Marit By Rise

Lifting the veil
from user participation
in clinical work –
What is it and does it work?

NTNU
Norwegian University of
Science and Technology

Å løfte sløret av brukermedvirkning i klinisk arbeid –
Hva er det og har det noen effekt?

Brukermedvirkning har blitt lovpålagt i mange land, blant annet i Norge. Dette innebærer at brukere skal medvirke i utforming, gjennomføring og evaluering av helsetjenestene, både som representanter i råd og utvalg og i egen behandling. Det finnes både teoretiske og ideologiske argumenter for brukermedvirkning og mange ulike måter å definere brukermedvirkning på. Det er imidlertid fortsatt uklart hva brukermedvirkning innebærer i klinisk arbeid og hva som er effekten av slik medvirkning. Hovedformålet med avhandlingen var derfor å kaste lys over hva brukermedvirkning innebærer og om det har noen effekt i det daglige kliniske arbeidet.

Det ble gjennomført fire studier i totalt tre distriktspsykiatriske sentre (DPS) i Midt-Norge. Totalt 635 brukere og helsepersonell deltok i studiene. De fire studiene inkluderte to kvalitative studier som undersøkte hvordan brukere og profesjonelle definerte brukermedvirkning, både generelt og i psykisk helsevern spesielt. Den tredje studien undersøkte, gjennom et ikke-randomisert kontrollert design, om innføringen av en strategi for brukermedvirkning i en hel organisasjon påvirket de ansattes kunnskaper, praksis og holdninger. Den fjerde studien brukte et randomisert kontrollert design for å undersøke effekten av å bruke tilbakemeldinger fra pasienter i terapisamtaler på terapeutisk allianse og pasienttilfredshet.

Resultatene i avhandlingen viste at gjensidig respekt, dialog og beslutninger tatt i fellesskap var grunnleggende elementer i brukermedvirkning. Respekt ble løftet fram, spesielt av brukerne, som en fundamental og undervurdert del av brukermedvirkning i klinikken. Resultatene viste også at målet om at beslutninger skal tas i fellesskap ble forhandlet om og omdefinert i dårlige sykdomsfaser. Beslutningstaking framsto som en avgjørende, men utfordrende prosess hvor respekt og dialog var like viktig som hvem som tar den endelige beslutningen.

Det var så godt som ingen effekt av å innføre en strategi for brukermedvirkning i en hel organisasjon på ansattes kunnskap, praksis og holdninger. Det var heller ingen korttidseffekt på pasienttilfredshet og opplevelse av terapeutisk allianse av å bruke tilbakemelding fra pasienter i terapisamtaler, men det var en korttidseffekt på motivasjon. To problemområder knyttet til effektstudier ble særlig belyst; Implementeringsprosesser har vist seg å være komplekse og utfordrende, og effektmål har blitt beskrevet som ufullstendige og lite brukbare. Videre arbeid på disse områdene må inkludere de som deltar i medvirkningsprosessene, altså brukere og helsepersonell.

Kandidat: Master i psykologi Marit By Rise, Institutt for samfunnsmedisin, NTNU
Institutt: Institutt for samfunnsmedisin
Veiledere: Professor Aslak Steinsbekk, Institutt for samfunnsmedisin, NTNU
Førsteamanuensis Hilde Grimstad, Institutt for samfunnsmedisin, NTNU
Sjefpsykolog og førsteamanuensis Lasse Eriksen, Nidaros DPS, St. Olavs hospital og Institutt for Nevromedisin, NTNU
Finansieringskilde: ExtraStiftelsen Helse og Rehabilitering gjennom Rådet for Psykisk Helse.

4

Table of contents

Acknowledgements

First and foremost I will thank the health service users and professionals who have participated in the studies included in this thesis. I also appreciate the cooperation and support from the leaders and administration at the three regional psychiatric centres which were the setting for the studies; Nidaros DPS, Tiller DPS, and Orkdal DPS.

This project was financed with EXTRA funds from the Norwegian ExtraFoundation for Health and Rehabilitation, through the Norwegian Council for Mental Health. I am very grateful for the three years of funding which enabled me to do this work.

My supervisors during this project have been Aslak Steinsbekk, Hilde Grimstad, and Lasse Eriksen. They have, in different ways, mentored, encouraged, supported, inspired, and influenced my work and rendered it more robust and interesting than I could ever have done on my own.

Heidi Westerlund at the Resource center for service user experience and service development (KBT Midt-Norge) participated in many parts of the project and co-authored two of the papers in my thesis. Thank you so much, Heidi, for speaking your mind, keeping us down to earth, and for continuously emphasising the importance of the project. Your participation has strengthened all parts of this work.

I have also had the great pleasure of being part of a research group for Patient Education and Participation (PEP), led by Aslak Steinsbekk, during these three years. Many thanks to Marit Solbjør, Borghild Lomundal, Kjersti Grønning, Hilde Strøm Solberg, Lisbeth Ø. Rygg, and Mariela Lara. The collaboration and partnership in the PEP-group has made me a better researcher and group member. A special thanks to my colleague and friend Marit who has worked closely and patiently together with me, and to my doves Borghild and Mariela who have taken turns in sharing office with me.

In addition to having had the best job ever, I have been lucky enough to be situated in the "penthouse" floor of the department together with fun, caring, and smart colleagues. I have really appreciated the nonsense- and laughter-filled lunches and the tea-breaks in the hallway.

To my mother Audhild and my father Jostein I would like to say thank you for teaching me the value of a critical, yet open mind and hard, honest work. I know you are proud of me and I love you both very much! I also salute my brothers Ola, Kjetil and Øystein for constantly reminding me that blood is (four times) thicker than water and that we all have many fine skills and abilities. Yes, I love you too. And to my in-laws for more than 25 years - Laila and Jan - thank you for supporting me and always treating me as an invaluable part of the family.

To my children Gabriel and Amalie I repeat; Pay your taxes, vote wisely, and be happy! I will always be tremendously proud of you and love you to bits.

And finally, a special thank you to my beloved husband and best friend who supported me continuously during the work with this thesis. I know I could have done it on my own, but your support, encouragement, and persistence have been invaluable.

Abbreviations

BASIS-32: Behaviour and Symptom Identification Scale-32

CPQ: Consumer Participation Questionnaire

OQ-45: Outcome Questionnaire-45

ORS: Outcome Rating Scale

PAM: Patient Activation Measure

PCOMS: Partners of Change Outcome Management System

PICS: Patient Involvement in Medical Care Scale

PM: Patient Motivation (questionnaire)

POC: Perception of Care

ROR: Ratio Odds Ratio

SRS: Session Rating Scale

TAS: Treatment Alliance Scale

Definitions

Consumerism: The protection or promotion of the interests of consumers.

Democratisation: To introduce a democratic system or democratic principle to make something accessible to everyone.

Empowerment: To make someone stronger and more confident, especially in controlling their life and claiming their rights.

Mental health hospital: In this thesis used as a name for what in Norway is called a regional district psychiatric centre which is part of a hospital trust.

Patient choice: A patient's possibility to choose between different treatment options.

Poor mental illness phases: Phases when a patient experiences or shows strong symptoms on mental illness.

Shared decision-making: A process where two or more persons share information, build consensus on the preferred decision, and reach an agreement.

Treatment session: A patient's visit in out-patient mental health services.

8

Summary in English

User participation in health care has been part of a large societal development where patient's rights have challenged the history of paternalism. Users' participation has been legislated in many countries and proposes that participation shall take place both on the system level and in individual treatment. Many theoretical and ideological arguments for user participation have been made and many definitions have been formulated. What user participation implies in the clinic and the effect of user participation initiatives in clinical work is however still unclear. The aim of this thesis was therefore to contribute to lift the veil from user participation in clinical work. The aim focused on two main aspects; what is user participation - and does it work?

To answer the main aim four studies were conducted mainly in a mental health hospital (regional psychiatric centre) in central Norway. A total of 635 health service users and providers participated in the studies. The four studies included two qualitative studies exploring how health service users and providers defined user participation in general and in mental health services in particular (definitions and perspectives on participation). The third study was a quasi-experimental study investigating the effect of implementing a development plan to enhance user participation in a mental health hospital on professionals' knowledge, practice and attitudes (effect on a system level). The fourth study was a randomised controlled trial investigating the short-term effect of using patient feedback in out-patient mental health treatment sessions on treatment alliance and patient satisfaction (effect on an individual level).

The results from the qualitative studies showed that respect, dialogue, and shared decision-making were core aspects of user participation and that the decision-making part was negotiated and redefined during poor phases of mental illness. The quasi-experimental study and the randomised controlled trial showed little or no effect of the investigated user participation interventions.

As a whole this thesis has illuminated respect as a fundamental and under-communicated aspect of user participation in the clinic, and decision-making as a crucial yet vulnerable and challenging part of user participation. The thesis has contributed with studies to enlarge the evidence-base on effect of user participation on system and individual level. Two problem

areas in effect studies have been illuminated. Implementation processes on a system level need to be followed closely, and there are potential problems with the outcome measures used to measure the effect of user participation.

Respect must be investigated further as a fundament of user participation, and users' perception of being respected should become one of the hallmarks of good health services. Decision-making must be seen as an integrated process where respect and communication are more important than who makes the final decisions. There is still a need for more high quality studies on the effect of user participation, especially on the system level.

List of papers

Paper I

Rise MB; Solbjør M; Lara M; Westerlund H; Grimstad H; Steinsbekk A. Same description, different values. How service users and providers define patient and public involvement in health care. Health Expectations, published online: August 2011, DOI: 10.1111/j.1369-7625.2011.00713.x

Paper II

Solbjør M; Rise MB; Westerlund H; Steinsbekk A. Patient participation in mental health care: when is it difficult? A qualitative study of users and providers in a mental health hospital in Norway. International Journal of Social Psychiatry, 2011, DOI: 10.1177/0020764011423464

Paper III

Rise MB; Grimstad H; Solbjor M; Steinsbekk A. Effect of an institutional development plan for user participation on professionals' knowledge, practice, and attitudes. A controlled study. BMC Health Services Research 2011, 11:296, DOI: 10.1186/1472-6963-11-296

Paper IV

Rise MB; Eriksen L; Grimstad H; Steinsbekk A. The short-term effect on alliance and satisfaction of using patient feedback scales in mental health out-patient treatment. A randomised controlled trial. Submitted to BMC Health Services Research.

"The idea of citizen participation is a little like eating spinach:
No one is against it in principle because it's good for you".
Arnstein, 1969.

1. General introduction

I start this introduction with accounting for my choice of terms in this thesis in section 1.1. In section 1.2 to 1.4 I describe the evolution of user participation in health care, in Norway, and in mental health care in particular. In section 1.5 I describe and investigate the different arguments for user participation including the challenges for user participation described in the literature. I subsequently report on the characteristics of some concepts adjacent to user participation in section 1.6. The current definitions of user participation are described in section 1.7. In section 1.8 and 1.9 I account for the various methods and the potential effects of user participation, concluding with a brief overview of the current research on the effect of selected areas of user participation.

1.1 Choice of terms

The phenomenon of user participation has many different names. Citizen participation/-involvement, consumer participation/involvement, user participation/involvement, patient participation/involvement, and patient and public involvement are among the names found in the literature. In addition involvement, participation, collaboration, and partnership are often used as synonym terms. I have chosen to use "participation" in this thesis.

The terms to describe service users are also many. In the literature the terms citizen, consumer, user, lay person, and patient are used interchangeably. I have chosen to use the term "users" to describe all participants in various participation processes who are not health service providers or policy makers. The term "user" thus includes both users currently in treatment (often referred to as patients) and users (former and future users or next of kin) who act as representatives on the system level of participation.

At present user participation in health care takes place mainly in two ways (Florin et al. 2004). One is commonly named participation on a system level. This is when representatives of previous, current, and future users of the health services are involved in planning and conducting the services. Participation on a system level usually takes place in

committees and boards in service institutions, and when designing and implementing changes in the services. Secondly, user participation takes place when patients participate in their own treatment. This is often called participation on an individual level. This thesis includes research on both levels of participation. I have chosen to use the term "user participation" to describe users' involvement on both levels and to specify which level I refer to when appropriate.

In this thesis I use the terms health care provider and professional interchangeably to describe all employees in the health services. The term health professionals are used when I write about employees who have health education and provide health care.

1.2 The evolution of user participation

In 1969 Sherry R Arnstein wrote an article asking; "What is citizen participation?" (Arnstein 1969). Although Arnstein's focus mainly was deprived and ignored groups in the United States, she highlighted the distance between participation as an empty ritual and as having the power necessary to affect an outcome. In her article she described "The ladder of participation", including eight rungs from "Manipulation" to "Citizen control", and stated that a redistribution of power was necessary to achieve genuine participation (figure 1).
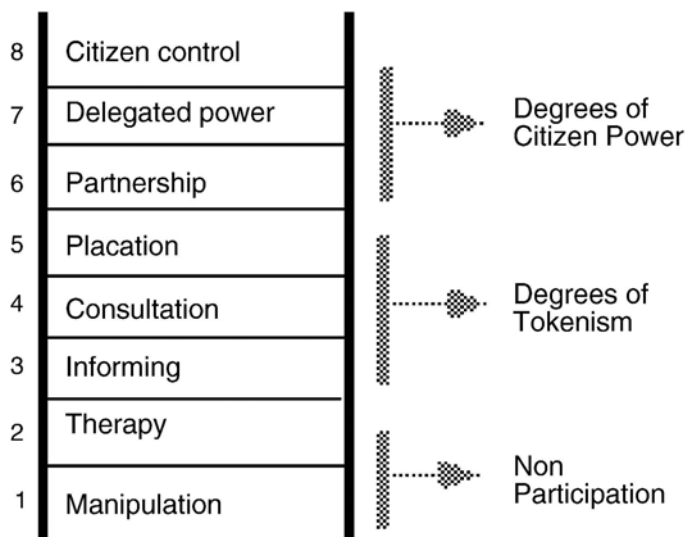
Figure 1 Arnstein's ladder of citizen engagement (Tritter & McCallum, 2006).

Arnstein's article was part of the civil rights movement which started in the United States in the 1960s and spread to Europe (Tritter et al. 2010). During the 1960s and 1970s a focus on patients' rights was raised, and has been linked to the development of concepts such as consumerism, democratisation, and empowerment. During this period disabled persons and other health service users formed groups to work towards changes regarding rights and choices in society and health care. The evolution of user participation was part of a larger development in society, starting in the 1960s, where the hegemony of paternalism and the passive and receptive patient was gradually challenged by the idea of a more active patient role and a partnership between health care user and provider (Coulter 1999;Hoving et al. 2010;Tritter et al. 2010).

Although the development of citizens' rights and consumerism started in the United States, the development of user participation has been explicit in Europe as well (Tritter et al. 2010). In a book about the globalisation, commercialisation, and consumerism in health care policy Tritter and colleagues describe the World Health Organization (WHO) and the European Union (EU) as central in the development of creating consensus and policy making regarding user participation (Tritter et al. 2010). The World Health Organisation put user participation on the agenda of public health in the "Declaration of Alma-Ata" in 1978;

"The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare"
(World Health Organisation 1978) (clause IV)

User participation was further emphasised in WHO documents during the 1980s and 1990s. The "Declaration on the Promotion of Patients' Rights in Europe" stated e.g. patients' rights to information, confidentiality, and respect (World Health Organisation Regional Office for Europe 1994). In 1996 the "Ljubljana Charter on reforming health care" stated that health care systems in Europe should be centred on people, and that the citizen's voice and choice should be listened to (World Health Organisation Regional Office for Europe 1996). The European Union followed the WHO, and adopted a programme of community action in public health where they stated;

"All health-related activities of the Community must have a high degree of visibility and transparency and allow consultation and participation of all stakeholders in a balanced

way, in order to promote better knowledge and communication flows and thus enable a
greater involvement of individuals in decisions that concern their health."
(European Commission 2001) (Article 1)

1.3 User participation in Norway

In Norway user participation emerged during the consumer orientation in the health care
system in the 1980s (Andreassen 2007). This was connected to the development of new
public management in the 1980s and 1990s (Christensen 2005). Andreassen describes in her
book about user participation in the Norwegian health care system how a governmental
report in 1997 (Norges offentlige utredninger 1997) started to point towards a change of
perspective in health care legislation; from a hospital perspective to a patient perspective
(Andreassen 2005). Subsequently the legislation followed; through a patients' rights law
and a health care trusts law. The patients' rights law (Lov om pasientrettigheter 1999) stated
patients' right to participation in treatment and the right to receive information (Report
No.16 (2010-2011) to the Storting 2011). The health care trust law (Lov om helseforetak
2001) made it mandatory to have user committees with a consultative function in the health
care trusts (Proposition No.66 (2000-2001) to the Odelsting 2001). Such user committees
include representatives from associations for disabled people and elderly people, as well as
people with mental health problems, chronic illnesses, cancer, drug addictions (Andreassen
2009). In a study on the occurrence of user participation in health care trusts in Central
Norway 72 % of administrational units reported involving users in the development of
health services (Steinsbekk et al. 2008). User representatives participated on the ward level,
in steering committees, and in educational initiatives. In addition user representatives were
employed by the trusts in patient education initiatives, the trust had contact with user
organisations, and user surveys were conducted (Steinsbekk et al. 2008). In primary care it
is so far only mandatory to have formal representation from the group of functionally
disabled people (Andreassen 2005).

The area of user participation in Norway resembles in many ways the United Kingdom
(Andreassen 2009), Sweden and Finland (Tritter et al. 2010), and has been described both as
a strategy and as a value in the health services in Norway (Andreassen 2005). In Norway, as
in similar countries, user participation has evolved somewhat embedded in consumerism.
Andreassen argues however that the Norwegian consumerism is "a consumerism of voice

more than choice" (Andreassen 2009) (page 117). Norwegian government has thus provided users with a voice in the debate on health care services through involving users in the forums where decisions take place, and not only provided various health care options to choose from. User involvement on a system level in Norway strongly involves user organisations, and representatives in committees are often recruited through such organisations. User representatives, as spokespersons on behalf of affected groups, often have direct contact with health professionals and managers. According to Andreassen, the tight bond between the disability movement and user groups in Norway has strengthened the position of user organisations and made it possible to involve users in complex discussions and genuine decision-making about chronic care (Andreassen 2009).

1.4 User participation in mental health care

During the last 2-3 decades user participation has become expected and demanded in mental health care, and efforts have been made to change the long-lasting hierarchies of power (Stickley 2006). Stickley argues that mental health care has been a very important arena for the movement arguing for changes in medical care due to the long history on aspects of power and control (Stickley 2006). Mental health care is also strongly associated with stigma which might hinder participation if users' and patients' ability to be involved is questioned (Double 2002;Hickey et al. 1998;Rose et al. 2007). Double has emphasised the cultural role of psychiatry as more exposed to criticism than other parts of medicine (Double 2002). He attributes this to psychiatry's relation to social control through mental health legislation. According to Double, the access to coercive treatment in mental health makes user participation both pressing and complicated.

Together with services for patients with cancer, mental health care has also been the setting for much of the research investigating the effect of participation initiatives (Tritter et al. 2010). One of the arguments for involving users and patients in mental health care is, in addition to provide services that correspond to the needs and wishes of the patients, to gain therapeutic value for patients through participation in the decision-making process both on system and individual level (Hickey et al. 1998). Mental health service is thus an area where user participation is viewed as helpful for the treatment outcome.

