts of recovery, and of the wide establishment of the recovery concept and recovery orientation in mental health services. Unfortunately, the notion of personal recovery may 'merely' become an empty label. Working in a new paradigm demands recognition of a new way of thinking, a different power balance and prioritising of the service offered. It is not clear that services and professionals in Norway fully recognise the implication of the recovery philosophy, including the importance of placing the service user's needs in the forefront. Consequently, if the professionals do not recognise the implications, recovery may become a different way of upholding existing structures in the old paradigm.

Various factors are at play when managing recovery in an ACT context. Despite the challenging living conditions caused by mental challenges and substance use, the participants in this study reported a high degree of recovery in an ACT context. In addition, flexibility in treatment, medication and access to a car were reported as important elements to promote personal recovery.

### 4.3 Paper 3 - Paradoxes in treatment

ACT service users have broad knowledge of being in mental health treatment, both by ACT teams and ordinary services. The aim of paper 3 was to explore the ACT service users' views on the possible positive and negative aspects of treatment in mental health services generally, and ACT teams specifically. This approach was a way to acknowledge the service users' broad competence and as a source of knowledge for mental health workers (Beresford & Boxall, 2015; D. Rose, 2014). This study uses a collaborative research approach and several of the ACT service users have been connected to different kinds of mental health treatment over the years, and thus obtained an in-depth knowledge about treatments and practices. The ACT service users spoke in interviews and focus groups about the consequences of being in mental health treatment, and two paradoxes emerged. The first paradox relates to normalcy and marginalisation. The second paradox entails the contradiction between autonomy and freedom of choice and limitation and coercion.

As Rappaport (1981) demonstrated, there are contradictions in community mental health services. These paradoxes and dilemmas exist when individuals in society have to make decisions on behalf of various interests, whether it is conflicting group interests or priorities of resources. In our complex world, any decision contributes to advantages for some groups and disadvantages for others. This complexity justifies exploring the paradoxes, according to Rappaport (1981).

Accounts from participants in this study confirmed Rappaport (1981) assumption about paradoxes in treatment. The participants described contradictions related to their life situations, but expressed gratitude for being enrolled into the ACT team, indicating that close follow-up and help with both medical and mental health issues, medication, housing, shopping and developing social relationships were positive experiences. At the same time, this 'exclusiveness' comes with a cost. Help may imply violation of human rights, such as lack of the right to privacy, coercion and administration of personal finances (Clausen, 2017; S. J. Johnson, 2011; Landheim et al., 2014).

Being 'normal' and included in the majority came up as an important concept to explore in the current study. The participants provided descriptions on how they were included into the group of 'us', meaning the majority, while feeling marginalised and excluded as 'others', as the minority. Stigma and discrimination may be one of the consequences of marginalisation, including negative consequences such as being unemployed, having a weak economic position and, often, living in poor housing conditions (Goffman, 1963; D. Rose et al., 2011; Ye et al., 2016). D. Rose et al. (2011) explain that mental health challenges have a negative impact on life in general and detail how "positive discrimination" due to diagnosis, results in benefits. The opposite is 'negative discrimination', where

being shunned and isolation results in the opposite experience. The current study's participants confirmed this extra burden of being a mental health service user.

Some ACT service users expressed a wish for a 'normal life' due to their experiences with chaos and disorder in their lives for many years. The 'paradoxical space' may provide a way to understand the longing for a normal life situation and inclusion (G. Rose, 1993; Spandler, 2009). The paradoxical space represents how ACT service users experience 'inside-ness', or being 'one of us', and 'outside-ness', being 'one of them'. This double competence may highlight the broad knowledge of the ACT service users and an acknowledgement of this double position related to paradoxical space may contribute important knowledge and insight to mental health services. The participants also described how they, in some senses, received a normal life when enrolled in the ACT teams. A feeling of being seen and heard and sense of belonging were frequently mentioned as examples.

Land, Rattray, and Vivian (2014) defined the state of liminality as "*a space of transformation in which the transition from an earlier understanding (or practice) to that which is required is effected*" (p. 200). 'Liminal space', or the threshold, may be a room for exploration of knowledge. A service user's liminal space, as the transition from 'not normal' to 'normal' or 'more normal', may be determined by the distance between 'us' and 'the others' (Goffman, 1963).

Participants in this study seemed to be ambivalent regarding the question about whether they maintained an upper hand in the power relation in their own life. Importantly, ACT treatment is both voluntary and entails a degree of involuntary treatment through CTO and medication. Side effects of medication, stigma and marginalisation are various contradictory elements in the service users' everyday life (Bonnington & Rose, 2014; Charles, 2013; Goffman, 1963; Read & Dillon, 2013; D. Rose et al., 2011; N. Rose, 2013; Sayce, 2000; Ye et al., 2016). Many of the ACT service users have to accept the encroachments in their individual way of life and independence to be included in the community. As such, these contradictory elements in mental health services are important to explore further and thus, the third paper's intention is to link clinical practice in mental health to human rights.

One role the ACT teams' have in clinical settings is to practice the CTOs, which are disputed because the individual's autonomy is violated. In addition, this practice may act against the service user's will. Studies have revealed that CTO treatment outcomes may vary. For example, Nytingnes et al. (2016) describe how coercion may negatively affect people subjected to coercion, and service users have used strong language to describe the sense of humiliation. Both Riley et al. (2014) and Stensrud et al. (2015) have demonstrated how a CTO may limit an individual's freedom. Stuen et al. (2015) state

that an ACT service user under CTO could be more willing to accept the order due to interaction with the team regarding the execution of the CTO. However, the literature is not conclusive, and researchers and service users disagree on whether CTOs are useful in a mental health treatment. That said, the literature does agree that forced medication and administration of finances are serious interventions in the individual's autonomy. The participants in the current paper confirm this understanding.