In Norway there has been strong emphasis on strengthening mental health services after 1996 (Andreassen 2009). In 1997 a white paper with a plan to strengthen mental health care was passed (Proposition No.63 (1997-1998) to the Storting 1998). This plan also focused on strengthening participation - both on the system and individual level. This indicates a distinct emphasis on user participation in mental health care in Norway the last 15 years.

1.5 Why should users participate?

The quote from Arnstein (1969) referring to spinach implies that user participation is "good for you" (Arnstein 1969), but why is it a good thing? There exist many arguments for involving users' and patients' views in health care services. Some have stated that involvement from users is one of the main ingredients in efficient and effective health services (Tritter et al. 2010). Wait & Nolte describe two main perspectives underlying the concept of user participation; the democratic perspective and the consumerist perspective (Wait et al. 2006). The democratic perspective assumes that user participation leads to more democratic decision-making, while the consumer perspective leans on economic theories which advocate participation to correct the health care markets through consumer choice (Wait et al. 2006). Patient participation is viewed as a democratic privilege, and is highly emphasised in the western world (Crawford et al. 2002;Longtin et al. 2010). Charles and DeMaio viewed user participation as a reflection of and response to three main aspects; a loss of faith in professional knowledge as the main decisive factor for decision-making, a redefinition of the local government's role in decision-making on resource allocation, and a wish to hold providers accountable towards the users they service (Charles et al. 1993). Charles and DeMaio call this a shift towards a more democratic decision-making.

Tritter and colleagues have highlighted that the health services need to be accountable to the users and patients since users and patients are taxpayers and voters (in publicly funded health services), as well as consumers (Tritter et al. 2010). Mizrahi and colleagues stated that participation has been advocated based on philosophical, pragmatic, and political reasons. Philosophical since participation is considered an essential part of a living society, pragmatic since it potentially lead to better services and political since it supposedly strengthens the power of the service users (Mizrahi et al. 2009). In Norway it is considered a democratic right for citizens to express their views before political decisions that affect them are made (Andreassen 2009). In a report written for the Norwegian directorate for welfare

and health user participation is advocated as a human right and a value in its own right (The Norwegian Directorate of Health 2006).

There are also many proposed concrete benefits from user participation in health care; reducing medical errors and increasing patient safety (Longtin et al. 2010), making services more accessible and improving information (Crawford et al. 2002), improving the co-ordination of care in chronic diseases (May et al. 2009), improving clinical decision-making (Coulter et al. 2007), and aligning the goals and agendas of patients' and providers' (Cegala et al. 2007). In Norway, participation is also argued to have some concrete benefits; to add therapeutic value, and to improve and ensure the quality of services (The Norwegian Directorate of Health 2006).

The theoretical or political arguments underpinning the idea of user participation have impact on the practice of participation. Kreindler argues that the choice of ideology behind participation is a prerequisite for the choice of methods for involving patients and users (Kreindler 2009). While consumerism focuses on the individual's needs, the democratic perspective focuses more on collective and interactive processes. According to Kreindler the choice of method is thus a political choice (Kreindler 2009). Similarly, Hickey & Kipping write that the rationale for user participation will determine which approach is chosen (Hickey et al. 1998). Wait and Nolte argue that an evaluative framework would be necessary to assess the possible impact of involving users' perspectives in policy making (Wait et al. 2006). In an evaluation of involvement processes in health services Gold and colleagues found that a clear direction on what user participation should imply and how it should be implemented was lacking (Gold et al. 2005). This lack led to a gap between the intention to involve users and their actual involvement in a user participation initiative on a system level.

Although many have described possible benefits, there is a debate on what should be the main outcome from user participation. Some have stated that the main goal of involving patients is nothing less than changing the services (Andreassen 2009;Kreindler 2009). This goal has also been underlined by health care managers during studies on the system level of participation (Bennetts et al. 2011). Bennetts and colleagues found that managers in mental health care perceived change of services as the most important potential impact of user participation. Andreassen similarly found that one of the professionals' main arguments for

having representation in the health care trusts was to help focus on the patients and to bring the patients' perspective into the trusts' work (Andreassen 2005). Others have described the main outcome from participation as providing user knowledge which could add new viewpoints to or support professional knowledge (Solbjor et al. 2011).

In a comprehensive review of studies on patient-focused interventions Coulter and Ellins describe seven health care areas where improvements would be the main outcomes; health literacy, clinical decision-making, self-care, patient safety, access to health advice, care experience, and service development (Coulter et al. 2006). They further describe potential outcome measures; patients' knowledge, patients' experience (i.e. satisfaction, communication, quality of life, self-efficacy, and involvement), service utilisation and costs, and health behaviour and health status.

Although Coulter and Ellins is concrete in the description of outcome measures, it is in general a lack of consensus on which concrete outcomes to study when investigating user participation (Crawford et al. 2002). Besides the wish for "better services" the wanted effect of participation is still unclear. Kreindler has highlighted the lack of focus on the outputs from participation; what is the result from different initiatives where users and patients are involved (Kreindler 2009)? The literature on different outcomes from various ways of participation is, according to Kreindler, neither homogenous nor focused. The question whether user participation is an end in itself or a means to other goals (Charles et al. 1993) is important. The answer would impact the arguments for user participation. It would also contribute in the search for focus and homogeneity; factors important for scientific work.

1.5.1 Challenges in user participation

Although there exist many well-funded arguments for user participation, challenges in carrying out user participation have been described by many. One of the challenges is that user participation becomes tokenism; that participation is not genuine, but only has symbolic value. Tokenism is a challenge highly emphasised by Arnstein (Arnstein 1969). Some have debated whether user participation as it is currently practiced in health services has any effect at all, or whether participation remains on a tokenistic level (Stickley 2006) where the degree of participation is evaluated as the number of user participants in boards or the number of patient satisfaction surveys (Rose et al. 2009). Doubting that participation is

genuine can lead to reluctance to participate among users. Some studies have indicated that participation initiatives become symbolic. An English public survey found for example that some users waived to provide feedback sought after by health services because they had no confidence that it would impact the services (Entwistle et al. 2003). Harrison and Mort's research investigating a participation initiative on a system level showed that while managers and professionals in health care services were positive to user participation, they simultaneously secured themselves latitude to ignore the outcomes from involving the users (Harrison et al. 1998). In addition they used the involvement process to legitimate internal political purposes.

Another challenge described is whether users want to participate, or whether they see any reasons for participating (Wait et al. 2006). Litva and colleagues found that although users wanted to be consulted before decisions on a system level was made they did not want to be held responsible for the decisions (Litva et al. 2002). Many have also emphasised that users have to be adequately resourced to have the necessary legitimacy and to feel comfortable about participating (Church et al. 2002;Litva et al. 2002;Martin 2008). Having knowledge and resources to participate would be particularly important on the system level, but also when participating in treatment processes. Simpson and House have argued that it is a challenge to user participation on a system level that some providers question whether users are representative for the group they work for (Simpson et al. 2003). The authors suggest that user representatives must be evaluated according to what experience he or she needs to participate on behalf of others. In addition they indicate that this questioning might be due to users and providers having different agendas, a diversity which providers must accept.

In addition many have shown that health personnel are reluctant to involve users (Crawford et al. 2002;Lester et al. 2006;Stringer et al. 2008). Collaboration and partnership between patients and health personnel has been described as essential in the process of participation (Larsson et al. 2007;Sahlsten et al. 2007;Tutton 2005), and professionals' willingness to accept user participation would thus be vital. And even though professionals are willing to take part in user participation, many have emphasised that different preconceptions and perceptions on user participation might complicate efficient communication and collaboration between the stakeholders in the participation process (Cahill 1998;Hickey et al. 1998;Jewell 1994;Longtin et al. 2010;Solbjor et al. 2011).

The effects of illness and the very nature of medical care have also been described as obstacles towards meaningful patient participation (Anthony et al. 2000;Breeze 1998;Hall 2008;Madison 2010;Tambuyzer et al. 2011). The power imbalance between the patient and the professional is therefore said to be obvious. One example is when treatment is given according to medical guidelines during acute somatic disease without asking the patient to participate in the decision-making process. We could assume that user participation is challenging in all areas of the health services when user groups are weak, vulnerable, and strongly dependant on the provider. This is probably a strong argument in mental health care.

1.6 Concepts adjacent to user participation

The phenomenon of user participation has been linked to and is overlapped by other similar concepts as patient-centred care, empowerment, and patient education.

Patient-centred care was initiated by the psychiatrist Balint who intended to complement a traditional medical approach by focusing on the patients' perception of disease, the patient as a whole, and the relationship between patient and physician (Balint 1969). Patient-centred care has its origin in psychology with Carls Rogers' client-centred method in psychotherapy (Rogers 1951). After Balint introduced the concept in medicine it has been adopted by a larger medical society, and has especially been associated with patient-centred communication (Meland et al. 2000). Patient-centred communication includes exploring the patients' perception of the health problem, that the physician perceives the patient as a "whole person", that the patient and physician reach a common understanding, a focus on prevention and health promotion, and strengthening the relationship between the patient and the physician (Stewart et al. 2000).

Several have described patient-centred care as a model for involving patients more in their own treatment process (Coulter 2002;Haywood et al. 2006;Ridley et al. 2001;Tritter et al. 2010), and thus as an approach promoting individual user participation. Patient-centred care implies an increased focus on patient experience and knowledge, and on self-management (Tritter et al. 2010). This approach calls for a new style of communication, and focuses on the communication processes between the patient and the health care provider. Patient-

centred care also ensures that the patients' views and needs are central when decisions about treatment are made (Tritter et al. 2010).

As described previously, Arnstein described participation as a redistribution of power (Arnstein 1969). The concept empowerment has been linked to user participation by many (Holmstrom et al. 2010;Rose 2003;Wait et al. 2006). The concept of empowerment originated as a reaction to oppression in society and involves citizen power and equal rights of weak groups (Holmstrom et al. 2010), and is based on human beings as capable of making choices and being responsible for these choices (Feste et al. 1995). Empowerment is described both as a relationship between health and power (implying that empowered people are healthier), and as the user's process of becoming empowered through interacting with the health services (Holmstrom et al. 2010). Empowerment in professional practices has been described as a reflexive activity where the user gains control over his or her life and the provider work to strengthen this process (Starkey 2003). Malterud emphasise the provider's responsibility to recognise the patient's suffering, identify their strengths, and thereby contribute to empowerment (Malterud 2010). As mentioned earlier, mental health care has been described as having a particular close relationship to empowerment due to the history of power and control (Stickley 2006).

Patient education is another concept adjacent to user participation. The evolution of user participation happened in parallel with the establishment of efforts to educate patients in order to increase self management in chronic care. Holmstrøm and Røing describe that empowerment happens through interaction with health services, e.g. through health education programs for patients (Holmstrom et al. 2010). The concept of patient education has over time covered the continuum from providing basic lifestyle information to strengthening the patients' ability to manage and cope with their health problems (Hoving et al. 2010). Current descriptions of patient education encompass self-management education to help patients identify their problems and become able to make appropriate actions and decisions during chronic illness (Bodenheimer et al. 2002). Education of patients and next of kin became a mandatory task in hospitals in Norway through the Law on specialised health services (Lov om spesialisthelsetjenesten 1999) the same year as user participation became statutory.

1.7 How can user participation be defined?

We have seen that user participation is linked and adjacent to several phenomena and concepts which were part of the same evolution. User participation is thus part of a development that includes a range of concrete ways to conduct participation in health services. This leaves us with the notion that user participation is a potentially huge field which includes every possible way users interact with health services. Does this mean that every interaction between the user and the service provider is user participation? We have looked at several arguments for user participation in society and health care, but what user participation is and implies in practice is not described in these arguments. A more profound investigation of the definition of user participation is therefore necessary.

Arnstein described user participation as a hierarchy where genuine participation implies a redistribution of power (Arnstein 1969). Arnstein's ladder of participation (see figure 1, page 12) includes eight steps; Manipulation, Therapy, Informing, Consultation, Placation, Partnership, Delegated power, and Citizen control, where Manipulation represents a total lack of participation and Citizen control represents total citizen power.

In 1993 Charles and DeMaio presented an analytical framework to describe the dimensions of user participation in decision-making in health care (Charles et al. 1993) (figure 2). The three-dimensional figure includes a number of types and levels of participation. Firstly, the figure includes a perspective on the decision-making domain classifying three different types of contexts where decisions are made (macro, service, and treatment). Secondly, it includes a role perspective classifying two different roles that individuals can bring into the decision-making contexts; the perspective of the individual health service user and the public policy perspective. Thirdly, the figure includes a perspective on different levels of participation (dominant, partnership, and consultation). The authors described this matrix as an analytic tool for conceptualising key dimensions of user participation in health care decision-making. They also emphasised that the concept of user participation have multiple meanings.

DECISION MAKING DOMAIN

Figure 2 diagram showing a 3D cube with ROLE PERSPECTIVE (Policy, User), DECISION MAKING DOMAIN (Macro, Service, Treatment), and LEVEL OF PARTICIPATION (Dominant, Partnership, Consultation). Cells labeled F, D, B, E, C, A.
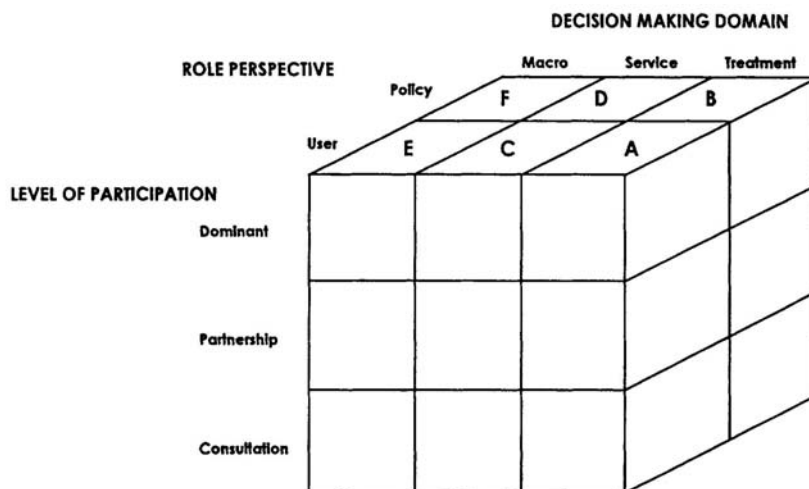
Figure 2 Dimensions of lay participation in health care decision-making (Charles et al. 1993).

Cahill has described a hierarchical relationship between different types of user participation, namely involvement/collaboration, participation, and partnership (Cahill 1996) (figure 3).

Pyramid diagram with "Patient partnership" at the top, "Patient participation" in the middle, and "Patient involvement/ collaboration" at the base.
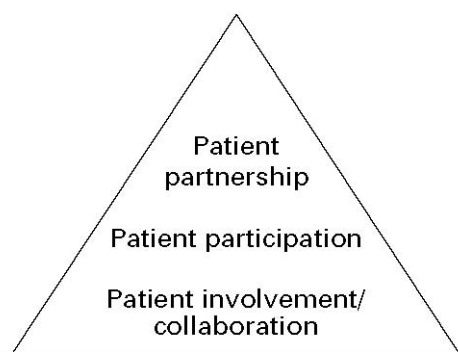
Figure 3 The hierarchical relationship between the concepts (Cahill 1996).

In the figure Cahill place patient involvement/collaboration in the base of the pyramid, as a precursor of patient participation. Participation is in turn a precursor to the top of the pyramid, patient partnership. Involvement and collaboration is described as a one-way process ignoring the patient's voice. Participation is on the other hand described as a two-way process. According to Cahill, this two-way process requires a narrowing of the competence gap between patient and provider and a surrender of some power and control

from provider to patient. Patient partnership is described as a working association and joint venture between the patient and the provider which includes commitment.

Hickey & Kipping have, among others, discussed and built on Arnstein's ladder of participation (Hickey et al. 1998). They described participation as a horisontal continuum from consumerist approach to democratisation approach (figure 4). Information and explanation sufficient to make choices are on the consumerist end while they emphasise Arnstein's focus on user control on the democratisation end of the continuum. They also reiterate Arnstein in describing user control as a redistribution of power from the provider to the user.

Information/ explanation	Consultation	Partnership	User control

Consumerist   Democratization
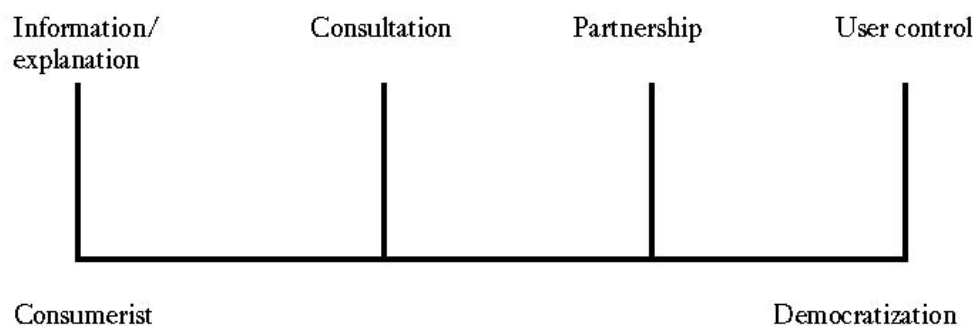
Figure 4 Hickey & Kipping's participation continuum (Hickey et al. 1998).

Tritter has argued that Arnstein's ladder does not include the complexity of user participation (Tritter 2009). Tritter & McCallum introduced the idea of an expanded model which, according to the authors, encompasses the dynamic and evolutionary nature of participation (Tritter et al. 2006) (figure 5). The conceptualisation was extended with a division into indirect and direct involvement (Tritter 2009). Indirect involvement is gathering and bringing information from service users into a decision-making process where the final decisions are made by professionals. In contrast, direct involvement means that users take actively part in the actual decision-making. In addition Tritter distinguished between participation initiatives that are aimed at individuals and those aiming at the collective. These two groups are identical to the division between participation on a system and an individual level. Tritter further divided participation into reactive and proactive, and related this to who is prompting the participation initiative. Reactive participation is thus a response to an already existing agenda in the health services while proactive participation is when users are contributing to shape the agenda (Tritter 2009).

	Direct		Indirect	
Individual	Proactive	Reactive	Proactive	Reactive
Collective	Proactive	Reactive	Proactive	Reactive

Figure 5 A model of involvement (Tritter 2009).

Thompson (Thompson 2007) combined Arnstein's (Arnstein 1969) ladder of participation with descriptions from Coulter (Coulter 1997) and Charles and colleagues (Charles et al. 1997) and described this ladder-like figure (figure 6). Thompson built on Coulter's (Coulter 1997) description of three different models for the interaction between patient and provider; the paternalistic model, the informed model, and the model where the professional is an agent. In the paternalistic model the user is a passive recipient of treatment, but the other two presuppose that the patient participates to some degree in the treatment process. In addition, Charles' and colleagues' (Charles et al. 1997) description of shared decision-making was used. Charles and colleagues described shared decision-making as an undertaking where at least two participants (user and provider) is involved, where both parties share information and both parties take steps to build a consensus about the preferred treatment, and where an agreement is reached on the treatment to implement.
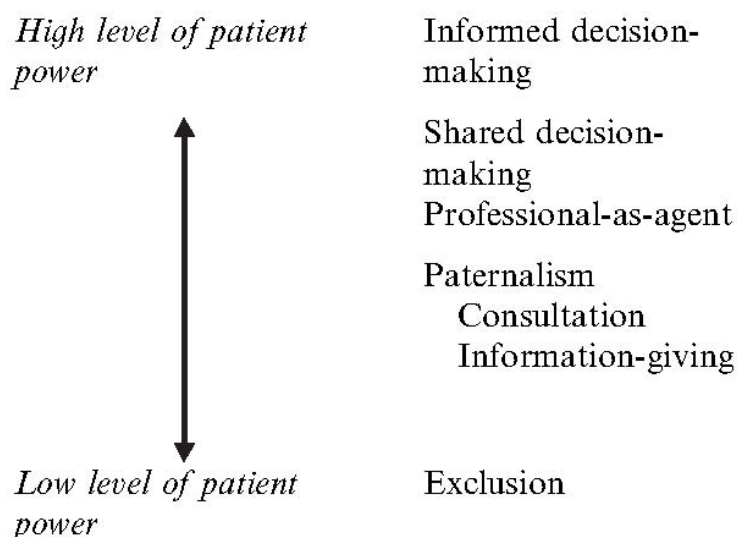
High level of patient power

Informed decision-making

Shared decision-making
Professional-as-agent

Paternalism
 Consultation
 Information-giving

Low level of patient power

Exclusion

Figure 6 (Thompson 2007).

Thompson also described a different classification of user participation (Thompson 2007). Built on the results from a large qualitative study investigating users' views and preferences regarding participation, he presented a taxonomy which encompassed a division between involvement determined by the patient and involvement determined by the professional (figure 7). Thompson's emphasised the importance of co-determined involvement, and described two aspects; dialogue and shared decision-making. According to Thompson, dialogue and shared decision-making constitute participation, which is only possible when both patient and professional wants it.

Patient-Desired Level	Patient-Determined	Co-Determined [PARTICIPATION]	Professional-Determined
4	Autonomous decision-making	Shared decision-making	Informed decision-making
3		Dialogue	Professional-as-agent
2	Information-giving		Consultation
1	Information-seeking/receptive		Information-giving
0	Non-involved		Exclusion

Figure 7 Levels of involvement (Thompson 2007).

We see that several have aimed at describing graphically the complexity and comprehensiveness of user participation. Although aspects and descriptions are similar and somewhat overlapping, they are also different. In line with this, several have stated that there exists no single definition of patient participation, and that the concept is inadequately articulated and insufficiently understood (Borg et al. 2009;Cahill 1998;Cegala et al. 2009;Longtin et al. 2010;Sahlsten et al. 2008), and that the area in general suffers from poor conceptualisation (Hickey et al. 1998;Staniszewska et al. 2008). Patient participation is thus a broad and complex concept which can include a variety of situations, including decision-making tasks (Florin et al. 2008;Longtin et al. 2010).

Pub Med's MESH database (http://www.ncbi.nlm.nih.gov/mesh) includes patient participation under the heading consumer participation. Consumer participation is defined as "community or individual involvement in the decision-making process" and was added in 1974. Patient participation is defined as "patient involvement in the decision-making

process in matters pertaining to health" (added in 1978). Others describe participation as patients' being involved in their own treatment (Cahill 1998;Florin et al. 2004), as the patients' right to be involved in decisions which affect them (Stringer et al. 2008), and as a change of the patients role from passive recipients to active participants (Happell et al. 2002). Patient participation is also described as emphasising the patient's participation and autonomy in decision-making, implementation and managing of their own care (Florin et al. 2006). Participation has also been described as ways for the public to influence the evaluation, development, organisation and delivery of health services (Tritter 2009), as an inclusive dialogue between stakeholders (Carr 2007), as involvement of the public in health service and policy decisions (Florin et al. 2004), as patients drawing on their experience (Cahill 1998;Florin et al. 2004), and as the patients' right to be involved in decisions that affect them (Hickey et al. 1998;Stringer et al. 2008).

These definitions vary considerably; some have a broad outlook and encompass the total area of participation, while others focus on specific parts i.e. of interactions. Some have the users' perspective, and others have the providers' point of view. Although the current definitions on user participation are somewhat overlapping and congruent they give an over all impression of a broad, many-sided, complex, and rather blurred area.

If we look more closely on the basis for the various definitions of user participation, few of them are grounded in the perceptions of those who are supposed to be a part of the participation process; health service users and providers. Many definitions are based on ideologies and on theories on development in society in general and health services in particular. Most definitions are not based on the actors' perceptions of what user participation is and implies. Some studies have investigated how health personnel perceive and experience patient participation (Frank et al. 2009;Sahlsten et al. 2005;Sahlsten et al. 2007), and some have investigated the patients' view (Eldh et al. 2004;Larsson et al. 2007;Sainio et al. 2001). Few smaller studies have investigated and compared how patients and health personnel experience the participation process in specific health care settings; i.e. during post-hospital rehabilitation (Lund et al. 2001), in a nursing home (Tutton 2005), and in a chronic heart failure clinic (Eldh et al. 2006). When searching relevant data bases and literature no studies that have compared and synthesised patients' and health personnel's perception of the concept of patient participation were found. There is thus a lack of definitions that are derived from and based on the perceptions and experiences of the actors

in the participation process, and which is connected to clinical practice. This lack indicated a gap between the theory of user participation and the practical performance of user participation in the clinic.

1.8 Different methods of user participation

We have seen that there exist many well founded, yet different, definitions of participation; some focusing on the system level, some on the individual level, and some encompassing both. Similarly, there are many ways to conduct user participation; in different contexts, including various actors, and with different goals.

1.8.1 Methods on the system level

User participation on a system level is commonly described as initiatives where users participate as representatives on behalf of a larger group of users. Methods described in the literature are; providing information to the public, obtaining feedback from users on quality of services or government proposals (through surveys or public meetings and debates), and involving users more actively in work processes; either as consultants, as partners, or as the decision-makers (Coulter et al. 2006). Including users in research projects; in planning, data collection, analysis, and/or the publication process is also defined as user participation on the system level (Gillard et al. 2010;Trivedi et al. 2002). Nilsen and colleagues have described user participation on a system level as ways of involving user representatives to inform or participate in decisions about health care policy and research, and to work out clinical practice guidelines and information material for patients (Nilsen et al. 2010). Simpson and House have described it as all ways of involving users in the delivery and evaluation of services; users involved as case managers, as client advocates in case management, as peer counsellors or specialists, as trainers, and as interviewers in research (Simpson et al. 2002). Crawford and colleagues described methods where patients, patient representatives, or the public were involved as active participants in planning, monitoring, and developing health services (Crawford et al. 2002). User participation on a system level thus includes multiple ways to involve service users in designing, delivering, and evaluating health services.

There are several examples on user participation initiatives on a system level. Andreassen undertook a qualitative study of a developmental project in mental health care intended to

motivate health services to listen to users' experiences (Andreassen 2009). User perspectives were collected and provided to the health services through regularly reports, and these reports were subsequently discussed in meetings. The feedback from users led to professionals becoming more perceptive towards user perspectives, and some practices were changed. The perspectives on mental health patients and the treatment ideology were however not so susceptible to influence.

Nathan and colleagues described a community participation program in Australia where users, carers, and the public was involved in planning, delivery, and evaluation of health services (Nathan et al. 2011). User participants received information before they were involved in a committee, and were matched with a professional participating in the same committee. Professionals received training, and were encouraged to consider why a user representative was wanted, and what the involvement was meant to include. The authors investigated the professionals' experience on the user role through a survey. They found a majority of positive attitudes among the professionals who emphasised possible influence on strategic planning, prioritising, delivery of services, and patient information.

Perreault and colleagues described a service user panel in a mental health university institute in Montreal, Canada during a five years period (Perreault et al. 2010). The panel consisted of decision-makers and outpatient service users who had meetings four times per year to discuss how to improve the quality of services provided by the institute. The authors investigated qualitatively the participants' experiences of the impact of the panel on the services. Both users and provides described a respectful and egalitarian atmosphere in the meetings. The panel had discussed important subjects such as patient information, patient experience, services changes, ethics, stigmatisation, and recruitment.

These examples illustrate some of the initiatives that are made in health care services to involve users on a system level.

1.8.2 Methods on the individual level

While methods of user participation on a system level are quite manageable to describe, user participation on the individual level takes on many forms. It is therefore especially challenging to limit the area. Is every encounter between a conscious patient and a health

professional user participation? Or is there a crossing point between what user participation is and what is basic and necessary interaction between user and provider for any treatment process to take place? Individual user participation potentially includes a multitude of efforts which aim at providing treatment, adding treatment effect and adding therapeutic value. Therefore, many efforts which are not initially defined as user participation might be classified as initiatives which increase participation.

User participation on the individual level takes place in the interaction between the health service user and the provider, and focuses on the health care of individual patients. These interactions mainly take place in out-patient treatment sessions or in interactions between user and provider during in-patient treatment. Haywood and colleagues have described individual user participation as interactions between a patient and a provider where the patient is active in providing information to improve diagnosis and problem solving, shares his or her preferences, asks questions, participates in shared decision-making, and contributes to find the treatment approach which meets the priorities of the patient (Haywood et al. 2006). When reviewing such interventions, Haywood and colleagues classified them as either patient-targeted or provider-targeted. Patient-targeted interventions found was checklists, educational materials, coaching, goal setting, group education, patient-held records, patient-reported outcome measures, questionnaires, and interventions to clarify the patient's values. Provider-targeted interventions included educational materials, prompt lists, and training.

Auerbach investigated and synthesised interventions targeting the relationship between patient and physician specifically (Auerbach 2009). Auerbach's study included interventions designed to improve the communication skills of health care providers, patient-targeted interventions designed to improve the communication process, and interventions targeting both user and provider. Provider-targeted interventions included different sources of information and training to improve communication. Patient-targeted interventions aimed at enhancing user participation through providing information, encouragement, prompt-lists, training, and sessions to clarify the patients' values. Intervention targeting both user and provider included training and activation, and the development of agreement contracts between the parties.

Patient feedback during treatment

Many have emphasised the relationship between patient and health service provider as a core aspect of individual user participation (Cahill 1996;Coulter A 2002;Stewart et al. 2000;Tritter et al. 2010). In mental health care the relationship between user and provider has been described as vital since psychotherapy is based on communicative and relational processes (Gelso et al. 1994;Martin et al. 2000;Rogers et al. 1993). Gilburt and colleagues showed that treatment experience in in-patient mental health care was closely related to the experiences of personal encounters (Gilburt et al. 2008). They described several important aspects of the relationships with providers; communication, coercion, safety, trust, and culture.

We have previously seen that the use of patient-reported outcome measures as feedback to providers has been described as individual user participation (Haywood et al. 2006). Using patient reported outcome measures is widespread in health services to assess the impact various services have on patients (Dawson et al. 2010). The results from such outcome measures are analysed by the health services and used to evaluate over all outcomes, and to improve treatment, information, and communication on a system level. The results are however rarely discussed with the patient during treatment to obtain information on the patient's perspective on what should be changed to improve outcome. Most definitions of user participation described in this introduction encompass a focus on the patient's view, the patient's influence on the treatment process, and the patient's influence on the decision-making process. Asking for concrete feedback from patients emphasises the patient's perspective on what is considered as good outcome and a good treatment approach. The focus thus shifts from whether a treatment works in general to whether this specific treatment approach works for this specific patient (Howard et al. 1996). This shift potentially invites the patient to participate in the evaluation of the treatment approach, and provides opportunities for the patient to participate in the decision-making on what to do next. Provided that the patient's perspective is actively used in the decision-making process, systems for assessing feedback can be considered individual user participation.

Active assessment, monitoring, and discussion of feedback from patients have been advocated as a means to detect lack of change during the treatment process, to prevent drop-out, and to enhance treatment outcome (Miller et al. 2005). Extensive instruments to assess feedback from patients in mental health care have been developed and used, i.e. the

Outcome Questionnaire-45 (OQ-45) (Lambert et al. 1996). To make feedback less
demanding for users and providers very brief instruments have also been developed; i.e. the
Partners for change outcome measurement system (PCOMS) (Miller et al. 2005). (The
PCOMS are described in detail in Paper 4.)

The PCOMS was developed in the United States, and is considered "best practice" in mental
health services in the state Arizona (Tuseth 2007). Since the 1990s the use of the PCOMS in
the Norwegian health and welfare services has increased (Sundet 2010;Tuseth et al.
2006;Tuseth 2007). The scales are currently used in a variety of services, including mental
health care for adults (Tuseth et al. 2006). Web sites providing the PCOMS scales,
information on how to use the scales, and research literature are currently accessible both in
English (http://heartandsoulofchange.com/) and in Norwegian (http://r-
bup.no/CMS/cmspublish.nsf/doc/475663A0E7F0A19DC12570870041C3DE).

1.9 The effect of user participation

We have seen that there are many methods of user participation, both on a system and
individual level. In the following the current knowledge on the effects of these initiatives is
described.

1.9.1 Effect of user participation on the system level

Crawford and colleagues conducted a systematic review on studies, published from 1996 to
2000, investigating participation in health care in general (Crawford et al. 2002). They
concluded that although patients have participated in planning, monitoring, and developing
health services in a range of settings, the effect of such initiatives is still unknown. Nilsen
and colleagues conducted a Cochrane review and concluded similarly (Nilsen et al. 2010).
They found little comparative research on the best way to involve users at a system level in
health care. They included six randomised controlled trials. Two of the trials investigated
the effect of involving consumers in the development of information material (Aabakken et
al. 1997;Chumbley et al. 2002). These two studies found moderate quality evidence (quality
assessment due to the Cochrane EPOC Group) that such material is more relevant, readable,
and understandable to patients, and lead to improvement of patients' knowledge. Two trials
(Clark et al. 1999;Polowczyk et al. 1993) investigated whether involving consumers as
interviewers in research interviews had any effect on patient satisfaction, the amount of

negative and positive feedback from participants, or the reported level of patient satisfaction with care. These studies found low quality evidence that consumer interviewers can have a small influence on the findings.

The last two trials in the review investigated the effect of involving consumers in developing a consent form (Guarino et al. 2006), and the effect of involving users in advisory health policy discussions (Abelson et al. 2003). Guarino and colleagues' study found little or no effect of the involvement on the research participants' understanding of the study, satisfaction with participation, adherence to research protocol, or refusal to participate. Abelson and colleagues found stronger engagement in consumers participating in deliberative health policy discussions, but the evidence had very low quality (Abelson et al. 2003). Nilsen and colleagues' thus concluded that there is little evidence from randomised controlled trials on the effect of user participation on a system level (Nilsen et al. 2010). Although only randomised trials were included in this review, the findings indicate that effect studies on user participation on a system level are few and that the current evidence-base is poor. A new review on consumer participation in health care confirmed earlier findings; that although may initiatives were found, the success rate of user participation projects in various areas of health care was moderate (Tempfer et al. 2011).

Simpson and House conducted a systematic review on user participation on the system level in mental health care specifically, and included 12 controlled trials (Simpson et al. 2002). Two of the studies were also included in Nilsen and colleagues' review (Clark et al. 1999;Polowczyk et al. 1993). Eight of the studies investigated the effect of involving users as service providers, mainly as case managers (engaging the patients and coordinate and maintain effective services) (Chinman et al. 2000;Chinman et al. 2001;Felton et al. 1995;Klein et al. 1998;Lyons et al. 1996;O'Donnell et al. 1999;Paulson et al. 1999;Solomon et al. 1995). These interventions had effect on the service delivery; user employees spent more time in supervision (Paulson et al. 1999), in direct contact with patients (Solomon et al. 1995), doing outreach work, and less time on the telephone and office work (Solomon et al. 1995). In addition user employed as case managers had more indistinct professional boundaries and the turnover was higher. Some of these trials showed improved quality of life in patients (Felton et al. 1995;Klein et al. 1998), fewer life problems (Felton et al. 1995), improved social functioning (Klein et al. 1998), and burdened their family less (O'Donnell

et al. 1999). There were some effects on use of hospitalisation (Klein et al. 1998;Paulson et al. 1999).

Two studies in Simpson and House's review investigated the effect of involving users as trainers or educators for providers (Cook et al. 1995;Wood et al. 1999). Such involvement improved the providers' attitudes towards mentally ill and towards mental illness in general. Simpson and House concluded that user participation on a system level in mental health care is not harmful to the patients, and that such participation is feasible. They emphasised the lack of good methodological research on the user participation on the system level in mental health care. This conclusion is in line with Nilsen and colleagues' review (Nilsen et al. 2010). All interventions described in the two reviews were implemented in specific areas of health services. Neither found any studies investigating user participation initiatives implemented in a whole health service organisation. This indicates a lack of studies on the effect of more comprehensive user participation initiatives in large health service organisations.

1.9.2 Effect of user participation on the individual level

Haywood and colleagues reviewed studies on the effect of individual user participation interventions in health care (Haywood et al. 2006). In 28 % of the studies patient-reported outcome measures were implemented. Some of these studies investigated the use of such outcome measures on provider diagnosis and management, while others investigated the effect on communication. 52 % of the studies investigating the effect on provider diagnosis and management showed improvement. 4 of the 5 studies investigating the effect on communication showed positive results. Evidence was nevertheless considered insufficient to advocate specific approaches. In the conclusion Haywood and colleagues emphasised the importance of more rigorous research designs with more specified interventions and outcomes.

As earlier mentioned, Auerbach published an overview of seven major reviews on interventions targeting specifically the relationship between patient and provider (Auerbach 2009). He included Haywood and colleagues' review in his synthesis (Haywood et al. 2006). In his synthesis Auerbach found that provider-targeted interventions had positive effect on providers' communication and inter-personal skills. Similarly, patient-targeted

interventions improved the communication between patient and provider, and led to more user participation in decision-making. He found however only moderate effect of interventions on patient satisfaction, and little effect on primary medical outcomes. Auerbach's overview shows that although many interventions are used and some effects are found, the knowledge base does not permit a clear conclusion regarding the effect of individual user participation in general.

There is a growing knowledge base on the effect of use of feedback instruments in clinical practice. Patient-reported outcomes scored on the feedback instruments are not just collected, but are used actively during treatment to discuss outcome and further treatment approach with the patient. A meta-analysis of studies on the effect of the feedback systems Outcome Questionnaire-45 (OQ-45) (Lambert et al. 1996) and the Partners for change outcome measurement system (PCOMS) (Miller et al. 2005) combined showed that patients who experienced little progress during treatment were detected through the use of the systems and obtained better treatment outcomes than patients where feedback was not assessed (Lambert et al. 2011). Four randomised controlled trials have investigated the effect of using the PCOMS scales specifically (Lambert et al. 2011). These trials have investigated effects in mental health treatment (Reese et al. 2009a), in couple therapy (Anker et al. 2009;Reese et al. 2010), and in training and supervision of psychology students (Reese et al. 2009b). All four trials have used the Outcome Rating Scale (ORS) score (Miller et al. 2005) as the main or only outcome measure. In all four studies the results showed that using the PCOMS scales during treatment led to greater improvement in ORS scores than treatment without using the PCOMS. Three of the studies were conducted in the United States, only one of them in mental health treatment (Reese et al. 2009a). The knowledge base on effect of using the PCOMS in individual mental health treatment is therefore scarce. Since the use of the PCOMS is growing in Norwegian health and welfare services (Tuseth et al. 2006), more research on the effect of use is important. Investigating effect of the PCOMS using other outcome measures than the ORS scale (which is a part of the intervention) would also be important to investigate whether using the PCOMS influences broader health outcomes.