Overall, receiving mental health treatment implies acceptance of paradoxes for the individual ACT service user. These paradoxes may even create ethical dilemmas, such as CTO and intervention in the individual's life. In this study, the ACT service users mentioned experiences with both positive and negative discrimination, and as such, their broad knowledge could be further explored to gain a deeper understanding of these paradoxes.

#### 4.4 Synthesis of all papers

The aim of this study is to describe and explore service users' experiences with Assertive Community Treatment (ACT) teams in Norway. The study demonstrates that participants express satisfaction and experiencing a positive recovery process, as well as being satisfied with the help and support associated with an ACT team. At the same time, several important thought-provoking issues were raised. This section discusses in more detail these issues raised in this study, namely, the ACT service users' broad knowledge and human rights in a context of mental health treatment.

One of this study's major contributions is to illuminate and explore the ACT service users' experienced position in a mental health service in a Norwegian context. This study supports much of the findings from prior research on the ACT model in other countries. Namely, there is a need to secure the individual service user's rights, the individual ACT service user's obligation to receive treatment is tied to compliance, and enrolling in an ACT team is voluntary. Also, receiving this outreach service may imply handing over responsibility for parts of self-determination and accepting the possible use of coercive means and medication.

In the introduction chapter, 'experience' is presented as knowledge of a process, as well as knowledge about being an active participant in the same process. I wish to point out three important aspects of experience mentioned in this study: user experience, user involvement and human rights.

Another of this study's major contributions is illuminating and exploring ACT service users' experienced positions within a mental health service in a Norwegian context. The study confirms much of the prior research on the ACT model in other countries. Importantly, there is an apparent need to secure the individual service user's rights, whose obligation to receive treatment is tied to compliance. To be enrolled in an ACT team is voluntary, but receiving this outreach service may imply handing over responsibility for parts of their self-determination and accepting the possible use of coercive means and medication.

#### 4.4.1 ACT service users are 'experts by experience'

Gaining insight into the paradoxes of treatment and using the liminal space to explore this concept, is one example of this study's contribution to the knowledge of ACT service users' treatment experiences, power relations and ethical dilemmas. We ask who holds the real expertise in the ACT model. Of critical importance is the ACT service users' honest contributions to the study and their being 'experts by experience' (McLaughlin, 2009). Also, the ACT team's efforts and help were praised by most of the participants, as evident by the results of the survey questionnaire, interviews and focus group. Face-to-face accounts between researchers and participants also likely provided a way for the participants to also raise critical voices.

The ACT service users' broad knowledge about being in treatment reveals how difficult it is to extract specific ACT experience from various other experiences with mental health treatment. Participants' personal stories and statements, represented in my three papers, reveal knowledge and wisdom about the importance of being treated as a human being. The ACT service users describe the happiness of being included into society, and the sorrow of being left out.

So, the question is raised as to why ACT service users report satisfaction and recovery related to a service that limits their autonomy and possible choices in life. Possibly, the Norwegian ACT teams have been able to balance the responsibility for the individual and the demands from the system. The fidelity assessment may be a way to maintain focus on the essential sides of the ACT model, such as outreach, user involvement and recovery orientation. (Landheim et al., 2014; Monroe-DeVita et al., 2011) The participants in this study emphasise these elements as important for their satisfaction and recovery. Notably, some participants expressed the ACT team's respect for their personal issues as a new experience in mental health treatment.

The participants' feeling of respect, sense of coherence and self-worth may promote Wertheimer (1993) claim that ACT becomes an offer, rather than a threat. The ACT team provides the service

users with a sense of worth by taking their personal needs and goals seriously. The service user's opinion seems important to the team because it is the foundation of their relationship to the service user, trust and a positive treatment outcome, as reported by the participants. On the other hand, the teams must work to meet ACT service users that report a lower degree of satisfaction and recovery in an ACT treatment, and whom experience the CTO as a threat.

Recovery orientation demands a shift in power balance and basis of knowledge (Monroe-DeVita et al., 2011), which could imply a lean towards the service users' opinions. The team must acknowledge that the ACT service users are the "experts of experience" in their own lives. Experiencing a chaotic life and long practice as a mental health service user produces challenges to mark out a course in life. At the same time, the framework of the ACT teams' activities demands placing the service user at the centre of attention. When these criteria are met, it may be understandable that ACT service users report a high degree of satisfaction and recovery, despite restrictions and negative discrimination.

#### 4.4.2 User involvement as a part of the "ACT experience"

There has been increased focus on user involvement in both health and social services and Norwegian politicians and legislators try to facilitate improved user involvement in these services (Andreassen, 2000; Askheim, 2012; Ekeland, 2011; Klausen, 2017). However, the question remains as to why a well-organised and regulated society such as the Norwegian requires legislation to ensure individuals participate in their own treatment as a part of their own lives.

It is possible that experiences with user involvement and recovery orientation starts with leadership (Borg & Karlsson, 2013; Monroe-DeVita et al., 2011). User involvement demands time and involving the service user in clinical activity may become a stressful factor in the hectic everyday life in the services. That said, all Norwegian ACT teams manage to meet the service user outside the office 80 per cent of the time and provide a close follow-up. Many participants reported enjoying visits by the team members as a break in a monotone everyday.