2. Aims of thesis and studies

The main aim of this thesis is to contribute to lift the veil from user participation in clinical work; what does user participation mean and imply, and what are the effects of concrete user participation initiatives?

The operational aims of the studies included in this thesis are;
- To explore how health service users and providers define user participation.
- To explore service users' and providers' view on user participation in mental health services.
- To study how implementing a development plan to enhance user participation in a mental health hospital affects professionals' knowledge, practice, and attitudes.
- To investigate the short-term effect on treatment alliance and patient satisfaction from using the PCOMS scales in out-patient mental health treatment compared to treatment without using feedback scales.

  Hypothesis 1: The PCOMS group has higher scores on treatment alliance than the treatment as usual group six weeks after starting treatment.

  Hypothesis 2: The PCOMS group has higher scores on patient satisfaction than the treatment as usual group six weeks after starting treatment.

3. Methods

This thesis includes four papers where three different methodological approaches are used; two qualitative interview studies (Paper 1 and 2), one quasi-experimental study (Paper 3), and one randomised controlled trial (Paper 4).

3.1 Background

This thesis is built on a research project conducted mainly in a mental health hospital in Central Norway (Nidaros regional psychiatric centre), in this thesis named the intervention hospital. The hospital was reorganised and relocated in January 2009. Several units were merged and co-localised, and an ambulatory acute treatment team was established. The reorganisation was based on an over-arching plan focusing on professional development and improvement of collaboration and patient flow, and user participation was a main focus in the plan. During the planning process of the reorganisation a development plan to enhance user participation was suggested and drawn up by the hospital. The implementation of this development plan became one part of the reorganisation process. This provided a unique opportunity to study various aspects of user participation in a mental health care setting.

3.2 Study settings

Norwegian health care is organised in four health authorities who each own several local hospitals. All service users and providers in the four studies were part of the Central Norway Regional Health Authority. The Central Norway Regional Health Authority encompasses three hospital trusts. One of them is St. Olav's Hospital Trust. St. Olav's encompasses the three mental health hospitals (regional psychiatric centres) where the four studies took place. In study 1 users and providers outside the mental health hospitals, but inside the Central Norway Regional Health Authority, were included.

The main setting for all four studies was the mental health hospital where the development plan was implemented (intervention hospital). This hospital is one of three regional psychiatric centres in St. Olav's Hospital Trust in Central Norway. It covers a catchment area of 96.000 persons, with urban and semi rural areas including parts of a large Norwegian city. The other two mental health hospitals cover catchment areas of 74.000 and 47.000 persons respectively, with urban, semi rural and rural areas including parts of the above-

mentioned city. The three hospitals provide the same types of service; in-patient treatment (5.4 beds per 10.000 inhabitants), out-patient treatment, and ambulatory services.

3.3 Methodological choices

Three methodological approaches were used to ensure the breadth and depth that the four operational aims required.

3.3.1 Qualitative studies

To explore users' and providers' experiences and attitudes in study 1 and 2 a qualitative approach and semi-structured interviews was chosen. Qualitative methods are recommended to explore experiences and attitudes in depth (Kvale et al. 2008) and described as useful when studying the human experience of communication, meaning, attitudes, and processes (Malterud 2001b). The general aim of qualitative studies is to investigate the meaning of phenomena as they are experienced by people themselves (Malterud 2001b). Since qualitative methods are more appropriate for understanding than for explanations, and suitable for investigating contextual issues (Malterud 2001b), we found this approach appropriate for exploring service users' and providers' perceptions and experiences.

Study 1 and 2 share a large part of the data and some of the participants thus participated in both studies. The analysis processes were however separate for the studies and the final results were presented in two different papers. I have therefore chosen to describe this as two separate studies throughout this thesis.

3.3.2 Quasi-experimental study

The aim in study 3 was to investigate the effect of a development plan on professionals. When investigating effect it is appropriate to choose an experimental design; a study which includes a deliberate influence (intervention) and an investigation of the effect of this intervention (Altman 1991). In contrary to an observational study, an experimental study includes one or several control groups to make comparison possible and allow for stronger inferences from the results. Since user participation is a phenomenon which has been evolving for many years, a change in professionals' knowledge, practice, and attitudes could be expected due to normal change. We therefore chose a controlled experimental design,

sometimes called a quasi-experimental design. A controlled experimental study (quasi-experimental) includes, in addition to the intervention group, one or several control groups (Altman 1991), and we therefore included two similar mental health hospitals in the same hospital trust as controls. This design would help ensure that any differences between the intervention group and the control group were due to the intervention. The development plan (intervention) was part of an extensive re-organisational process, and was developed and implemented by the hospital. It was thus not possible to choose a randomised controlled trial and allocate the hospitals randomly to intervention or control.

3.3.3 Randomised controlled trial

In study 4 the aim was to investigate the effect of an intervention (the Partners for Change Outcome Management System (PCOMS) (Miller et al. 2005)) on service users (patients). (A thorough description of the PCOMS can be found in the introduction and in Paper 4.) Although the PCOMS was a part of the hospital's development plan, the implementation had not started before we designed the study. It was therefore possible to choose a randomised controlled design to investigate the effect of the intervention compared to a control group. Random allocation is a fundamental principle in experimental design, and randomisation is preferred because it prevents bias (Altman 1991). We intended to compare a patient group where the PCOMS are used with a group where it is not used, and have to be sure that the groups not differ in any systematic way. Randomisation ensures this. In addition, randomisation implies that the groups are comparable in the same way as other random samples, and we can therefore make inferences from the results. Since this was a randomised controlled trial conducted in a natural setting it was not possible to conduct any blinding procedures.

3.4 Participants

Paper 1 and 2 included health care users and providers in both the in-patient and out-patient units. In paper 1 we also (at the final stage of analysis) included data from somatic and mental health services in the same regional health authority to investigate whether the findings were supported. The study described in paper 3 included a large sample of professionals at the intervention hospital which formed an intervention group. Professionals at two other similar mental health hospitals in the same hospital trust (control hospital 1 and 2) constituted the control group. Paper 3 thus included professionals at all mental health

hospitals (regional psychiatric centres) in the same hospital trust. The study described in paper 4 took place in the three out-patient units at the intervention hospital, and included 75 patients seeking health care for various mental health problems. The different parts and types of the health care services and participants included in the thesis as a whole are described in the figure below (figure 8).
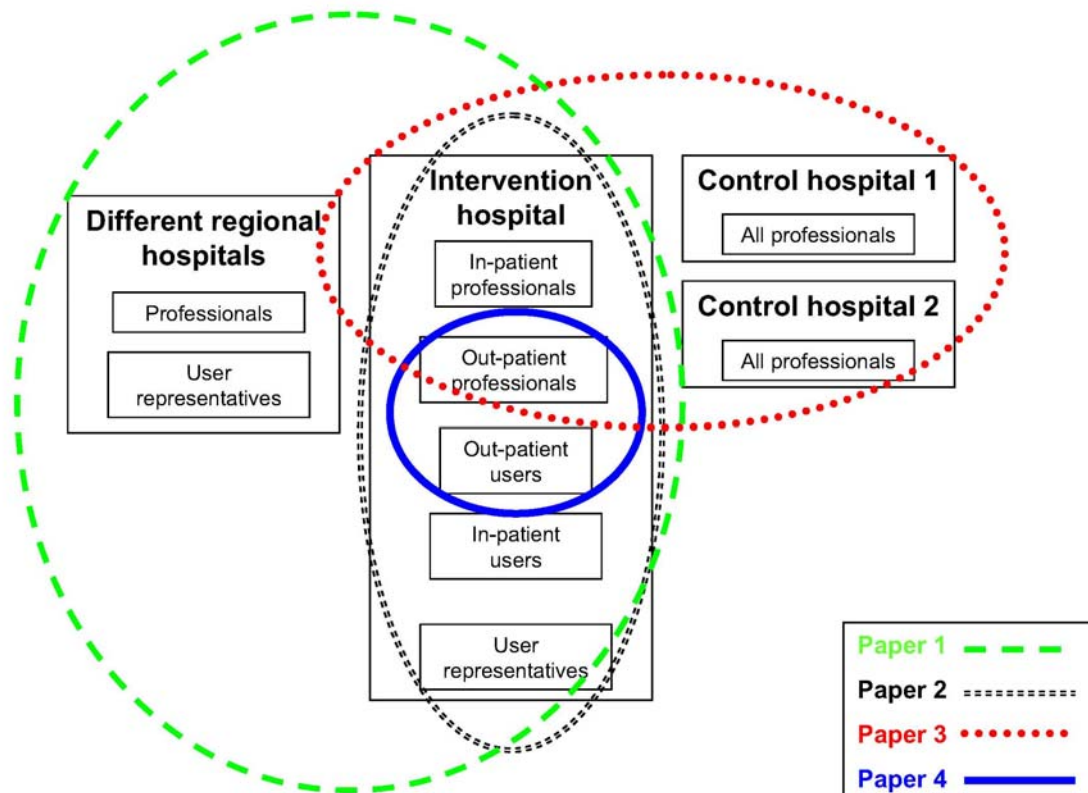
Figure 8 Settings and participants in Paper 1-4.

The circles encompass the setting and sample in the four studies; the green (far left) the qualitative study presented in paper 1, the black (largest in the middle) the qualitative study presented in paper 2, the red (far right) the quasi-experimental study presented in paper 3 and the blue (small in the middle) the randomised controlled trial presented in paper 4.

3.5 Recruitment

In study 1 and 2 most patients were recruited through answering an invitation letter sent out to 60 service users who had previously answered a questionnaire about user participation. In addition, some patients volunteered responding to a note we had posted in the in-patient

units at the intervention hospital. User representatives were known by the intervention hospital or the hospital trust, and were asked directly by the researchers whether they wanted to participate. User participants were recruited to ensure a sample with experience from various departments and different types of participation. Professionals were also asked directly by the researchers. In study 1 some professionals were identified by the hospital administration and others were identified by professionals or user representatives participating in initial interviews.

In study 3 professionals received an invitation letter and a questionnaire mailed to all registered employees at the mental health hospitals who had received salary the previous month. Employee lists were provided by the administrational offices at the hospitals.

In study 4 an invitation letter was sent to all eligible users together with a letter from the intervention hospital. One week after the letter was sent a nurse at the intervention hospital or the main researcher (MBR) phoned the users to invite them to participate in the trial. Those who accepted were invited to a meeting with the main researcher. At the meeting information was given, a written consent was signed, and the baseline questionnaire answered. The professionals providing the intervention volunteered to participate after receiving an invitation. The professionals who provided the treatment as usual volunteered or were requested to participate by the unit managers.

3.6 Data collection

In the qualitative studies data were collected through semi-structured interviews (individually and in focus groups). Interviews were conducted according to a preset topic guide to ensure that all aspects of interest were covered, but participants were also encouraged to talk about other topics if they wanted. Interviews were tape recorded and transcribed, and the transcriptions were used in the analyses. The data material collected at the intervention hospital was used in both study 1 and 2. In study 1 data from somatic and mental health service users and providers both inside and outside St. Olav's Hospital Trust was added. This data material was added in the final stage of the analysis to test the findings (see further details in paper 1). The data used in both study 1 and 2 was collected between January and June 2009. The data added to study 1 was collected between June 2007 and September 2008.

To collect data for study 3 we used a questionnaire which was mailed privately to all registered employees at the intervention hospital and the two control hospitals. An identical questionnaire was sent to all employees after a period of 16 months. The data collection for study 3 was done between December 2008 and April 2010. In study 4 all participants answered a questionnaire two times; before randomisation and six weeks after treatment started. Data for study 4 was collected between February 2010 and March 2011.

The data collection for the thesis as a whole took place from June 2007 and March 2011.

3.7 Data analysis

Grounded theory (Corbin et al. 2008) was used in the two qualitative studies, study 1 and 2. According to this approach, data collection and analysis was done in parallel, and memo writing was conducted during the process. Through discussions in a research group data was coded, categories were developed and refined, the categories were merged into larger themes, and these themes were discussed until the results were clear. Categories and themes were validated through constant comparison with the transcripts. Analysis of data was mainly conducted in a group with researchers with different educational backgrounds and clinical experience.

Data from the quasi-experimental study (study 3) was analysed using several statistical methods. Pearson's chi square was used to identify any differences in proportions within the intervention group and the control group at the two points of measurement. Binary logistic regression was used to analyse changes from baseline to 16 months in the intervention hospital and the control hospitals respectively. Demographic variables with trends for difference ($p<0.1$) within each group (intervention group; number of years worked at the unit - control group; category of patients working with) were added to the time of measurement variable in the regression model. A test of proportion (Altman et al. 2003) was used to calculate ratio odds ratio (ROR) to compare the changes (odds ratio) in the intervention group with the changes (odds ratio) in the control group. This test allows us to compare two estimates (in this case odds ratios) of the same quantity in two independent samples. A ratio odds ratio tells us whether there are any differences between the changes in two different groups.

In the randomised controlled trial (study 4) data was analysed using both intention to treat and per protocol analyses. Between-group differences for outcomes where no baseline values existed were analysed using two-tailed independent t-tests. Between-group differences for the other outcomes were analysed using analyses of covariance with the baseline value as a covariate. Within-group differences (from baseline to six weeks) were calculated using two-tailed paired t-tests.

3.8 Ethics

All four studies were approved of by the regional committee for medical and health research ethics in Central Norway, the Norwegian Data Inspectorate, and the hospitals' management. In study 1, 2, and 4 all participants received information about the study, and gave a written consent before participation. All participants were informed about their right to withdraw from the study at any time. One of the professionals participating in study 1 waived to sign a consent form, arguing it was part of his job to participate in the interview. Since no professionals provided sensitive information about themselves, this professional was not excluded from the study. In study 3 professionals accepted to participate by answering and returning the anonymous questionnaire. In all studies mail lists were kept separate from the data and deleted after data collection was concluded.

Protecting the health service users who participated in these studies was very important. Due to ethical considerations we were not able to contact current service users (patients) directly, and had to limit the sample to those who volunteered. Users of mental health services have different degrees of problems, and we made efforts to ensure that all participants felt safe and not forced to participate or answer all questions. Although all participants were competent to give consent to participate, extra care was taken to ensure that participants were comfortable with the interview situation. Interviews were conducted at a place of their choice, either in their homes, at the hospital, or in the researchers' offices. Although no participants were excluded due to poor illness phases, appointments were altered when participants indicated that they were in doubt about completing the interview. Extra care was also taken to make all information anonymous. Personal and detectable information was not registered in the data files (interview transcripts or statistical files), but

kept safe and separate from the data. Users participating in the studies were also anonym in the presentation of quotes in the qualitative papers.

4. Summary of main results and conclusions in the studies

Figure 9 displays the final samples in the four studies including the services involved:
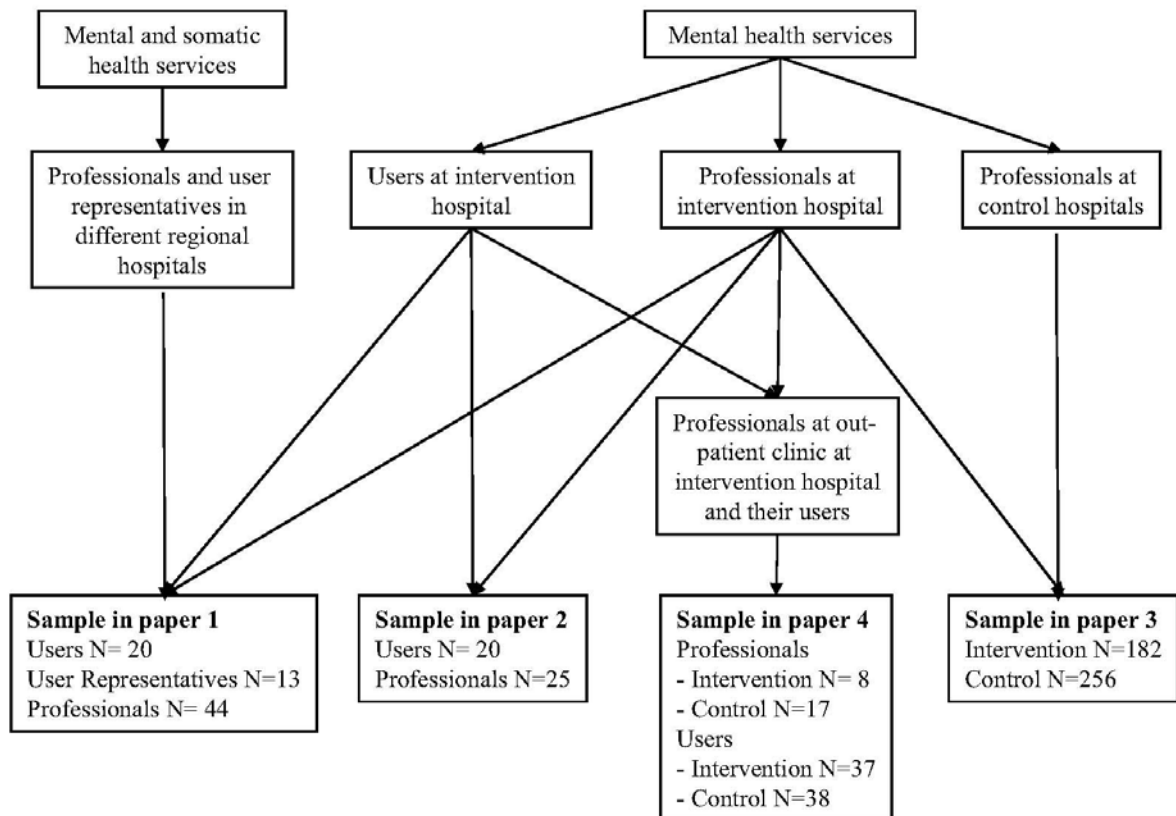
Figure 9 Description of samples in all 4 papers.

The main results and conclusions from all four study aims are described in the following section.

Aim 1: To explore how health service users and providers define user participation.

A total of 20 patients, 13 public representatives and 44 health service providers/managers in both somatic and mental health care were interviewed in the qualitative study. The main result was a definition on user participation. According to the users and providers, user participation is founded on mutual respect, carried out through dialogue aiming at achieving shared decision making. This definition was shared by users and providers. Nevertheless, users and providers assigned different values to the core aspects: Respect was imperative for

service users and implied for providers, dialogue was a way to gain respect for service users and to achieve good outcome for providers, and both worried that the other party wanted to make sole decisions. Users and providers need to consider that although they have a common definition of user participation in health care, they assign different values to its different aspects. Increasing and improving user participation therefore requires knowledge on and dialogue between the parties about these differences.

Aim 2: To explore service users' and providers' view on user participation in mental health services.

A total of 20 patients and 25 health professionals in mental health care participated in the qualitative study. Both users and professionals perceived poor illness phases as an obstacle towards user participation. Poor illness phases were characterised as phases where the patient had lack of insight, lack of verbal abilities and difficulty in cooperating. During poor illness phases, patient participation was redefined by both users and professionals. Such phases lead to a shift in responsibility where professionals took charge through strategies of providing information, motivating patients, and reducing the amount of choices. Respect and dignity for the patients were maintained and not redefined. Patient participation was redefined and weighed against what was perceived to be the patient's best interest.

Aim 3: To study how implementing a development plan to enhance user participation in a mental health hospital affects professionals' knowledge, practice, and attitudes.

A total of 438 professional participated (55 % response rate) in the quasi-experimental study. 277 participated in the intervention group and 256 participated in the control group. The plan included several initiatives intended to enhance user participation in the hospital. The implementation of the development plan had no measurable effect on the professionals' knowledge, practice, or attitudes at the intervention hospital, compared to the control hospitals. The lack of effect can be due to the quality of the development plan, the implementation process, and/or the suitability of the outcome measures

Aim 4: To investigate the short-term effect on treatment alliance and patient satisfaction from using the PCOMS scales in out-patient mental health treatment compared to treatment without using feedback scales.

Seventy-five patients participated in the randomised controlled trial investigating the effect of using the Partners of Change Outcome Measurement System (PCOMS) in addition to usual treatment in out-patient treatment sessions six weeks after starting treatment. 36 patients participated in the intervention group and 37 participated in the control group. The hypotheses were higher scores on treatment alliance and patient satisfaction in the intervention group. Results showed no significant differences at a 0.05 level between the groups on neither treatment alliance nor patient satisfaction six weeks after the treatment started. The intervention group had significantly stronger motivation for treatment than the control group, and the per protocol analyses showed higher effect sizes than the intention to treat analyses on alliance and satisfaction.

5. Discussion of methods

5.1 Four papers and three different methods

This thesis includes four study aims where three different methods were used for data collection and analysis. Qualitative methods were used to investigate users' and providers' perceptions and experiences in study 1 and 2, and quantitative methods were used to investigate the effect of interventions intended to enhance user participation in study 3 and 4. Using several methods when investigating a research area is considered as strength since it allows for a broad approach in the investigations. Combining qualitative and quantitative approaches is recommended to reduce the weaknesses of each approach (Malterud 2001b). Although qualitative and quantitative methods have not been combined in the same study, different approaches provide a more comprehensive picture. In addition it widens the scope and thereby allows for more comprehensive knowledge on the research area.

Several approaches can also be a limitation. The application of different approaches and methods in one thesis could lead to a superficial investigation on several subjects without going deep into the different aspects. Over all I have found the different approaches a benefit since it has provided a broader understanding of user participation. Combining qualitative and quantitative approaches allowed for a more comprehensive understanding of statistical data, and added information about interventions, implementation processes, and outcome measures. It became for example evident that the core aspect respect is poorly represented in most outcome measurements, and that the decision-making process is far more complex than it is possible to interpret from most quantitative results. Similarly, the quantitative studies added sobriety to the complex phenomena described in the qualitative findings, and emphasised the importance of and challenges in transferring and "translating" qualitative findings into measurable units.

5.2 The qualitative studies – reflexivity, transferability, and interpretation

Paper 1 and 2 in this thesis describe qualitative studies on user participation. The aims of both studies were to explore perceptions and experiences, an approach common for qualitative studies (Malterud 2001b). Qualitative studies are described as useful when

studying the human experience of e.g. communication, meaning, attitudes, and processes (Malterud 2001b), and is thus appropriate for the aims in these two studies. The topic guides used for interviewing in study 1 and 2 (Appendix 1) included several open questions to let the participants talk as freely as possible without loosing any of the important topics we wanted to investigate. The interviews had to be adjusted to some users who had trouble with concentration. In such cases we asked more questions which were less open, and the interviews became shorter.

Qualitative methods have been described as susceptible to the effect of the researcher (Malterud 2001a). The researchers' background and point of view are important influences in qualitative studies. Malterud emphasises three main aspects that affect research; reflexivity, transferability, and interpretation/analysis (Malterud 2001a). Reflexivity is to take the researchers' preconceptions into account by assessing the effect of the researchers on all aspects of the research process. Multiple researchers have been recommended as a method to strengthen the study design and to help ensure reflexivity (Malterud 2001a). In both study 1 and 2 the interviews were conducted by two researchers, and some of the interviews were conducted by the two researchers together. This contributed to limiting that only one researcher's preconceptions influenced the data collection, and helped ensure that the two researchers' approaches were not too dissimilar. The analysis process was conducted in a research group where a user representative participated together with other researchers who had various educational and clinical backgrounds. The research group included one medical doctor, two sociologists, one psychiatric nurse, one user participant, and one researcher with background from psychology. A broad spectre of backgrounds and preconceptions was thus represented in the group. The group discussed the diversity of backgrounds and related the findings to this during the analysis process. This helped ensure that the researchers' different preconceptions and different frames of reference were described and discussed during analysis. The mix of health professionals, user representative, and theoreticians in the group resulted in many discussions where different viewpoints were considered. The perspectives of service users, health professionals, and managers were ensured, in addition to relating the findings to more theoretical considerations.

To ensure transferability Malterud recommends that the sample should be adequate and sufficient, and that the relevance of the findings should be considered (Malterud 2001a).

The choice of sample is highly related to validity; whether the study investigates what it is supposed to (internal validity) and whether the participants in the study are representative for the appropriate contexts where the findings are relevant (external validity). Since the mental health users in study 1 and 2 volunteered to participate, a sample bias could be suggested. It could be argued that volunteers have more interest in the topic investigated, as well as less symptoms and problems. Recruiting current users (patients) any different way would however raise many ethical concerns. During recruitment in study 1 and 2 we made an effort to include as many patients with chronic illnesses as possible. The final sample of users was large and varied, and sampling was conducted until theoretical saturation (Corbin et al. 2008). Theoretical sampling ensured that all perceptions relevant for the research question have emerged before the sampling process is stopped. Whether saturation was reached in the data material was discussed several times in the research group, and this ensured that data collection was not prematurely terminated.

According to Malterud interpretation and analysis of qualitative data should be thorough, well prepared, and well documented (Malterud 2001a). The researchers' frames of reference should be described, and the research procedures should be transparent and systematic. In study 1 and 2 system and transparency were ensured by working in a group. All stages of analysis were discussed thoroughly before the results were clear. According to the grounded theory approach, the process of analysis also proceeded into the writing of the papers, and the results were refined throughout these discussions. In addition, the grounded theory approach, where analysis and sampling are done in parallel, represents a well described and often used method for data analysis. Using this approach in data collection and analysis ensured that specific and well defined procedures were used during the qualitative research process.

Including a researcher with user experience in the research group was a wise choice, and has contributed to the research process and the findings. Although this researcher did not conduct any of the interviews, her knowledge has added to the composition of the research group. In addition to offering a unique preconception and background, the presence of a researcher with user experience helped the group focus on the users' perspective and to limit technical research language in the analysis processes and in the presentation of results.

5.3 The quantitative studies – reliability and validity

In study 3 and 4 the study aims were to investigate the effect of experimental quantitative studies. To ensure the trustworthiness of these studies, the reliability and validity has to be assessed. In general reliability concerns whether what we measure is stable, and validity concerns whether we are really measuring what we intended to measure (Langdridge 2004). The most central aspects of these issues are discussed in the papers, but whether the findings can be generalised and the quality of the outcome measures are discussed here.

Whether we can generalise the findings to the real world is often called ecological validity (whether the setting is "natural"). And whether we can generalise from the study sample to a larger population is called population validity (Langdridge 2004). Study 3 included a large number of real life professionals from all three mental hospitals (regional psychiatric centres) in the St. Olav's hospital, and should therefore be representative for the total population of professionals working in similar institutions, at least in Norway. Similarly, the sample in study 4 was from a normal clinical practice, and included patients with the same diagnosis and demographic characteristics as a larger sample of eligible patients (see paper 4 for further details). In addition, the study took place in a natural setting. Study 3 and 4 were thus quite solid when it comes to generalising from the findings.

Replication of an investigation is also an important aspect of scientific approach. In study 3 and 4 we investigated quite novel research aims. Both study 3 and study 4 were the first studies investigating these particular aims using these particular outcome measures, and replication thus has to be left to further research. Both study 3 and 4 included complex interventions which are difficult to replicate accurately. We made thorough descriptions of interventions and implementations in the publications to make replication possible.

5.3.1 Outcome measurements

In both studies several outcome measures were chosen and used to assess effect. We have to consider aspects of reliability and validity when assessing the suitability of the measurements. Reliability concerns whether the chosen instrument measures something that can be reproduced and provide similar results; on different occasions, by different observers, or by similar tests (Streiner et al. 2008). There are several ways to obtain measures of reliability. Internal consistency describes whether several items in a

questionnaire in fact measure the same underlying dimension. Analyses of the baseline scores of the outcome measures used in study 4 showed a Cronbach's alpha (Streiner et al. 2008) between 0.70 and 0.95, and showed thus good internal consistency; indicating that each of these instruments measure the underlying dimension.

Reliability also concerns whether our measures are stable over time and settings. Since internal consistency just considers a single administration of the measure, tests of stability are part of the procedure when outcome measures are tested. Such tests investigate i.a. whether we would get the same result if the same persons completed the outcome twice within a short period of time (test-retest reliability). In study 3 and 4 we used some outcome measures which are quite new, and although some work is done to test the reliability of these measures, further work is warranted.

While reliability assesses that an instrument measures something which is reproducible, validity assesses whether it measures what it is supposed to. If other measures of the concept already exist administering both the new and the old instrument would assess whether the results correlate (criterion validity). If no similar instrument exist construct validity should be assessed by comparing two or more populations who we assume would score differently on the property we want to measure (Streiner et al. 2008). If we for example wanted to test a questionnaire intending to measure symptoms of mental health problems we could compare the scores from a population without mental problems to the scores of the participants in study 4. If the scores did not correlate, we could be more confident that the questionnaire was in fact measuring mental health symptoms.

Outcome measures are usually tested for reliability and validity through rigorous and systematic procedures. In study 4 we used Treatment Alliance Scale (TAS), an outcome measure which has shown strong internal consistency and test-retest reliability (Blais 2004). In study 3 we used the Consumer Participation Questionnaire (CPQ) (Kent et al. 1998). Although the CPQ has not been formally tested (Kent et al. 1998), it showed good face and content validity and was considered reasonable and appropriate (Streiner et al., 2008). Happell and colleagues have later developed and tested a modified version if the CPQ for professionals in mental health services specifically, focusing mainly on professionals' attitudes towards participation (Happell et al. 2010). For in-patient mental health settings Storm and colleagues have also developed and tested a provider-reported questionnaire

(including some of the questions from the CPQ) where the main focus, according to the article, is user participation activities (Storm et al. 2010).

6. Discussion of findings

In the following discussion I will highlight the main findings in the thesis as a whole. First I will discuss whether, in light of the findings in this thesis, user participation in mental health services is especially challenging (section 6.1). Afterwards I highlight the finding of respect as a fundament for user participation (section 6.2). I also argue that respect is an under-communicated part of user participation. Decision-making will be discussed thoroughly in section 6.3, and I will argue that decision-making is both the crux of participation and also the part where misunderstandings, limitations, negotiations, and resistance take place. Afterwards I will discuss whether the idea that patient choice is user participation does not agree with current research (section 6.4). And finally, I will discuss the evidence-base on effect of user participation in section 6.5. Three areas will be evaluated and discussed; user participation interventions (section 6.5.1), implementation processes (section 6.5.2), and outcome measures (section 6.5.3).

6.1 Is user participation in mental health care especially challenging?

As described in the introduction, mental health care has for some time been an important arena for user participation (Andreassen 2009;Tritter et al. 2010). User participation also has been described as particularly valuable in mental health services (Hickey et al. 1998;Stickley 2006). Hickey and Kipping emphasised that mental health service users can gain significant therapeutic value through participating in the decision-making process (Hickey et al. 1998). It has been found that although mental health professionals embrace the ideal that the user is an equal and competent partner, the concerns and problems voiced by the users are often attributed to their mental health problems (Andreassen 2009). Andreassen investigated user participation in both mental health services and in a rehabilitation facility for patients suffering from cognitive disabilities after brain injury. In both services former users were involved in participation processes on a system level. Andreassen found that professionals brushed off certain statements from user representatives in the mental health service, attributing them to mental health symptoms. One professional was quoted; "When you know their diagnosis, it is difficult to take all statements seriously because you identify them as symptoms." (Andreassen 2009) (page 120). However, although professionals recognised cognitive disabilities as impairment after brain injury, they did not attribute these users' views and opinions to the injury. In addition,

professionals rarely questioned their own interpretations of the mental health users' statements and appeared dominant during attempts of participation. Similarly, Rutter and colleagues found that professionals in mental health services used language that patronised and devaluated the users and their contributions (Rutter et al. 2004).

This is in line with the findings in Paper 2, where users and professionals described how poor illness phases make participation difficult, and how user participation is redefined in such phases. Mental health problems are perceived as challenging in such phases because the patients are viewed as lacking insight and verbal abilities, and as having difficulties cooperating. Impairment of rationality, described as inability to make sound and healthy decisions, has been described as one of the valid arguments for paternalism (Breeze 1998) and coercion (Woodward 1998). The findings in study 2 are in line with Hickey and Kipping's description of a participation continuum in mental health care where mental health problems could be a constraint to user participation (Hickey et al. 1998). They described mental health problems as a hindrance towards user participation since users' decision-making abilities could be influenced by the illness. They argued further that if mental health service users were perceived as continually irrational, the surroundings, e.g. professionals, would believe patients incapable of giving valid views or making sound decisions and thus hinder user participation in decision-making processes. The impact of mental illnesses on users' ability and motivation to participate has also been found previously (Anthony et al. 2000;Tambuyzer et al. 2011). Study 2 supports that, according to both users and providers, a patient's ability to make healthy and sound decisions and to act in his or her own best interest seems to be a prerequisite for user participation. This makes user participation in mental health services, both on system and individual level, especially challenging. Efforts to enhance user participation on both levels should therefore be implemented with thorough consideration of the factors which influence how users are perceived in the mental health services.

6.2 Is respect an understated aspect of user participation in clinical work?

For many users user participation implies that their perspectives are acknowledged and regarded as valuable (Andreassen 2007). My thesis is not the first to show this. Being respected is a basic human need, and users who report being treated respectfully have higher

probability for reporting a high level of satisfaction and receiving optimal preventive care (Beach et al. 2005).

Mutual respect between users and providers, and protection of the user's dignity in all situations, were vital aspects of user participation found in both study 1 and 2. In study 1 the users emphasised that respect was both a fundament in participation, and one of the main benefits from participating. Study 2 showed that respect was an aspect of user participation that was non-negotiable even during poor illness phases. No matter how ill the user might become, the professionals endeavoured to maintain respect and dignity.

However, the results in study 1 also showed that professionals viewed respect as an inherent and self-evident part of their everyday work, and it became clear that users and professionals had different emphasis on respect. This raises the question whether respect is an under-communicated aspect among providers. Providers might not be aware of the strong requirement from users to be treated respectfully. Some findings in study 4 illustrate this. Two of the items in the questionnaire were specifically focusing on respect and dignity. In the Treatment Alliance Scale (TAS, table 3, paper 4) the statement; "I feel respected by my therapist" was posed to the users. On a scale from 0 to 6 where 0 is "totally disagree" and 6 is "totally agree" only 50 % of the users scored "totally agree" six weeks after starting treatment. The same proportion of users (51.4 %) agreed totally with a similar statement in the Patient Participation scale (PP, table 3, paper 4); "I am treated with respect by my therapist and others I have contact with during my treatment." These numbers are quite low, given that professionals describe respect as an inherent and self-evident part of their work. These proportions are more in line with the users' description in study 1; that respect from professionals is not something they take for granted or always experience. It thus seems likely that the professionals understated and under-communicated respect in the clinical encounters. As emphasised in paper 1; professionals may have described respect as an inherent value due to a sincere perception of the user as an equal partner. According to the findings this is nevertheless not evident to service users. A stronger focus on this aspect in clinical work is thus warranted.

These findings are confirmed by Beach and colleagues (Beach et al. 2006). They found that patients are able to perceive when they are respected by their providers (physicians), and when they perceive it wrongly they overestimate the provider's respect. Users are thus not a

"black hole" where large amount of clearly communicated respect simply go unnoticed. Health service providers might not be aware of how much clear communication is needed for users to experience that they are respected and acknowledged. Others have also highlighted that respect and dignity are not given sufficient attention in health care (Elwyn et al. 2007). Due to a long history of stigma, this might be particularly significant in mental health care.

Several have described respect as a part of the relationship between user and provider, and as a complex concept where respect for autonomy is just one of many aspects (Beach et al. 2005;Joffe et al. 2003). Users have also emphasised communication as essential for a good relationship between user and provider (Gilburt et al. 2008). In Paper 1 the users emphasised the increase of respect from being involved in dialogue. Sundet has also showed that systematically asking for feedback from users is perceived as an invitation to communicate (Sundet 2010). He explored how users and providers in family therapy experienced using the Partners for change outcome measurement system PCOMS as a tool in treatment sessions. The results showed that the stakeholders found the PCOMS helpful for the therapy process by creating and shaping conversations and in opening for questions. The tool was not perceived as a technique but as a means to enhance dialogue and collaboration. Mol describes a "logic of care" in her book about chronic health care (Mol 2008). In Mol's description the patient is a vital and natural member of the care team, and the relationship between user and provider is emphasised. Her description is in line with the focus on open communication and collaboration found by Sundet. Study 2 showed that maintaining a dialogue between the user and the provider also was attempted in phases of poor illness, although dialogue was influenced by the perceived difficulties in verbal communication.

Respect is also linked to trust, recognition, and a personal relationship. Providers' ability to listen to users, showing empathy and personal attention seems to have universal value (Bensing et al. 2011), and being respected is one of service users' main expectations (Elwyn et al. 2007). User participation has previously been linked to the relationship between user and provider (Cahill 1996;Coulter A 2002;Stewart et al. 2000;Tritter et al. 2010). Two new studies have explored the aspects of trust, recognition, and relationship. Laugharne and colleagues found that patients with a psychosis diagnosis emphasised the personal relationship with professionals and linked this to aspects of trust and power (Laugharne et

al. 2011). In Petersen and colleagues' study users described self-determination and recognition as important aspects of user participation during mental health rehabilitation (Petersen et al. 2011). Petersen and colleagues found that recognition was linked to confidence, respect, and to feeling equal, and that recognition was closely connected to being able to decide and have influence. The relationship between users and providers and the interactions embedded in this relationship are thus important aspects which should be viewed in relation to respect.

Respect is so far an under-explored aspect of user participation, and further work might be helpful to make the most of this seemingly indisputable aspect in clinical work. Exploring ways to measure the experience of respect and acknowledgement might also be useful in further work with outcome measurements (see also section 9, Implications for clinical work and research). To help fortify service users' experience of respect professionals could work consciously to maintain a respectful attitude and communicate the importance of this aspect in the daily work. Vital questions after every interaction with a user, either on a system or an individual level, should be; "Did the user experience my behaviour as respectful?" and "Did I acknowledge the service user in this interaction?" In addition professionals should anticipate that users treat them respectfully as well, but since professionals are considered the stronger part in this dyad the professionals are responsible for constituting good examples. On an organisational level health service providers should make mutual respect and acknowledgement a hallmark of good services, and the organisation should work towards that all service users experience respect and acknowledgement in their interactions with the services.