This study demonstrates that management must provide the clinician with the possibility for user involvement so the service user may grow as a person. Sometimes, this need is not in accordance with the administrations' perspective. In the current study, the participants discuss whether they received sufficient help from the team and most seemed pleased with the flexibility in the service delivery, the possibility to participate in own treatment and the outreach element. In other

important issues, such as medication, administration of personal finances and access to work, the ACT service users expressed more discontent.

The current study acknowledges the importance of service user experiences in clinical studies and several of our participants report a high degree of satisfaction and recovery, and some feel seen and heard, whereas others do not. These critical voices are important to the development of sustainable services. As Barnes and Cotterell (2012) point out: *“the importance of understanding what the world looks like from the perspective of those who have little power to determine the way in which the world is structured, is fundamental to an understanding of user involvement as necessary to social justice”* (p. 232).

#### 4.4.3 Human rights and ACT treatment experience

A critical gaze with the transformative lens on negative consequences related to mental health treatment and human rights is a recurring theme throughout this study. All three articles emphasise human rights and mental health treatment, as represented by the ACT model.

This study’s participants raised human rights issues regarding user participation in treatment. Some participants noted the possibility to discuss important elements with the team, such as medication, CTOs and flexibility in treatment, as unique in a clinical setting. These elements are usually decided by the ACT team, and some participants described an everyday life framed by others, meaning the ACT team. Several participants also mentioned new and safe housing as a major contribution from the ACT team. As I understand the participants, the limitations of autonomy outweighed the potential advantages related to enrolment in an ACT team.

Although the Norwegian government has ratified the UN declaration of human rights, it is still challenging to secure human rights in treatment, especially related to criticisable issues, such as CTOs and medication (Fabris, 2011; Molodynski et al., 2016). The challenge to secure human rights may be associated with power relations in a treatment setting; patients or service users are still in an inferior position in relation to the clinicians and the system they represent.

The Norwegian government has, however, taken steps to meet criticism of mental health treatment. The ratification of The UN Convention on the Rights of Persons with Disabilities (CRPD) in 2013 is one example (Barne- og likestillingsdepartementet, 2016; Forente Nasjoner [United Nations], 2016). The Equality and Anti-Discrimination Ombudsman’s (EADO) report on coercion was critical, but failed to mention CTOs as a tool in mental health treatment (Likestillings- og diskrimineringsombudet [The

Equality and Anti-Discrimination Ombudsman], 2015). When considering medication and mental health treatment, the Norwegian health trusts are obliged to offer medicine-free treatment (Helsedirektoratet [The Norwegian Directorate of Health], 2018b; Nasjonalt senter for erfaringskompetanse innen psykisk helse [National Centre for Knowledge through Experience in Mental Health], 2017).

Human rights and ethical issues are typically interrelated. This study's participants raised questions related to important ethical dilemmas in mental health treatment. Namely, the right to a private life, freedom of choice, access to their children when service users are in a state of distress, equality and discrimination. These are important values stated in the UN Declaration of Human Rights and implicit in our society. As this study highlights, dilemmas arise when the individual's needs conflict with the various interests of the system delivering the service.

Overall, service users experience the ACT model as an improved mental health service that promotes recovery and user involvement, especially for those under CTOs. The participants exhibit broad knowledge about treatment in a Norwegian setting, and this insight must be acknowledged.

This study raises questions related to dilemmas and areas of further improvements in the Norwegian ACT treatment. These challenges, such as the experience of autonomy versus coercion must be addressed. Norway needs ongoing ethical reflections and increased user involvement to manage these dilemmas and develop practice in accordance with the service users' needs.

## 4.5 Methodological discussion

I applied a transformative lens in this thesis, with the intention to explore the experiences of the users of the Norwegian ACT treatment. Inspired by Mertens (2003) and Sweetman et al. (2010), raise important issues around managing positive and negative experiences of ACT treatment, such as user involvement, CTO, satisfaction and civil rights for the ACT service users. The papers presented here demonstrate how user perspectives may contribute to new and different knowledge and provide a reminder of what is important for the service users (Klausen, 2017; Sweeney et al., 2009).

This transformative lens demands that the affected party is involved in research (Mertens, 2003). This study's design addresses user involvement in the entire research process, from designing the study to data collection, data analyses and publishing, thus providing an opportunity to explore the service users' experiences with ACT treatment. None of the collaborative researchers or service user researchers was, or has been, an ACT service user. That said, the knowledge about being a service

user was emphasised in different phases of the study. I met several of the individual ACT service users that could have been excellent collaborative researchers, but using the ACT service users as researchers was not pursued in this study. On the other hand, I gained inspiration to include service users in my future research projects.

The transformative lens also encourages me to discuss important issues related to human rights. The power relations at different levels in ACT treatment must be highlighted. With such an approach, we may experience closer encounters with the ACT service users' experiences with the services. In addition, the ACT service users may identify important aspects with treatment in general.

Furthermore, collaborative research combines different experiences and viewpoints. As such, it is worth mentioning that there was a difference in perspectives between the two researchers with clinical experience and the five researchers with a service user background. The latter group was distinctly more skeptical regarding the ACT treatment than the former group. The critical view of the majority of the researchers led to an additional focus on the flaws and disadvantages of ACT treatment. In accordance with this critical stand among the researchers, the current study's results do not present a one-dimensional account of the ACT treatment. As such, the results presented may be more convincing.

It is also important to note that the ACT model has been accused of being paternalistic and intrusive (Brodwin, 2013; S. J. Johnson, 2011). For example, Heiervang et al. (2014) have demonstrated that paternalism and intrusive manner are not representative of the user experience of Norwegian ACT teams where treatment entails use of CTOs in treatment. Majority of the Norwegian ACT service users have stated they do not find the teams behaving in an intrusive way and expressed that their personal freedom was not restricted by the teams (Heiervang et al 2014).

In this context, it was important for me to meet many of the participants. First, the meetings altered my understanding of who the ACT service user might be, and I experienced first-hand the heterogeneity of the group. I could relate to them and their situation and gain a deeper understanding of their positive and negative attitudes towards the team. Last, but not least, the participants became real people to me.

The interviews provided an opportunity to internally validate the results from the survey questionnaire. The participants recognised the findings by comparing their own experiences as ACT service users and some participants even had experiences with CTOs. Their knowledge and insight made it important to investigate whether personal restrictions influenced their satisfaction with the services.

Some methodological adjustments were implemented in this study; “User Interview User” was used quantitatively for the first time and the open-ended questions became an important source in the last two papers. From the start, this was a quantitative study, but there were several reasons for methodical adjustments. One reason was the low participation rate in the quantitative part of the study. Second, I have a qualitative background and my acknowledgement for in-depth knowledge about the participants’ experiences made me consider mixed methods. In addition, selecting this methodology resulted in a broader data set.

## 4.6 Ethical considerations

The ACT service users have been mentioned as a socially marginalised group in Norway (Aakerholt, 2013; Helse-og Omsorgsdepartementet [Norwegian Ministry of Health and Social Affairs], 2009). A marginalised group must be heard and it is mandatory for society to listen to their citizens. Although this study’s participation sample is low, I have an ethical obligation as a researcher to raise the ACT service users’ voices and present their experiences. My own service user background implies an additional obligation, thus my knowledge of belonging to a marginalised group placed greater emphases on highlighting human rights. At the same time, as a researcher, I must bear in mind the challenge of epistemic injustice, and retell the participants’ narratives in an unbiased way (Fricker, 2007).

Accordingly, how the researcher is portrayed to the interviewee is pivotal. In the present study, the recruited service user researchers were described as having ‘recovered’ from mental challenges. There is a possibility that the service user researchers’ conduct affected how the ACT service users answered the questionnaire and open-ended questions. It is also possible that the participants wanted to describe a better service to be taken seriously. Bourdieu (1996) highlights that interviewers have authority and control the situation (p. 610). As I understand Bourdieu, one’s own position as a researcher in relation to the respondent is important. In light of this argument, the participants might have held back important negative experiences. Having various empirical data, such as the survey questionnaire, qualitative interviews and baseline data contributed to a relatively balanced presentation of the ACT service users’ experiences with ACT treatment.

This is a small study with a relatively low participation rate. As such, we must be careful when interpreting the findings, e.g. dividing the participants into larger subpopulation (gender, CTO). Piper

and Simons (2005) emphasise informed consent, confidentiality and anonymisation of the participants' data as vital guidelines for social research. I used Creswell (2013) table of ethical issues as a guideline for this study (p. 58-59). In addition, during the process of supervision, we continuously raised and discussed themes related to ethics.

#### 4.7 Strengths and limitations

A strength of this study is the collaborative research design, which enabled both a critical service user perspective and a more positive clinical perspective. This mixture of perspectives allowed for a difference in foci throughout the study. Applying mixed methods ensured we could obtain a supplementary and overall picture of the ACT service users' experiences. The various data sources covered several aspects and different data sets and methods applied provided a more complete overview of the participants' experiences. In addition, we managed to recruit participants that are considered hard to reach, both in urban and rural ACT teams.

Several participants in the study expressed, as a methodological advantage, that the service user researchers had service user experience, and as such, they did not have to explain what they meant by 'struggling mentally', because the interviewers already knew. This aspect could create common ground between the interviewer and the participants. At the same time, this common understanding could lead to the loss of important information, such as symptoms, illness and treatment, due to these points being considered trivialities by both parties.

The survey questions prompted important reflections among the service users. If we had recorded the conversations during the survey questionnaires, the discussion related to the participants' reflections and how they answered the open-ended questions would have been stored. Listening to tone of voice could have also provided additional and informative information when analysing the content.

Another limitation is low participation rate, which is a challenge for statistical analyses. We could not use the quantitative data to compare teams because the number of users per ACT team was too small for adequate statistical power and low participation numbers could have threatened participant anonymity according to ethical standards of research (De nasjonale forskningsetiske komiteene [The Norwegian National Research Ethics Committees], 2018). However, we could compare larger groups, for example, by gender or being exposed to CTOs.

Due to the sample size, the participants may not be a representative selection of the ACT service user population, and the results may be skewed. However, using both qualitative and quantitative data was one way of validating the results by asking the same questions in the survey and face-to-face interviews and comparing these results with results from the national evaluation. Importantly, although the study is small, it is important that the individuals who contributed to this research have their say.