6.3 Who should make the decisions in clinical practice?

Arnstein's ladder represents a continuum of power to make decisions – from the lowest level, where those participating are "educated" or "cured" but do not participate in decision-making, to the three highest levels where the citizen is in partnership (level 6), has delegated power (level 7), or is in full control (level 8). Responsibility for decision-making is thus increasing up the ladder (Arnstein 1969). Arnstein described the top rung as situations where citizens have the majority of the decision-making seats and thereby full managerial control. In Arnstein's model decision-making is the crux of user participation, and

transference of power means that users gain power to make decisions. The degree of decision-making power thus determines the level of participation.

Although Arnstein's ladder originally described participation on a system level I have found it highly relevant for user participation on both levels. In study 1 decision-making was found to be an area of misunderstandings where insecurity and resistance appeared. Providers were worried that user participation, both on a system and an individual level, would imply the top rung on Arnstein's ladder; full user governance. Such uncertainty threatens the professional role and the professional knowledge (Solbjor et al. 2011). Rutter and colleagues found similar professional attitudes where professionals worried that user participation could go too far; "Like the user representative could say "jump", and the services might respond "how high"?" (Rutter et al. 2004) (page 1980).

Coulter has acknowledged professionals' anxiety for being reduced from decision-makers to facilitators for patients' decision-making (Coulter A 2002). She states that it is not possible to reverse the development towards patients making decisions about their own health care in general. She underlines that patients' are likely to make what professionals would consider sound decisions and adhere to treatments when provided with good information. Coulter's argument is in line with the findings in study 1; that health service providers gained confidence in users' abilities to make sound decisions after experiencing participation in practice. Mol also supplies nuances in her book about chronic health care in general (Mol 2008). She describes emancipation of patients through legislating patients' rights as a great improvement over paternalism, but still as an ideal with many limitations. She further argues that patients' rights must diffuse into the arenas of treatment without threatening the professionals' roles.

In study 2 users and professionals describe challenges in user participation during poor illness phases. Decision-making was found to be the most negotiated and altered element of user participation during such phases. User participation was redefined, and professionals adjusted the decision-making process to the user's level of rationality. The findings in study 2 underline that decision-making is one of the most important parts of user participation, but also the most vulnerable in poor phases of illness. Although study 2 described decision-making in individual care, Andreassen has found the same negotiation of decision-making

in her study on user participation on a system level (Andreassen 2009). Decision-making seems thus to be a vulnerable part in user participation on both levels.

6.3.1 Should the user always be involved in the decision-making?

In both study 1 and 2 the results showed that shared decision-making was viewed as the main goal of user participation and that such decision-making was based on the user's and provider's shared understanding. However, the decision-making process had to be adjusted to certain limitations, such as the degree of illness and the wishes of the patient. The results in study 1 and 2 showed that it was not always crucial who made the final decision. In Paper 2 users and providers were in unison describing that professionals sometimes must and should be responsible for the final decision-making. Some users might even relinquish the final decision-making to professionals, a choice which is in line with for example the left end of Hickey and Kipping's participation continuum (Hickey et al. 1998).

The pragmatism regarding decision-making was also found among the professionals in study 3. When asked "In your opinion, should users be involved in the planning of their own treatment?" 97 % of the professionals answered "yes" at baseline. Similarly on question 19; "How would mental health services change if users were involved in the planning and/or delivery of those services?" 86 % of the professionals answered that the services would improve. These results show that professionals view the users as important partners in the decision-making process. Simultaneously they have reservations towards the notion that <u>all</u> patients could be involved in the evaluation, diagnosis and planning of treatment at <u>all</u> points during a treatment process. This is in line with the findings in Paper 2 where decision-making was altered when the users' decision-making abilities were impaired. When professionals in study 3 were asked "In most cases, where does the responsibility for deciding the goals of treatment usually lie?" nobody answered that the user should have the responsibility alone. Only 10 % answered the user should have most of the responsibility and the professional a little. 37 % answered that the responsibility should be shared 50/50, and 45 % that the professional should have most responsibility and the user a little. Only 7% answered that the professional should have all the responsibility. This shows that professionals are positive towards shared responsibility, but not ready to abdicate all responsibility for the decision-making about treatment goals.

The findings in this thesis show that neither user nor providers advocate full user government. That user participation should imply full patient government is a notion which holds no reality in the clinic, neither with the users' and professionals' perceptions described in paper 1 and 2, nor in the professionals' attitudes described in paper 3. It seems on the other hand to be vital whether the user has been respected, heard and has taken part in the process towards the decision. Investigating the users' preferences for decision-making has been emphasised by many as important to adapt the decision-making process to the clinical world (Brown et al. 2007;Epstein 2000). This is important since several have emphasised that mutual respect and open communication do not necessarily imply agreement (Bennetts et al. 2011;Mol 2008). Authors have previously argued that a strong focus on decisions is problematic and emphasises instead a good relationship between user and provider (Entwistle et al. 2010). Steihaug and colleagues found for example that when the provider expresses a basic respect for the user's experience this impacts the relationship between user and provider and allows disagreement without arising conflicts (Steihaug et al. 2011). Factors which are more important than the final decision have thus been found in previous studies.

Decision-making in user participation thus seems to go far beyond who should make the final decision. Van Audenhove and Vertommen have described a negotiation approach in psychotherapy where deliberation comes before determination, and where the perspectives of the patient and the therapist should be mutually acceptable (Van Audenhove et al. 2000). Exploring the patients' perceptions of and wishes for treatment is also an important part of patient-centred medicine (Stewart et al. 2003). Eldh and colleagues also found that interacting with professionals was more important for the users than merely partaking in the decision-making (Eldh et al. 2010). The findings in this thesis imply that decision-making is a dynamic process where respect and dialogue are important influential factors, and where all stakeholders in principle aim at shared decision-making. The findings indicate a user participation continuum where the users' abilities to communicate (and the providers' abilities to facilitate the communication) determine the degree of altering, negotiation, and limitation of the decision-making.

6.4 Patient choice: user participation misunderstood?

The connection between user participation and patient choice has been highlighted by many (Church et al. 2002;Hickey et al. 1998;Mol 2008;Tritter et al. 2010). Patient choice has been closely linked to consumerism in health care (Tritter et al. 2010). Hickey and Kipping described that the provision of choices between competing services is one of the possible methods for user participation (Hickey et al. 1998). Many have been critical towards the notion that patient choice equals user participation (Anthony et al. 2000;Hickey et al. 1998;Mol 2008;Tritter et al. 2010). The only aspect of patient choice emerging in the results in this thesis was in study 2 where limiting and simplifying choices was one of the ways user participation was redefined during poor phases of mental illness. These adjustments were done to make choices easier and more accessible for the users, and to ensure that the user made the choice that ensured the patient's best interest. Making choices simple and limited was thus a technique to facilitate decision-making during poor illness phases.

As mentioned in the introduction, Andreassen described the consumerism in Norwegian health services as "a consumerism of voice more than of choice" (Andreassen 2009) (page 117). According to Andreassen, the Norwegian health policy has given patients a strong voice and implemented principles of openness. Tritter has argued that the health systems are based on needs instead of "wants", and that narrowing user participation down to patient choice makes patient empowerment difficult (Tritter 2009). Mol also highlights the difference between a choosing citizen and a patient in need for treatment and care (Mol 2008). She argues that patient choice is not a key aspect of good care. While choice is to say yes or no to something, care resembles, according to Mol, a process without clear boundaries where the opportunity to make choices is more dynamic. It seems to me that the logic of consumerism and patient choice contains arguments that are instrumental and distanced from clinical practice, and that aspects such as mutual respect, good communication, and a sense of partnership are closer to the concrete work with user participation. In this perspective patient choice becomes a very instrumental and limited version of user participation, perhaps even an antagonism. In my opinion, decision-making stands out as a dynamic process with at least to actors, which is much more complex than choosing between treatment options. Acknowledging this complexity and focusing on the

important aspects would be more fruitful than providing service user with choices which they, according to research, don't ask for.

6.5 Does user participation have any effect in clinical practice?

Part of the main aim of this thesis was to contribute to lift the veil from the effect of user participation in clinical work through measuring the effect of implementing a strategy for user participation at a system level (study 3) and the effect of using feedback scales (PCOMS) at an individual level (study 4). In both studies there was little or no measurable effect on the main outcomes.

So what type of user participation interventions are good and provide effect? According to the reviews on the effect of user participation there are several initiatives on a system level that are effective (Nilsen et al. 2010;Simpson et al. 2002). Involving users in the development of information material lead to more relevant, readable, and understandable information which lead to better patient knowledge (Aabakken et al. 1997;Chumbley et al. 2002). Involving users in deliberate health policy discussions lead to stronger engagement in users (Abelson et al. 2003). Employing users as case managers in mental health care influenced the delivery of health services and improved several aspects related to those who were involved (Simpson et al. 2002). Involving users in training of professionals (in a course in assertive community treatment services), and in education of mental health nurse students, improved the professionals' attitudes towards mental health users and mental illness (Simpson et al. 2002).

If we focus on broad interventions which encompass larger parts of health care organisations there are fewer studies which have shown effect. Storm and colleagues conducted a controlled study on the effect of implementing a plan for user participation on both system and individual level in an in-patient setting in mental health services (Storm et al. 2011). The results showed no improvement on the patient-reported outcomes on satisfaction with treatment and care, but professionals reported a stronger organisational focus on user participation, more patient collaboration, and more involvement of family members.

Fudge and colleagues conducted a large ethnographic study on a modernisation program where user participation on a system level was intended to improve the stroke services (Fudge et al. 2008). Although a wide range of activities were described as user participation, the researchers failed to detect any impact on the services. Andreassen (2009) investigated an improvement process in mental health care where users were involved to provide feedback to the services. Although professionals became more aware and sensitive to users' feedback, the treatment ideology was hard to impact and the status of the user were not improved (Andreassen 2009).

Perreault and colleagues studied a panel of service users who were involved in meetings discussing the services (Perreault, Renaud, Bourassa, Beauchesne, Mpiana, Bernier, & Milton 2010). Although both users and providers reported a friendly and egalitarian atmosphere and the users reported personal benefits, little concrete impact on the health services was described from this intervention. Taken together, these studies on the system level show that the intended effect sometimes fails to appear, and that some aspects are hard to impact. On a system level it in general seems that the more concrete interventions have shown effect and the larger comprehensive programs have not.

Effective user participation initiatives on the individual level are classified as either provider-targeted (communication skills training) or patient-targeted (educational materials, coaching, goal setting, and patient-reported outcome measures feedback to the providers) (Haywood et al. 2006). Results have shown that interventions targeted on providers have improved the providers' communication and inter-personal skills, while patient-targeted interventions have improved the communication between patient and provider, and led to more user participation in decision-making (Haywood et al. 2006). The use of feedback tools has previously been shown to improve treatment outcome, both in psychotherapy and in couples therapy (Anker et al. 2009;Lambert et al. 2005;Reese et al. 2009a;Reese et al. 2010).

When summarising the literature presented in this thesis, there is too little high quality research published to draw very clear conclusion regarding the direct effect of user participation. There are few studies on the effect of user participation on a system level, and those investigating the effect on professionals have rarely investigated initiatives in large health care organisation. Furthermore, some of the studies on the effect of interventions on a

system level have shown effect while others have not. On an individual level there are more studies; also here some have showed effect of the initiatives while others have not, but there are in general more indications of an effect.

The findings in the two studies investigating effect in this thesis showed no measurable effect. There was no effect on the professionals from a system level intervention (study 3). The hypothesis on effect of the individual level intervention was refuted, although there were indications of some effects (study 4). Although these studies contribute to the evidence-base, they do not contribute enough to change the overall conclusion summarised above. More studies are needed before any definite conclusions can be drawn. It is of course possible that user participation has no effect and that we, sometimes in the future when the evidence base is solid enough, would reach this conclusion. Thus far, however, we do not have enough knowledge to conclude, and research therefore has to continue. In my opinion we have to consider three main aspects of further work in this field; the interventions (i.e. the participation initiatives), the process of implementing the interventions, and the outcome measurements. These aspects will be discussed in the following chapters.

6.5.1 User participation interventions

When evaluating the effect of user participation, one has to consider the initiatives that are investigated and whether they are appropriate. Do the user participation interventions that are investigated encompass the elements of user participation in clinical practice? If we are to investigate the effect of user participation we have to be sure that the initiatives encompass the nature of user participation in the clinic. When studying clinical change, little attention has so far been given to the characteristics of the intervention and how these characteristics hinder or facilitate change (Grol et al. 2003). Grol and Wensing described several aspects of the intervention as possible barriers to or incentives for change; the intervention's advantages in practice, and the feasibility, credibility, attractiveness, and accessibility of the intervention (Grol et al. 2004). Several of these are the organisations' or the professionals' perception of the intervention; whether those conducting clinical work find the intervention advantageous, feasible, credible, attractive, and accessible. Who are initiating the intervention has also been described as an important influence on the potential for change from interventions (Fudge et al. 2008).

In study 3 we investigated the effect of a complex user participation development plan. This plan included many initiatives, some were concrete and clear, others were more indefinite and diffuse. If we compare the initiatives in the development plan with previous studies we see that there are many similar initiatives; improving information materials, purchasing user expertise, and influencing the attitudes and culture among the professionals. The development plan in study 3 also had similarities to the user participation plan in Storm and colleagues' study, which included improved information to patients, more involvement of patients in treatment planning, organisational collaboration with user representatives, and more involvement of family members (Storm et al. 2011). Although some of these initiatives include embedded goals which are difficult to evaluate (e.g. improved attitudes), the over all impression is that the initiatives investigated intends to include users as important contributors in the development, delivering, and evaluation processes. In study 4 we investigated the short-term effect of using a feedback tool in therapy sessions. I have already (in the introduction and in paper 4) argued that feedback tools are initiatives which capture the essence of user participation.

It is my opinion that most of the user participation initiatives used in investigations described in this thesis over all correlate well with many of the definitions on and arguments for user participation. Although the lack of effect for some of these interventions indicates that the interventions in themselves are not effective, there are elements of the studies that could also have an influence on the lack of effect. In my opinion there is therefore no urgent need to reconsider the initiatives presently considered user participation in studies of effect.

6.5.2 The implementation of user participation interventions

The other part of effect studies that I want to focus on is the process of implementing user participation initiatives. Results from implementation processes are in general mixed (Arnold et al. 2005;Grol 1997;Walker et al. 2007), and there are many potential barriers to and incentives for implementation of interventions (Grol et al. 2004;Tambuyzer et al. 2011). Gold and colleagues found that user participation implementations were hampered by lack of clear directions and clarification of responsibility (Gold et al. 2005). Other potential barriers and incentives mentioned are the individual professional, the patient, the social context, the organisational context, and the economic and political context (Grol et al. 2004).

Authors have also described established practices and institutional beliefs as very persistent (Andreassen 2009). Due to the long history of stigmas and myths such changes in attitudes might be even more difficult and slow in mental health care. Rutter and colleagues investigated users' and providers' experiences from user participation in mental health services, and found that providers hung on to their control over the decision-making and preferred to consult users instead of acknowledging them as partners (Rutter et al. 2004). The professionals questioned the legitimacy of the users' views and whether they were representative for other service users. In addition, there are other factors in the health services which influence the professionals' possibilities to have impact on clinical practice. Lack of professional power to influence clinical decisions and resource priorities are potential barriers to increased user participation (Goodwin et al. 2006;McCloughen et al. 2011).

Difficulties in the implementation of user participation interventions can also be viewed in the light of the findings in study 1. Misunderstandings about decision-making could help explain why some professionals might be reluctant to implement user participation interventions. This reluctance could be especially strong in mental health services if professionals anticipate that user participation implies full user government for all patients in all situations.

System level

Study 3 investigates the effect of implementing a development plan for user participation in a large mental health care organisation. The work with this development plan was initiated and lead by the management. Since most organisational implementations intending to make change in the whole organisation end up as failures (Arnold et al. 2005), more knowledge on implementation processes are needed to improve them (Grol et al. 2004). Implementation processes in general include several steps where many complex systems interact, and where each step has to be conducted thoroughly to ensure the quality of the whole process (Arnold et al. 2005;Grol 1997). Organisations have been described as complex social systems where changes often are difficult (Arnold et al. 2005;Walker et al. 2007). Some have argued that it is flawed to assume that changes at a high organisational level, although perceived happening by management, necessarily will trickle down to other levels in mental health service organisations (Rose 2003). Implementations of large and complex programs might

appear to the professionals as a top-down initiative where their professional competence and autonomy is questioned.

Since the intervention in study 3 included a large organisation it might be that the implementation process in study 3 had weaknesses which could have contributed to the lack of measurable effects. Some of these potential weaknesses are discussed in paper 3. Grol and Wensing propose more thorough examinations of the incentives and barriers for change in health services (Grol et al. 2004). According to Grol and Wensing, it would be relevant to investigate possible incentives and barriers on the organisational level to illuminate such processes; the organisation of care processes, the staff, capacities, resources, and structures. These aspects were not investigated in this thesis and remain an area for further investigation.

Individual level

It is common sense that implementation on a system level which involves an entire organisation is more difficult than influencing the practice of single clinicians. In study 4 implementation of the intervention (the PCOMS) was directed on the individual professionals. The implementation included training of professionals, encouraging the professionals to use the tool, and to ensure that the intervention was in fact conducted. These procedures were in line with previous studies on the PCOMS (Anker et al. 2009). The training in the Partner for change outcome management system (PCOMS) that the professionals received was also similar to training given in previous studies, and in accordance with training given for clinical purposes to improve patient functioning and progress (Miller et al. 2004). In addition, there was high adherence to the intervention.

According to Grol and Wensing incentives and barriers on the patient level are; knowledge, skills, attitude, and compliance (Grol et al. 2004). In addition they emphasise social contexts in the work place such as the opinion of colleagues, the culture of network, collaboration, and leadership. Looking into these aspects is recommended when investigating the reasons for the results. Several efforts were done in study 4 to provide sufficient knowledge and skills, and to ensure adherence to the protocol. In Paper 4 we discussed the process of implementation and questioned several aspects which could have contributed to impairment of the implementation process, e.g. the amount of training and the low average number of

therapy sessions. However, all in all the implementation seems to be in line with what is recommended and what is done in other studies.

In sum, it is reasonable to believe that, when implementing a broad user participation initiative aimed at influencing a whole organisation, it is equally important to consider the implementation process as well as the type of intervention. Even if the intervention in itself is effective, faults and weaknesses in the implementation process could be a reason for finding no effect.

6.5.3 Measuring the effect of user participation

When investigating the effect of user participation we have to consider which measures are used to assess outcome. If the outcome measure is designed to measure something else than what is aimed at in the intervention, it is not likely that any effect would be found. One voiced prerequisite for initiatives to involve users in services is that they are based on evidence and on outcomes that are identifiable and achievable (Tobin et al. 2002). Several have highlighted the lack of robust measurements of change and impact of user participation and relating concepts (Elwyn, Buetow, Hibbard, & Wensing 2007;Elwyn et al. 2001;Hudon et al. 2011;Staniszewska, Herron-Marx, & Mockford 2008;Storm et al. 2010). Staniszewska and colleagues have described that although there is a need to measure the impact of user participation, the focus on developing robust measurement of change is lacking (Staniszewska et al. 2008). They highlight the need for an agreed set of criteria for assessing the quality of studies investigating user participation. Staniszewska and colleagues have recently proposed a checklist for the reporting of studies on user participation (Staniszewska et al. 2011). The authors argue that better reporting will strengthen the evidence-base in the area and make it easier to evaluate user participation.