# 5 Conclusion and implications for practice

## 5.1 Conclusion

The current study describes ACT as a beneficial treatment model for the targeted service users. The participants report satisfaction with treatment, recovery and overall, an improved life. These findings demonstrate that the ACT teams have successful elements. A flexible attitude among the team workers to put the service user 'behind the wheel' in their own life and a respectful approach is important for the participants. In most cases, ACT teams manage to meet the needs of the individual ACT service user. Still, obstacles remain regarding the ACT model, which includes restrictions and marginalisation. Worthy living conditions and personal finances and integration into society on the service users' terms, are dimensions to prevent the ACT service users remain as a marginalised group in the Norwegian welfare system. In addition, we need to continue the discussion of the use of coercive means in treatment.

## 5.2 Implications for policy and practice

Nine years after 14 ACT teams in Norway were established, the status is as follows: there are two evaluation reports demonstrating that the ACT model has had a positive effect for those who require this approach. Nevertheless, three teams have been disbanded and three others have been converted into FACT teams. Eight remain ordinary ACT teams.

An important implication for practice is to focus on the service users' needs and rights. Mental health systems are under constant development, which results in dilemmas and paradoxes. In this context, one of the challenges may be to ensure continuity for individuals with various mental health service projects define practice. This is our professional, ethical and moral obligation.

The ACT model has provided valuable experience in terms of implementation of a treatment model. However, the ACT teams are under constant pressure. Strict financial priorities mean that all costs must be justified and explained. A challenging economic situation for local authorities implies that different mental health teams who work with different marginalised groups are competing for the same money. Those who make their voice heard are usually the ones who receive the support. Currently, there is a notably large establishment of Flexible ACT (FACT) teams in Norway

(Helsedirektoratet [The Norwegian Directorate of Health], 2018a). The flexible approach relates to the FACT service user's needs for continuous follow-up. Hopefully, these new FACT teams acknowledge what has constituted successful treatment for the ACT service users and transfer the ACT service users' knowledge to benefit FACT service users.

In addition, this study evaluates the ACT service users' experience with a project organisation for a defined and often limited period. The ACT model in a Norwegian context has been a new way of delivering services to a marginalised group and this model may be ahead of its time in the Norwegian mental health field. ACT service users emphasise the importance of a holistic approach by the services, and this perspective may be one of the elements to achieve the experienced positive treatment. As one of the participants stated in an open-ended question: "Finally, there is someone who can tie the loose ends together. See me as an individual".

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# Appendix 1

## 6.1 User Ask User about ACT team survey questionnaire

# Intervju med bruker av ACT-team

## Hensikt med intervjuet

Intervjuet er et ledd i en undersøkelse om brukeres erfaringer med ACT-team. Den er et ledd i en nasjonal evaluering av ACT-team på oppdrag fra Helsedirektoratet.

Undersøkelsen gjennomføres av en forskergruppe ved Akershus universitetssykehus og Erfaringskompetanse, brukerorganisasjonenes senter for brukererfaringer.

## Innhold i intervjuet

Intervjuet vil ta omtrent en time. Det inneholder spørsmål om brukers erfaringer med ACT-teamet, forholdet til viktige personer i teamet og ellers, og brukers opplevelse av sin egen utvikling eller bedring.

## Gjennomføring av intervjuet

Intervjuet gjennomføres av en som selv har erfaring fra bruk av helsetjenester for psykisk helse, og som har fått opplæring i intervjuet.

ACT-teamet gir en kopi av intervjueskjemaet til bruker som har gitt samtykke til å bli spurt om et intervju. Brukeren kan dermed på forhånd se gjennom intervjuet og vite hvilke spørsmål som blir stilt. Men brukeren trenger ikke å gjøre det og skal ikke fylle ut svar på forhånd. Intervjueren vil lese opp alle spørsmålene under intervjuet.

Under intervjuet har brukeren skjemaet foran seg. Intervjuer leser opp alle spørsmål. For hvert spørsmål velger brukeren det svaret som passer best med sin erfaring.

Sett kryss eller ring rundt tallet foran det svaret du synes passer best.

## Dette fylles ut av intervjueren under intervjuet

ACT-team:	Pas-ID:	Hvem som var med brukeren: <input type="checkbox"/> Pårørende eller venn <input type="checkbox"/> Teammedlem fra ACT-teamet <input type="checkbox"/> Annen helsearbeider <input type="checkbox"/> Annen: <input type="checkbox"/> Ingen
Dato:	Intervjuer:	
Hvor lang tid det tok å svare på spørreskjemaet: ____ timer _____ minutter		

Her er noen innledende spørsmål om dine erfaringer med ACT-teamet

Vi ber deg først svare på de åtte spørsmålene nedenfor om dine erfaringer med ACT-teamet.

Vi er interessert i dine ærlige meninger, enten de er positive eller negative. Vennligst svar på alle spørsmålene. Intervjueren vil merke av dine svar på sin kopi av skjemaet.

**1 Hvordan er kvaliteten på tjenesten du har mottatt?**

- 4 Utmerket
- 3 God
- 2 Grei
- 1 Dårlig

**2 Fikk du den type tjeneste du ønsket?**

- 1 Nei, definitivt ikke
- 2 Nei, ikke egentlig
- 3 Ja, stort sett
- 4 Ja, definitivt

**3 I hvilken grad har ACT møtt dine behov?**

- 4 Nesten alle mine behov er møtt
- 3 De fleste av mine behov er møtt
- 2 Bare noen få av mine behov er møtt
- 1 Ingen av mine behov er møtt.

**4 Hvis en venn av deg skulle trenge lignende hjelp, ville du da anbefale ACT til han/henne?**

- 1 Nei, definitivt ikke
- 2 Nei, jeg tror ikke det
- 3 Ja det tror jeg
- 4 Ja, definitivt

**5 Hvor fornøyd er du med mengden hjelp du har mottatt?**

- 1 Ganske misfornøyd
- 2 Likegyldig eller litt misfornøyd
- 3 Stort sett fornøyd
- 4 Veldig fornøyd

**6 Har tjenestene du har mottatt fra ACT-teamet hjulpet deg å håndtere problemene dine på en bedre måte?**

- 4 Ja, de var til stor hjelp
- 3 Ja, de hjalp litt
- 2 Nei, de hjalp virkelig ikke
- 1 Nei, de syntes å gjøre ting verre

**7 Alt i alt, hvor fornøyd er du med tjenestene du har mottatt?**

- 4 Svært fornøyd
- 3 Stort sett fornøyd
- 2 Likegyldig eller litt misfornøyd
- 1 Ganske misfornøyd.

**8 Hvis du skulle søke hjelp igjen, ville du gå tilbake til ACT-teamet?**

- 1 Nei, definitivt ikke
- 2 Nei, jeg tror ikke det
- 3 Ja, det tror jeg
- 4 Ja, definitivt

(Client Satisfaction Questionnaire)

## Spørsmål om dine erfaringer med ulike sider ved kontakten med ACT-teamet

Denne delen av intervjuet inneholder spørsmål om ulike sider ved de tjenestene fra ACT-teamet, og om dine erfaringer med disse. Vennligst sett ring rundt tallet for det svaret som passer best på hver linje.

	Veldig lite	Lite	Ganske lite	Verken lite eller mye	Ganske mye	Mye	Veldig mye
1	1	2	3	4	5	6	7
2	1	2	3	4	5	6	7
	Veldig dårlig	Dårlig	Ganske dårlig	Verken bra eller dårlig	Ganske bra	Bra	Veldig bra
3	1	2	3	4	5	6	7
4	1	2	3	4	5	6	7
5	1	2	3	4	5	6	7
6	1	2	3	4	5	6	7
7	1	2	3	4	5	6	7
8	1	2	3	4	5	6	7
	I veldig liten grad	I liten grad	I nokså liten grad	I verken stor eller liten grad	I nokså stor grad	I stor grad	I veldig stor grad
9	1	2	3	4	5	6	7
10	1	2	3	4	5	6	7
11	1	2	3	4	5	6	7
12	1	2	3	4	5	6	7
13	1	2	3	4	5	6	7

	I veldig liten grad	I liten grad	I nokså liten grad	I verken stor eller liten grad	I nokså stor grad	I stor grad	I veldig stor grad	
14	Var det viktig for deg at ACT-teamet brukte lang tid på å bli kjent med deg?	1	2	3	4	5	6	7
15	Får ACT-teamet deg til å ta medisiner du ikke ønsker å ta?	1	2	3	4	5	6	7
16	Bli din oppfatning og erfaring med virkninger og bivirkninger av medisiner tatt alvorlig?	1	2	3	4	5	6	7
17	Bli din mening og erfaring vektlagt i beslutninger om medisiner for deg?	1	2	3	4	5	6	7
18	I hvilken grad synes du ACT-teamet er for pågående eller påtrengende?	1	2	3	4	5	6	7
19	Er du nødt til å motta behandling fra ACT selv om du ikke ønsker det?	1	2	3	4	5	6	7
20	Bli din personlige frihet begrenset av ACT-teamet?	1	2	3	4	5	6	7
21	Kan du slutte å motta tjenester fra ACT-teamet hvis du ønsker det?	1	2	3	4	5	6	7
	Veldig misfornøyd	Misfornøyd	Ganske misfornøyd	Verken fornøyd eller misfornøyd	Ganske fornøyd	Fornøyd	Veldig fornøyd	
22	Hvor fornøyd er du med at ACT-teamet kommer hjem til deg eller møter deg ute, istedenfor på deres kontor?	1	2	3	4	5	6	7
23	Hvor fornøyd er med å motta tjenester fra flere i ACT-teamet istedenfor å ha en enkelt behandler?	1	2	3	4	5	6	7
24	Hvor fornøyd er du med å motta mange ulike typer hjelp fra ACT-teamet fremfor å få spesialisert hjelp fra mange ulike tjenester?	1	2	3	4	5	6	7
	Mye dårligere	Dårligere	Litt dårligere	Verken bedre eller dårligere	Litt bedre	Bedre	Mye bedre	
25	Hvordan er din helse nå sammenliknet med før du begynte å ha kontakt med ACT-teamet?	1	2	3	4	5	6	7
26	Hvordan har ACT-teamet vært for deg sammenliknet med tjenester du tidligere har mottatt?	1	2	3	4	5	6	7

**27. Hva slags behandling har du fått?**


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Sett kryss i en av de første kolonnene på hver linje

1= mye, 2= en del, 3= lite, 4= ikke noe

**For B:** Sett kryss på linja om du ønsket slik behandling

Jeg har fått:	1	2	3	4	B
Samtaleterapi					
Medisiner					
Hjelp med arbeid/utdanning					
Hjelp med bolig					
Hjelp med rusmisbruk					
Hjelp med kontakt med familie					
Aktivitetstilbud					
Praktisk hjelp					

**28. Hvor mange ganger har du møtt en behandler fra ACT-teamet den siste måneden?**

- 1 en gang
- 2 to ganger
- 3 mellom 2-5 ganger
- 4 mellom 5-10 ganger
- 5 10-20 ganger
- 6 20-30 ganger
- 7 mer enn 30 ganger