When presenting their study on a system level initiative Fudge and colleagues concluded that it would be difficult to undertake more rigid designs such as randomised controlled trials before the active component and anticipated outcomes from participation are established (Fudge et al. 2008). They argued that more research is needed to establish which factors are shaping and constraining user participation. This highlights that studies investigating the effect of user participation uses outcome measures where we cannot be sure if initiatives have any impact. In my opinion it is currently not clear whether the

instruments which have been used so far measure the effect of user participation - or whether they measure other factors linked to or included in the interventions. The outcome measures should thus be tailored to the intervention. To do that, more knowledge about the intended or likely effect of different forms of user participation is needed.

That outcome measures in user participation and adjacent areas are mainly focused on the professionals' point of view has been emphasised previously (Britten 2003). To develop appropriate and valid instruments it is necessary to include the patients' view (Britten 2003) and reflect what users define as good evidence in a field where they are highly affected (Rose et al. 2006;Rose et al. 2011). Rose and colleagues have described a new model for creating general outcome measures in mental health; a mixed method approach which is entirely based on the users' perspective and where users are involved in all steps of the development, testing and validation of questionnaires (Rose et al. 2011).

The lack of user participation in development of instruments is also the case with patient-reported outcome measures. Lerman and colleagues developed the "Patient involvement in medical care scale" (PICS) for primary care (Lerman et al. 1990), and Eisen and colleagues developed the "Perception of care scale" (POC) for mental health care (Eisen et al. 2000), both without involving users in their work. A systematic review of tools for measuring patients' perceptions of patient-centred care (Hudon et al. 2011) found 13 instruments, and the brief description of these instruments' origin showed that only four reported involvement by users. To measure professionals' knowledge, practice, and attitudes towards user participation in study 3 we used the Consumer Participation Questionnaire (CPQ) (Kent et al. 1998). In paper 3 we have discussed several limitations in using this instrument. Both the CPQ and other newer questionnaires building on it (Happell et al. 2010;Storm et al. 2010) seem to have been developed by professionals and researchers, without involving service users.

Due to the lack of outcome measures derived from and based on the users point of view we developed and added several questions to the questionnaires used in study 4 (Appendix no. 2). We based these questions on the results from study 1 where respect, dialogue, and shared decision-making emerged as the main aspects of user participation. The questions developed for study 4 can be used further to develop an instrument based on the users' perspective.

6.5.4 Intervention, implementation, or outcome measure?

Besides the possibility that user participation do not have any effect, we have described three parts of effect studies on user participation which, in my opinion, has to be considered in further research; intervention, implementation, and outcome measures. My understanding of the current status of knowledge based on the literature is as follows;

- The interventions that have been used in studies on effect of user participation on both system and individual level are mainly in concordance with the core elements of user participation (respect, dialogue, and decision-making). However, it might be that these core elements do not have the capacity to produce any effects through interventions on a system level.

- The process of implementing interventions is a possible reason for lack of effect of interventions on a system level. It is a known fact that implementations are difficult, and extra attention is thus needed. To gain further knowledge the implementation process should be monitored and evaluated. For studies on interventions on an individual level, the implementation process seems to be less vulnerable.

- The instruments used to measure the effect of user participation both on a system and individual level are a potential reason for the lack of effect. Some outcome measures can probably not capture the core elements of user participations or the anticipated change from interventions. In future development and testing of outcome measures users should be included in all aspects to ensure reliability and validity.

7. Conclusions

The main aim of this thesis was to lift the veil from user participation in clinical work. As a whole, this thesis has shed light on what user participation is, and the effect of user participation in the clinic.

7.1 User participation in clinical work – what is it?

This thesis has illuminated respect as a non-negotiable fundament for user participation and as a benefit from successful participation in clinical practice. The importance of respect as the core of user participation in the clinic has not previously been emphasised widely, and it is likely that professionals have under-communicated respect in the clinic.

This thesis confirms that decision-making is a crucial part of user participation, as well as the part where misunderstandings and resistance arise. Shared decision-making was described as the desired outcome from participation, but users and providers agreed on certain limitations to this ideal. Decision-making was the part of user participation which was negotiated and altered during poor phases of mental illness. The thesis has shown that the anxiety among professionals on whether user participation implies full user government is unfounded. The experience of participation seems thus to be dependent on other aspects besides who makes the final decision.

7.2 User participation in clinical work – does it work?

This thesis has contributed to the evidence-base on user participation with two new studies. Due to very few studies, there is still too little evidence to conclude on the effect of user participation on a system level. There are indications of limited effect of broad user participation initiatives implemented across whole organisations. Concrete and clearly defined initiatives seem however to indicate more effect. For user participation on an individual level there are indications that these tend to be effective. For individual user participation including feedback scales the evidence points towards an effect, even though the findings in this thesis showed a lack of short-term effect on treatment alliance and patient satisfaction.

This thesis has highlighted two problem areas in effect studies; implementation processes on a system level and outcome measures. Implementation processes on a system level are complex and challenging. When trying to investigate the effect of user participation, implementation is a crucial aspect that needs to be considered along with the intervention itself. In addition, the thesis has highlighted the weaknesses of outcome measures for user participation on both levels. Service users have not been involved in the development of most outcome measures, and it is an open question whether they measure the core purposes of user participation.

8. Implications for clinical work and research

There are four main areas where this thesis has highlighted implications for clinical work and research:

- Respect as a core but under-communicated aspect of user participation.
- Shared decision-making as a negotiable goal where the process is important.
- Implementation of user participation on a system level as a big challenge.
- Outcome measures as an area for future development.

To further work on these areas and bring new and relevant knowledge to the clinic, research should integrate different methodologies and include the service users.

Since respect emerged as the fundament for user participation and something users experience as lacking, this aspect deserves more attention in further clinical work and research. Health service providers should include respect as a core value in clinical work and strive to develop ways of expressing it so that patients experience them as respectful. The users' perception of respect should be one of the hallmarks of good services. Conducting research that investigates how respect is expressed by professionals and perceived by users is needed to give better advice to professionals.

Decision-making is a central tenet in user participation. In this thesis I also found that decision-making was a crucial, yet negotiable and challenging aspect of user participation. The findings in this thesis suggest that decision-making is a process where respect and dialogue play important roles, and where the final decision can be somewhat subordinate to the process as a whole. The whole process should therefore be included in discussions and investigations regarding the role of decision-making in user participation.

The implementation of broad user participation initiatives on a system level are complex and challenging, and might hinder the effect of appropriate interventions. Implementation processes therefore have to be conducted and monitored thoroughly, both in the clinic and in research projects, to ensure that the intended intervention is used. In the clinic the focus needs to be as much on the implementation as the intervention. Although there is much research on implementations in general, future research investigating the implementation of user participation is warranted.

Although controlled trials have been advocated as the best possible designs to investigate effects, many have emphasised the importance of using qualitative methods when studying complex phenomena (Malterud 1996), and when investigating the implementation of complex interventions (Craig et al. 2008;Lewin et al. 2009). Nesting qualitative studies within controlled studies could be helpful to understand why the actual results occur, and could give a more comprehensive understanding of controlled studies as processes of change. I also agree with Grol and Wensing who suggest testing of existing theories on health care changes in prospective trials, as well as more thorough investigations of the implementation process, analyses of the success/failure factors, and meta-analyses (Grol et al. 2004). Rose and colleagues recommend multi-methods research that encompasses multiple perspectives for investigations in mental health services (Rose et al. 2006). Rose and colleagues have also described a new model for creating outcome measures which is entirely based on the users' perspective and where users are involved in all steps (Rose et al. 2011). If user participation should have any real meaning, including the users in clinical work and research on user participation should be an inherent property. It is therefore a striking finding that e.g. outcome measures in the area of user participation are developed and tested with little or no involvement from users. Involving users in all phases of user participation; in clinical work and research is thus vital.

8.1 Concluding paragraph

I started this thesis quoting Sherry Arnstein (1969);

>*"The idea of citizen participation is a little like eating spinach:*
>*No one is against it in principle because it's good for you".*

This quote illustrates the notion of an indisputable fact; that user participation is a good thing. There seems to be two main arguments for user participation in health care; because it is the right thing to do, and because it works. The legislation on user participation in health care has come before and despite any conclusive evidence that participation is effective. We could thus say that user participation has become a part of the health services because it is this the right thing to do, not because it has a measurable effect. The currently inconclusive evidence-base should nevertheless not diminish the importance of investigating if, how, and

why user participation influences the actors and the health services as such. So, to use Arnstein's metaphor a last time; we might discuss whether spinach tastes good, but probably not whether it is a healthy vegetable. Similarly we might discuss whether user participation is effective, convenient, easy, helpful, or pleasant, but not whether it is going to be a fundamental part of health services in the future.

9. References

Aabakken, L., Baasland, I., Lygren, I., & Osnes, M. 1997, "Development and evaluation of written patient information for endoscopic procedures", *Endoscopy*, vol. 29, no. 1, pp. 23-26.

Abelson, J., Eyles, J., McLeod, C., Collins, P., McMullan, C., & Forest, P. 2003, "Does deliberation make a difference? Results from a citizens panel study of health goals priority setting", *Health Policy*, vol. 66, no. 1, pp. 95-106.

Altman, D. 1991, *Practical statistics for medical research.* Chapman & Hall/CRC, London.

Altman, D. & Bland, J. 2003, "Interaction revisited: the difference between two estimates", *BMJ*, vol. 326, no. 7382, p. 219.

Andreassen, T. 2005, *[User involvement in health care]* Gyldendal Norsk Forlag AS, Oslo.

Andreassen, T. 2007, "Assymetric Mutuality: User Involvement as a Government-Voluntary Sector Relationship in Norway", *Nonprofit and Voluntary Sector Quarterly*, vol. 37, no. 2, pp. 281-299.

Andreassen, T. 2009, "The consumerism of "voice" in Norwegian health policy and its dynamics in the transformation of health services", *PMM* no. March, pp. 117-122.

Anker, M., Duncan, B., & Sparks, J. 2009, "Using client feedback to improve couple therapy outcomes: a randomized clinical trial in a naturalistic setting", *J Consult Clin Psychol*, vol. 77, no. 4, pp. 693-704.

Anthony, P. & Crawford, P. 2000, "Service user involvement in care planning: the mental health nurse's perspective", *J Psychiatr Ment Health Nurs*, vol. 7, no. 5, pp. 425-434.

Arnold, J., Silvester, J., Patterson, F., Robertson, I., Cooper, C., & Burnes, B. 2005, *Work psychology. Understanding human behaviour in the workplace.* Pearson Education Limited, Harlow, England.

Arnstein, S. 1969, "A ladder of citizen participation.", *Journal of the American Planning Association*, vol. 35, no. 4, pp. 216-224.

Auerbach, S. 2009, "The impact on patient health outcomes of interventions targeting the patient-physician relationship", *Patient*, vol. 2, no. 2, pp. 77-84.

Balint, E. 1969, "The possibilities of patient-centered medicine", *J R Coll Gen Pract*, vol. 17, no. 82, pp. 269-276.

Beach, M., Sugarman, J., Johnson, RL., Arbelaez, JJ., Duggan, PS., & Cooper, LA. 2005, "Do patients treated with dignity report higher satisfaction, adherence, and receipt of preventive care?", *Ann Fam Med*, vol. 3, no. 4, pp. 331-338.

Beach, MC., Roter, DL., Wang, NY., Duggan, PS., & Cooper, LA. 2006, "Are physicians' attitudes of respect accurately perceived by patients and associated with more positive communication behaviors?", *Patient Educ Couns*, vol. 62, no. 3, pp. 347-354.

Bennetts, W., Cross, W., & Bloomer, M. 2011, "Understanding consumer participation in mental health: Issues of power and change", *Int J Ment Health Nurs*, vol. 20, no. 3, pp. 155-164.

Bensing, JM., Deveugele, M., Moretti, F., Fletcher, I., van, V. L., Van, B. M., & Rimondini, M. 2011, "How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands", *Patient Educ Couns*, vol. 84, no. 3, pp. 287-293.

Blais, MA. 2004, "Development of an inpatient treatment alliance scale", *J Nerv Ment Dis*, vol. 192, no. 7, pp. 487-493.

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. 2002, "Patient self-management of chronic disease in primary care", *JAMA*, vol. 288, no. 19, pp. 2469-2475.

Borg, M., Karlsson, B., & Kim, H. S. 2009, "User involvement in community mental health services--principles and practices", *J Psychiatr Ment Health Nurs*, vol. 16, no. 3, pp. 285-292.

Breeze, J. 1998, "Can paternalism be justified in mental health care?", *J Adv Nurs*, vol. 28, no. 2, pp. 260-265.

Britten, N. 2003, "Clinicians' and patients' roles in patient involvement", *Qual Saf Health Care*, vol. 12, no. 2, p. 87.

Brown, J., Weston, W., & Stewart, M. 2007, "The third component: finding common ground.," in *Patient-Centered Medicine. Transforming the clinical method.*, M. Stewart et al., eds., Radcliff Medical Press Ltd, Abingdon, UK.

Cahill, J. 1996, "Patient participation: a concept analysis", *J Adv Nurs*, vol. 24, no. 3, pp. 561-571.

Cahill, J. 1998, "Patient participation-a review of the literature", *J Clin Nurs*, vol. 7, no. 2, pp. 119-128.

Carr, S. 2007, "Participation, power, conflict and change: Theorizing dynamics of service user participation in the social care system of England and Wales", *CSP*, vol. 27, no. 2, pp. 266-276.

Cegala, D. J., Street, R. L., Jr., & Clinch, C. R. 2007, "The impact of patient participation on physicians' information provision during a primary care medical interview", *Health Commun*, vol. 21, no. 2, pp. 177-185.

Cegala, D. & Post, D. 2009, "The impact of patients' participation on physicians' patient-centered communication", *Patient Educ Couns*, vol. 77, no. 2, pp. 202-208.

Charles, C. & Demaio, S. 1993, "Lay participation in health care decision making: a conceptual framework", *J Health Polit Policy Law*, vol. 18, no. 4, pp. 881-904.

Charles, C., Gafni, A., & Whelan, T. 1997, "Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango)", *Soc Sci Med*, vol. 44, no. 5, pp. 681-692.

Chinman, MJ., Rosenheck, R., Lam, JA., & Davidson, L. 2000, "Comparing consumer and nonconsumer provided case management services for homeless persons with serious mental illness", *J Nerv Ment Dis*, vol. 188, no. 7, pp. 446-453.

Chinman, MJ., Weingarten, R., Stayner, D., & Davidson, L. 2001, "Chronicity reconsidered: improving person-environment fit through a consumer-run service", *Community Ment Health J*, vol. 37, no. 3, pp. 215-229.

Christensen, T. 2005, "The Norwegian State Transformed?", *West Eur Polit*, vol. 28, no. 4, pp. 721-739.

Chumbley, GM., Hall, GM., & Salmon, P. 2002, "Patient-controlled analgesia: what information does the patient want?", *J Adv Nurs*, vol. 39, no. 5, pp. 459-471.

Church, J., Saunders, D., Wanke, M., Pong, R., Spooner, C., & Dorgan, M. 2002, "Citizen participation in health decision-making: past experience and future prospects", *J Public Health Policy*, vol. 23, no. 1, pp. 12-32.

Clark, CC., Scott, EA., Boydell, KM., & Goering, P. 1999, "Effects of client interviewers on client-reported satisfaction with mental health services", *Psychiatr Serv*, vol. 50, no. 7, pp. 961-963.

Cook, J., Jonikas, J., & Razzano, L. 1995, "A randomized evaluation of consumer versus nonconsumer training of state mental health service providers", *Community Ment Health J*, vol. 31, no. 3, pp. 229-238.

Corbin, J. & Strauss, A. 2008, *Basics of qualitative research techniques and procedures for developing grounded theory.* Sage, Thousand Oaks, California.

Coulter A 2002, *The autonomous patient* Nuffield Trust, London.

Coulter, A. 2002, "After Bristol: putting patients at the centre", *BMJ*, vol. 324, no. 7338, pp. 648-651.

Coulter, A. & Ellins, J. 2007, "Effectiveness of strategies for informing, educating, and involving patients", *BMJ*, vol. 335, no. 7609, pp. 24-27.

Coulter, A. 1997, "Partnerships with patients: the pros and cons of shared clinical decision-making", *J Health Serv Res Policy*, vol. 2, no. 2, pp. 112-121.

Coulter, A. 1999, "Paternalism or partnership? Patients have grown up-and there's no going back", *BMJ*, vol. 319, no. 7212, pp. 719-720.

Coulter, A. & Ellins, J. 2006, *Patient-focused interventions. A review of the evidence.*, The Health Foundation, London.

Crawford, M., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. 2002, "Systematic review of involving patients in the planning and development of health care", *BMJ*, vol. 325, no. 7375, p. 1263.

Dawson, J., Doll, H., Fitzpatrick, R., Jenkinson, C., & Carr, A. J. 2010, "The routine use of patient reported outcome measures in healthcare settings", *BMJ*, vol. 340, p. c186.

Double, D. 2002, "The limits of psychiatry", *BMJ*, vol. 324, no. 7342, pp. 900-904.

Eisen, SV., Dickey, B., & Sederer, LI. 2000, "A self-report symptom and problem rating scale to increase inpatients' involvement in treatment", *Psychiatr Serv*, vol. 51, no. 3, pp. 349-353.

Eldh, AC., Ehnfors, M., & Ekman, I. 2004, "The phenomena of participation and non-participation in health care--experiences of patients attending a nurse-led clinic for chronic heart failure", *Eur J Cardiovasc Nurs*, vol. 3, no. 3, pp. 239-246.

Eldh, AC., Ehnfors, M., & Ekman, I. 2006, "The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure", *Eur J Cardiovasc Nurs*, vol. 5, no. 1, pp. 45-53.

Eldh, AC., Ekman, I., & Ehnfors, M. 2010, "A comparison of the concept of patient participation and patients' descriptions as related to healthcare definitions", *Int J Nurs Terminol Classif*, vol. 21, no. 1, pp. 21-32.

Elwyn, G., Buetow, S., Hibbard, J., & Wensing, M. 2007, "Respecting the subjective: quality measurement from the patient's perspective.", *BMJ*, vol. 335, pp. 1021-1022.

Entwistle, VA., Andrew, JE., Emslie, MJ., Walker, KA., Dorrian, C., Angus, VC., & Conniff, AO. 2003, "Public opinion on systems for feeding back views to the National Health Service", *Qual Saf Health Care*, vol. 12, no. 6, pp. 435-442.

Entwistle, VA., Carter, SM., Cribb, A., & McCaffery, K. 2010, "Supporting patient autonomy: the importance of clinician-patient relationships", *J Gen Intern Med*, vol. 25, no. 7, pp. 741-745.

Epstein, RM. 2000, "The science of patient-centered care", *J Fam Pract*, vol. 49, no. 9, pp. 805-807.

European Commission 2001, *White paper: European Governance*, European Commission, Brussels.

Felton, CJ., Stastny, P., Shern, DL., Blanch, A., Donahue, SA., Knight, E., & Brown, C. 1995, "Consumers as peer specialists on intensive case management teams: impact on client outcomes", *Psychiatr Serv*, vol. 46, no. 10, pp. 1037-1044.