**29. Hvor mange samtaler med behandlere har du hatt i forhold til det du har ønsket?**

- 1 altfor få
- 2 for få
- 3 ganske få
- 4 stort sett passe
- 5 litt mange
- 6 for mange
- 7 altfor mange

**30. Hvor ofte har din behandler hatt nok tid til deg i samtale dere har hatt?**

- 7 alltid
- 6 nesten alltid
- 5 ofte
- 4 noen ganger
- 3 nå og da
- 2 nesten aldri
- 1 aldri

**31. Hvor mye har samtale med dine behandlere vært til hjelp for deg?**

- 7 veldig nyttige
- 6 nyttige
- 5 ganske nyttige
- 4 verken nyttige eller unyttige
- 3 ganske unyttige
- 2 unyttige
- 1 veldig unyttige

**32. Har du fått for mye eller for lite medisiner?**

0 = har ikke fått medisiner

- 1 altfor mye medisiner
- 2 for mye medisiner
- 3 litt for mye medisiner
- 4 omtrent riktig mengde medisiner
- 5 litt for lite medisiner
- 6 for lite medisiner
- 7 altfor lite medisiner

**33. Hvor viktig er det for deg å få hjelp utenom teamets åpningstid?**

- 7 veldig viktig
- 6 viktig
- 5 ganske viktig
- 4 verken viktig eller uviktig
- 3 ganske lite viktig
- 2 lite viktig
- 1 helt uviktig

**34. Hvor stor innflytelse har du hatt på planen som ble laget for behandlingen din?**

- 7 veldig stor
- 6 stor
- 5 ganske stor
- 4 verken stor eller liten
- 3 ganske liten
- 2 liten
- 1 veldig liten

**35. Hvordan har bivirkningene av medisinerne vært? 0 = har ikke fått medisiner**

- 1 veldig plagsomme
- 2 plagsomme
- 3 litt plagsomme
- 4 merkbare
- 5 ikke veldig plagsomme
- 6 nesten ikke plagsomme i det hele tatt
- 7 nesten ikke til å merke

**36. Hvor høye krav har det vært stilt til deg under behandlingen?**

- 1 altfor høye
- 2 for høye
- 3 litt for høye
- 4 stort sett riktig
- 5 litt for lave
- 6 for lave
- 7 altfor lave

**37. Hvor ofte har du følt at du kunne stole på behandlerne i ACT-teamet?**

- 1 aldri
- 2 nesten aldri
- 3 nå og da
- 4 noen ganger
- 5 ofte
- 6 nesten alltid
- 7 alltid

## Her kommer noen spørsmål om forholdet ditt til kontaktpersonen din i ACT-teamet

Med din kontaktperson mener vi her den personen i ACT-teamet som du har mest kontakt med eller synes er viktigst for deg, enten teamet har sagt at personen sagt at det er slik eller ikke.

Vi ber deg tenke på denne personen når du svarer på spørsmålene nedenfor. For hvert spørsmål ber vi deg velge det svaret du synes passer best på det spørsmålet.

		Aldri	Sjelden	Av og til	Ofte	Alltid
1	Kontaktpersonen min snakker med meg om mine personlige mål og tanker om behandling	0	1	2	3	4
2	Kontaktpersonen min og jeg er åpne mot hverandre	0	1	2	3	4
3	Kontaktpersonen min og jeg har et gjensidig tillitsforhold	0	1	2	3	4
4	Jeg tror at kontaktpersonen min holder tilbake sannheten for meg	0	1	2	3	4
5	Kontaktpersonen min og jeg er ærlige mot hverandre	0	1	2	3	4
6	Kontaktpersonen min og jeg jobber mot mål vi har blitt enige om	0	1	2	3	4
7	Kontaktpersonen min er streng med meg når jeg snakker om ting som er viktige for meg og min situasjon	0	1	2	3	4
8	Kontaktpersonen min og jeg har fått en felles forståelse av hva slags forandringer som ville være bra for meg	0	1	2	3	4
9	Kontaktpersonen er utålmodig med meg	0	1	2	3	4
10	Kontaktpersonen min ser ut til å like meg uansett hva jeg sier eller gjør	0	1	2	3	4
11	Vi er enige om hva som er viktig for meg å jobbe med	0	1	2	3	4
12	Jeg tror kontaktpersonen min forstår hva erfaringene mine har betydd for meg	0	1	2	3	4

(STAR)

## Spørsmålene nedenfor er om hvordan du opplever din egen bedringsprosess

Spørsmålene er tenkt til hjelp for å forstå mer om prosessen din med å få det bedre, - om hva som er nyttig og hva som ikke er så nyttig. Alle er forskjellige og det vil være forskjeller for alle. Disse spørsmålene ble utarbeidet ut fra intervjuer med brukere av tjenester om deres vei til bedring. Vi håper at du ved å svare på disse spørsmålene kan hjelpe oss å forstå hva som er viktig for deg og din egen bedringsprosess. Ikke alle spørsmål vil gjelde noe som er viktig for deg, siden alle er forskjellige.

Vennligst ta deg litt tid til å tenke gjennom hvordan ting er for deg nå for tiden med hensyn til din psykiske helse og bedringsprosess, særlig de siste 7 dagene. Vennligst svar på følgende utsagn ved å sette ring rundt tallet for det svaret som best beskriver din opplevelse.

		Helt uenig	Uenig	Hverken enig eller uenig	Enig	Helt enig
1	Jeg har det bedre med meg selv.	1	2	3	4	5
2	Jeg føler meg i stand til å ta sjanser i livet.	1	2	3	4	5
3	Jeg er i stand til å utvikle positive forhold til andre mennesker.	1	2	3	4	5
4	Jeg føler meg som en del av samfunnet og ikke isolert.	1	2	3	4	5
5	Jeg er i stand til å hevde meg selv.	1	2	3	4	5
6	Jeg føler at livet har en mening	1	2	3	4	5
7	Mine erfaringer har endret meg til det bedre.	1	2	3	4	5
8	Jeg har klart å godta ting som har skjedd med meg i fortiden og gått videre i livet mitt.	1	2	3	4	5
9	Jeg er i grunnen sterkt motivert for å bli bedre.	1	2	3	4	5
10	Jeg kan verdsette de positive tingene jeg har gjort.	1	2	3	4	5
11	Jeg er i stand til å forstå meg selv bedre.	1	2	3	4	5
12	Jeg kan ta ansvar for livet mitt.	1	2	3	4	5
13	Jeg er i stand til å skaffe meg uavhengig støtte.	1	2	3	4	5
14	Jeg kan se både fordeler og ulemper med psykiatrisk behandling.	1	2	3	4	5
15	Jeg føler at mine erfaringer har gjort meg mer forståelsesfull mot andre.	1	2	3	4	5
16	Å møte andre som har hatt lignende erfaringer får meg til å føle meg bedre	1	2	3	4	5
17	Min bedring har bidratt til å utfordre andre menneskers syn på det å få det bedre.	1	2	3	4	5
18	Jeg er i stand til å forstå mine vanskelige opplevelser.	1	2	3	4	5
19	Jeg kan engasjere meg aktivt i livet mitt.	1	2	3	4	5
20	Jeg innser at de synspunkter enkelte helsearbeidere har ikke er den eneste måten å se ting på.	1	2	3	4	5
21	Jeg kan ta kontroll over deler av livet mitt.	1	2	3	4	5
22	Jeg kan finne tid til å gjøre de tingene jeg liker.	1	2	3	4	5

(QPR)

**Her er noen spørsmål til slutt der du kan si eller skrive det du vil.**

1.Hva har du likt best ved ACT-teamet og kontakten med de som arbeider der?

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2. Hva har du likt minst ved ACT-teamet og kontakten med de som arbeider der?

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3.Hvis du kunne forandre noe i din kontakt med ACT-teamet, hva ville det være?

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4.Har du opplevd noen hendelse underveis som ble et vendepunkt i tiden du har hatt kontakt med ACT-teamet? – noe som gjorde at ting vendte seg til det bedre? I så fall hva, og hvordan forstår du det?

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5.Er det noen viktige ting du ikke er blitt spurt om?

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**Takk for at du har tatt deg tid til å svar på dette spørreskjemaet!**



## 6.2 Interview guide

### Recovery

Forskningsspørsmål

Hvilke faktorer mener brukerne er viktige for deres recovery?

Åpningsspørsmål: Kan dere beskrive deres bedringsprosess?

1. Er prosessen avhengig av dere selv, eller ACT-teamet en viktig bidragsyter til at livet er blitt bedre?
2. Er dere blitt involvert og ansvarliggjort i egen behandling?
3. Vi snakker om store og små mål. Ble det satt av dere selv, eller var det behandlerne som var sentrale i å utforme dem?
4. Ble deres egne mål og ønsker om framtida diskutert?
5. Følte dere press og fikk dere dårlig samvittighet om dere ikke klarte å nå teamets forventninger?
6. Er det andre ting i livet som har påvirket recoveryprosessen deres?
7. Er det noen viktige deler av ACT-tilbudet som har vært viktig for deres prosess?
8. Hva liker/likte du ikke ved ACT-tilbudet?

### Etiske dilemmaer

Forskningsspørsmål:

Hvilke etiske dilemmaer som medarbeidere møter, er viktige for brukerne?

Hvordan påvirker sentrale etiske dilemmaer utøvelsen av ACT-modellen?

Her ønsker jeg å vite hva dere mener om tre viktige etiske dilemmaer som medarbeiderne står i: a) hva mener dere er etiske dilemmaer medarbeidere står i b) oppsøkende virksomhet og c) muligheter til å bruke tvangsmidler.

- A. Hva tenker dere er etiske dilemmaer som medarbeidere står i?  
Har du opplevd at teamet diskuterte etiske dilemmaer med deg?
- B. Oppsøkende virksomhet
1. Hvordan er det å ha et privatliv når dere er knyttet til et ACT-team?
  2. Hva tenker dere om ACT-teamets oppsøkende virksomhet – at de ikke gir seg?
  3. Kan den oppsøkende virksomheten bli påtrengende og masete?
  4. Er det vanskelig å få behandling i eget hjem i stedet for på et kontor/sykehus?
- C. Tvang
1. Hva tenker dere rundt tvang og at ACT-medarbeidere må bruke det? (Her i Norge snakker vi om Tvang uten døgnopphold. Det innebærer et krav om å gå i behandling, men kan også bety tvangsmedisinering og økonomisk administrasjon)
  2. Hva er deres oppfatninger om tvangsmedisinering og at noen tar over økonomien?
- D. Hva tenker dere om at medarbeidere har makt over andre

## 7 Appendix 2, Paper 1, 2 and 3