Feste, C. & Anderson, RM. 1995, "Empowerment: from philosophy to practice", *Patient Educ Couns*, vol. 26, no. 1-3, pp. 139-144.

Florin, D. & Dixon, J. 2004, "Public involvement in health care", *BMJ*, vol. 328, no. 7432, pp. 159-161.

Florin, J., Ehrenberg, A., & Ehnfors, M. 2006, "Patient participation in clinical decision-making in nursing: A comparative study of nurses' and patients' perceptions", *J Clin Nurs*, vol. 15, no. 12, pp. 1498-1508.

Florin, J., Ehrenberg, A., & Ehnfors, M. 2008, "Clinical decision-making: predictors of patient participation in nursing care", *J Clin Nurs.*, vol. 17, no. 21, pp. 2935-2944.

Frank, C., Asp, M., & Dahlberg, K. 2009, "Patient participation in emergency care - a phenomenographic analysis of caregivers' conceptions", *J Clin Nurs*, vol. 18, no. 18, pp. 2555-2562.

Fudge, N., Wolfe, CD., & McKevitt, C. 2008, "Assessing the promise of user involvement in health service development: ethnographic study", *BMJ*, vol. 336, no. 7639, pp. 313-317.

Gelso, C. & Carter, J. 1994, "Components of psychotherapy relationship: Their interaction and unfolding during treatment.", *J Couns Psychol*, vol. 41, no. 3, pp. 296-306.

Gilburt, H., Rose, D., & Slade, M. 2008, "The importance of relationships in mental health care: a qualitative study of service users' experiences of psychiatric hospital admission in the UK", *BMC Health Serv Res*, vol. 8, p. 92.

Gillard, S., Borschmann, R., Turner, K., Goodrich-Purnell, N., Lovell, K., & Chambers, M. 2010, "'What difference does it make?' Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients", *Health Expect*, vol. 13, no. 2, pp. 185-194.

Gold, SK., Abelson, J., & Charles, CA. 2005, "From rhetoric to reality: including patient voices in supportive cancer care planning", *Health Expect*, vol. 8, no. 3, pp. 195-209.

Goodwin, V. & Happell, B. 2006, "In our own words: consumers' views on the reality of consumer participation in mental health care", *Contemp Nurse*, vol. 21, no. 1, pp. 4-13.

Grol, R. 1997, "Personal paper. Beliefs and evidence in changing clinical practice", *BMJ*, vol. 315, no. 7105, pp. 418-421.

Grol, R. & Grimshaw, J. 2003, "From best evidence to best practice: effective implementation of change in patients' care", *Lancet*, vol. 362, no. 9391, pp. 1225-1230.

Grol, R. & Wensing, M. 2004, "What drives change? Barriers to and incentives for achieving evidence-based practice", *Med J Aust*, vol. 180, no. 6 Suppl, p. S57-S60.

Guarino, P., Elbourne, D., Carpenter, J., & Peduzzi, P. 2006, "Consumer involvement in consent document development: a multicenter cluster randomized trial to assess study participants' understanding", *Clin Trials*, vol. 3, no. 1, pp. 19-30.

Hall, M. 2008, "The legal and historical foundations of patients as medical consumers", *Georgetown Law J*, vol. 96, no. 583, pp. 583-597.

Happell, B., Moxham, L., & Platania-Phung, C. 2010, "A psychometric analysis of the Mental Health Consumer Participation Questionnaire", *Int J Ment Health Nurs*, vol. 19, no. 6, pp. 377-384.

Happell, B., Pinikahana, J., & Roper, C. 2002, "Attitudes of postgraduate nursing students towards consumer participation in mental health services and the role of the consumer academic", *Int J Ment Health Nurs*, vol. 11, no. 4, pp. 240-250.

Harrison, S. & Mort, M. 1998, "Which champions, which people? Public and user involvement in health care as a technology of legitimation.", *Soc Policy Adm*, vol. 32, no. 1, pp. 60-70.

Haywood, K., Marshall, S., & Fitzpatrick, R. 2006, "Patient participation in the consultation process: a structured review of intervention strategies", *Patient Educ Couns*, vol. 63, no. 1-2, pp. 12-23.

Hickey, G. & Kipping, C. 1998, "Exploring the concept of user involvement in mental health through a participation continuum", *J Clin Nurs*, vol. 7, no. 1, pp. 83-88.

Holmstrom, I. & Roing, M. 2010, "The relation between patient-centeredness and patient empowerment: a discussion on concepts", *Patient Educ Couns*, vol. 79, no. 2, pp. 167-172.

Hoving, C., Visser, A., Mullen, PD., & van den, B. B. 2010, "A history of patient education by health professionals in Europe and North America: from authority to shared decision making education", *Patient Educ Couns*, vol. 78, no. 3, pp. 275-281.

Howard, KI., Moras, K., Brill, PL., Martinovich, Z., & Lutz, W. 1996, "Evaluation of psychotherapy. Efficacy, effectiveness, and patient progress", *Am Psychol*, vol. 51, no. 10, pp. 1059-1064.

Hudon, C., Fortin, M., Haggerty, JL., Lambert, M., & Poitras, ME. 2011, "Measuring patients' perceptions of patient-centered care: a systematic review of tools for family medicine", *Ann Fam Med*, vol. 9, no. 2, pp. 155-164.

Jewell, SE. 1994, "Patient participation: what does it mean to nurses?", *J Adv Nurs*, vol. 19, no. 3, pp. 433-438.

Joffe, S., Manocchia, M., Weeks, JC., & Cleary, PD. 2003, "What do patients value in their hospital care? An empirical perspective on autonomy centred bioethics", *J Med Ethics*, vol. 29, no. 2, pp. 103-108.

Kent, H. & Read, J. 1998, "Measuring Consumer Participation in Mental Health Services: Are Attitudes Related to Professional Orientation?", *Int J Soc Psychiatry*, vol. 44, no. 4, pp. 295-310.

Klein, AR., Cnaan, RA., & Whitecraft, J. 1998, "Significance of peer social support with dually diagnosed clients: Findings from a pilot study", *Res Soc Work Pract*, vol. 8, no. 5, pp. 529-551.

Kreindler, S. 2009, "Patient involvement and the politics of methodology", *Can Public Adm*, vol. 52, no. 1, pp. 113-124.

Kvale, S. & Brinkmann, S. 2008, *Interviews. An introduction to qualitative reserach.* Sage, London.

Lambert, MJ., Burlingame, GM., Umphress, V., Hansen, NB., Vermeersch, DA., Clouse, GC., & Yanchar, SC. 1996, "The reliability and validity of the outcome questionnaire", *Clin Psychol Psychother*, vol. 3, no. 4, pp. 249-258.

Lambert, MJ., Harmon, C., Slade, K., Whipple, JL., & Hawkins, EJ. 2005, "Providing feedback to psychotherapists on their patients' progress: clinical results and practice suggestions", *J Clin Psychol*, vol. 61, no. 2, pp. 165-174.

Lambert, MJ. & Shimokawa, K. 2011, "Collecting client feedback", *Psychotherapy (Chic)*, vol. 48, no. 1, pp. 72-79.

Langdridge, D. 2004, *Introduction to research methods and data analysis in psychology.* Pearson Education Limited, Harlow.

Larsson, IE., Sahlsten, MJ., Sjostrom, B., Lindencrona, CS., & Plos, KA. 2007, "Patient participation in nursing care from a patient perspective: a Grounded Theory study", *Scand J Caring Sci*, vol. 21, no. 3, pp. 313-320.

Laugharne, R., Priebe, S., McCabe, R., Garland, N., & Clifford, D. 2011, "Trust, choice and power in mental health care: Experiences of patients with psychosis", *Int J Soc Psychiatry*.

Lerman, CE., Brody, DS., Caputo, GC., Smith, DG., Lazaro, CG., & Wolfson, HG. 1990, "Patients' Perceived Involvement in Care Scale: relationship to attitudes about illness and medical care", *J Gen Intern Med*, vol. 5, no. 1, pp. 29-33.

Lester, H., Tait, L., England, E., & Tritter, J. 2006, "Patient involvement in primary care mental health: a focus group study", *Br J Gen Pract*, vol. 56, no. 527, pp. 415-422.

Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J., & Morgan, K. 2002, "'The public is too subjective': public involvement at different levels of health-care decision making", *Soc Sci Med*, vol. 54, no. 12, pp. 1825-1837.

Longtin, Y., Sax, H., Leape, LL., Sheridan, SE., Donaldson, L., & Pittet, D. 2010, "Patient participation: current knowledge and applicability to patient safety", *Mayo Clin Proc*, vol. 85, no. 1, pp. 53-62.

Lov om helseforetak. 2001-06-15 nr. 93. 2001.

Lov om pasientrettigheter. 1999-07-02 nr. 63. 1999.

Lov om spesialisthelsetjenesten. 1999-07-02 nr: 61. 1999.

Lund, ML., Tamm, M., & Branholm, I.-B. 2001, "Patients' perceptions of their participation in rehabilitation planning and professionals' view of their strategies to encourage it", *Occup Ther Int*, vol. 8, no. 3, pp. 151-167.

Lyons, JS., Cook, JA., Ruth, AR., Karver, M., & Slagg, NB. 1996, "Service delivery using consumer staff in a mobile crisis assessment program", *Community Ment Health J*, vol. 32, no. 1, pp. 33-40.

Madison, K. 2010, "Patients as "regulators"? Patients' evolving influence over health care delivery", *J Leg Med*, vol. 31, no. 1, pp. 9-34.

Malterud, K. 1996, *[Qualitative methods in medical research. An introduction]* Tano-Aschehoug, Oslo.

Malterud, K. 2001a, "Qualitative research: standards, challenges, and guidelines", *Lancet*, vol. 358, no. 9280, pp. 483-488.

Malterud, K. 2001b, "The art and science of clinical knowledge: evidence beyond measures and numbers", *Lancet*, vol. 358, no. 9279, pp. 397-400.

Malterud, K. 2010, "Power inequalities in health care-empowerment revisited", *Patient Educ Couns*, vol. 79, no. 2, pp. 139-140.

Martin, D. J., Garske, J. P., & Davis, M. K. 2000, "Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review", *J.Consult Clin.Psychol.*, vol. 68, no. 3, pp. 438-450.

Martin, GP. 2008, "Representativeness, legitimacy and power in public involvement in health-service management", *Soc Sci Med*, vol. 67, no. 11, pp. 1757-1765.

May, C., Montori, VM., & Mair, FS. 2009, "We need minimally disruptive medicine", *BMJ*, vol. 339, p. b2803.

McCloughen, A., Gillies, D., & O'Brien, L. 2011, "Collaboration between mental health consumers and nurses: shared understandings, dissimilar experiences", *Int J Ment Health Nurs*, vol. 20, no. 1, pp. 47-55.

Meland, E., Schei, E., & Baerheim, A. 2000, "[Patient centered medicine-a review with emphasis on the background and documentation]", *Tidsskr Nor Laegeforen*, vol. 120, no. 19, pp. 2253-2256.

Miller, SD. & Duncan, BL. 2004, *The Outcome and Session Rating Scales: Administration and scoring manual.* Scott Miller & Barry Duncan, Chicago, IL.

Miller, SD., Duncan, BL., Sorrell, R., & Brown, GS. 2005, "The partners for change outcome management system", *J Clin Psychol*, vol. 61, no. 2, pp. 199-208.

Mizrahi, T., Humphreys, M., & Torres, D. 2009, "The social construction of client participation: The evolution and transformation of the role of service recipients in child welfare and mental disabilities.", *J Sociol Soc Welf*, vol. 36, no. 2, pp. 35-61.

Mol, A. 2008, *The logic of care: health and the problem of patient choice.* Routledge, London.

Nathan, S., Johnston, L., & Braithwaite, J. 2011, "The role of community representatives on health service committees: staff expectations vs. reality", *Health Expect*, vol. 14, no. 3, pp. 272-284.

Nilsen, E., Myrhaug, H., Johansen, M., Oliver, S., & Oxman, A. 2010, "Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review)", *Cochrane Database Syst Rev* no. 1.

Norges offentlige utredninger 1997, *[The Patient First. Management and organisation in hospitals]* 2.

O'Donnell, M., Parker, G., Proberts, M., Matthews, R., Fisher, D., Johnson, B., & Hadzi-Pavlovic, D. 1999, "A study of client-focused case management and consumer advocacy: the Community and Consumer Service Project", *Aust N Z J Psychiatry*, vol. 33, no. 5, pp. 684-693.

Paulson, R., Herinckx, H., Demmler, J., Clarke, G., Cutler, D., & Birecree, E. 1999, "Comparing practice patterns of consumer and non-consumer mental health service providers", *Community Ment Health J*, vol. 35, no. 3, pp. 251-269.

Perreault, M., Renaud, J., Bourassa, F., Beauchesne, L., Mpiana, A., Bernier, S., & Milton, D. 2010, "Implementation of a panel of service users for the evaluation of mental health outpatient services", *Eval Health Prof*, vol. 33, no. 4, pp. 480-496.

Petersen, K., Hounsgaard, L., Borg, T., & Nielsen, CV. 2011, "User involvement in mental health rehabilitation: a struggle for self-determination and recognition", *Scand J Occup Ther*.

Polowczyk, D., Brutus, M., Orvieto, AA., Vidal, J., & Cipriani, D. 1993, "Comparison of patient and staff surveys of consumer satisfaction", *Hosp Community Psychiatry*, vol. 44, no. 6, pp. 589-591.

Proposition No.63 (1997-1998) to the Storting 1998, *on the escalation plan for mental health 1999 - 2006*.

Proposition No.66 (2000-2001) to the Odelsting 2001, *on the Health care trust law*.

Reese, R., Norsworthy, L., & Rowlands, S. 2009a, "Does a continuous feedback system improve psychotherapy outcome?", *Psychotherapy (Chic)*, vol. 46, no. 4, pp. 418-431.

Reese, R., Usher, E., Bowman, D., Norsworthy, L., Halstead, J., Rowlands, S., & Chisholm, R. 2009b, "Using client feedback in psychotherapy training: An analysis of its influence on supervision and counselor self-efficacy", *TEPP*, vol. 3, no. 3, pp. 157-168.

Reese, RJ., Toland, MD., Slone, NC., & Norsworthy, LA. 2010, "Effect of client feedback on couple psychotherapy outcomes", *Psychotherapy (Chic)*, vol. 47, no. 4, pp. 616-630.

Report No.16 (2010-2011) to the Storting 2011, *on National plan on Health and care*.

Ridley, J. & Jones, L. 2001, *Users and public involvement in health services: A literature review*, Partners in change, SHS Trust.

Rogers, A. & Pilgrim, D. 1993, "Service users' views of psychiatric treatment.", *Sociol Health Illn*, vol. 15, no. 5, pp. 612-632.

Rogers, C. 1951, *Client-Centered Therapy. Its current practice, implications, and theory.* Houghton Mifflin Company, Boston.

Rose, D. 2003, "Partnership, co-ordination of care and the place of user involvement.", *J Ment Health*, vol. 12, no. 1, pp. 59-70.

Rose, D., Evans, J., Sweeney, A., & Wykes, T. 2011, "A model for developing outcome measures from the perspectives of mental health service users", *Int Rev Psychiatry*, vol. 23, no. 1, pp. 41-46.

Rose, D., Fleischmann, P., & Schofield, P. 2009, "Perceptions of User Involvement: A User-Led Study", *Int J Soc Psychiatry*.

Rose, D., Thornicroft, G., Pinfold, V., & Kassam, A. 2007, "250 labels used to stigmatise people with mental illness", *BMC Health Serv Res*, vol. 7, p. 97.

Rose, D., Thornicroft, G., & Slade, M. 2006, "Who decides what evidence is? Developing a multiple perspectives paradigm in mental health", *Acta Psychiatr Scand Suppl* no. 429, pp. 109-114.

Rutter, D., Manley, C., Weaver, T., Crawford, MJ., & Fulop, N. 2004, "Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London", *Soc Sci Med*, vol. 58, no. 10, pp. 1973-1984.

Sahlsten, MJ., Larsson, IE., Lindencrona, CS., & Plos, KA. 2005, "Patient participation in nursing care: an interpretation by Swedish registered nurses", *J Clin Nurs*, vol. 14, no. 1, pp. 35-42.

Sahlsten, MJ., Larsson, IE., Sjostrom, B., Lindencrona, CS., & Plos, KA. 2007, "Patient participation in nursing care: towards a concept clarification from a nurse perspective", *J Clin Nurs*, vol. 16, no. 4, pp. 630-637.

Sahlsten, MJ., Larsson, IE., Sjostrom, B., & Plos, KA. 2008, "An analysis of the concept of patient participation", *Nurs Forum*, vol. 43, no. 1, pp. 2-11.

Sainio, C., Lauri, S., & Eriksson, E. 2001, "Cancer patients' views and experiences of participation in care and decision making", *Nurs Ethics*, vol. 8, no. 2, pp. 97-113.

Simpson, EL. & House, AO. 2002, "Involving users in the delivery and evaluation of mental health services: systematic review", *BMJ*, vol. 325, no. 7375, p. 1265.

Simpson, EL. & House, AO. 2003, "User and carer involvement in mental health services: from rhetoric to science", *Br J Psychiatry*, vol. 183, pp. 89-91.

Solbjor, M. & Steinsbekk, A. 2011, "User involvement in hospital wards: Professionals negotiating user knowledge. A qualitative study", *Patient Educ Couns*, vol. 85, no. 2, p. e144-e149.

Solomon, P. & Draine, J. 1995, "The Efficacy of A Consumer Case-Management Team - 2-Year Outcomes of A Randomized Trial", *J Ment Health Adm*, vol. 22, no. 2, pp. 135-146.

Staniszewska, S., Brett, J., Mockford, C., & Barber, R. 2011, "The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research", *Int J Technol Assess Health Care*, vol. 27, no. 4, pp. 391-399.

Staniszewska, S., Herron-Marx, S., & Mockford, C. 2008, "Measuring the impact of patient and public involvement: the need for an evidence base", *Int J Qual Health Care*, vol. 20, no. 6, pp. 373-374.

Starkey, F. 2003, "The "empowerment debate": consumerist, professional and liberational perspectives in health and social care.", *Social policy and society*, vol. 2, no. 4, pp. 273-284.

Steihaug, S., Gulbrandsen, P., & Werner, A. 2011, "Recognition can leave room for disagreement in the doctor-patient consultation", *Patient Educ Couns*.

Steinsbekk, A. & Solbjor, M. 2008, "[User participation in hospital wards]", *Tidsskr Nor Lægeforen*, vol. 27, no. 1, pp. 1944-1945.

Stewart, M., Brown, J., Weston, W., McWhinney, I., McWilliam, C., & Freeman, T. 2003, *Patient-Centered Medicine. Transforming the clinical method.* Radcliffe Medical Press, Abingdon.

Stewart, M., Brown, JB., Donner, A., McWhinney, IR., Oates, J., Weston, WW., & Jordan, J. 2000, "The impact of patient-centered care on outcomes", *J Fam Pract*, vol. 49, no. 9, pp. 796-804.

Stickley, T. 2006, "Should service user involvement be consigned to history? A critical realist perspective", *J Psychiatr Ment Health Nurs*, vol. 13, no. 5, pp. 570-577.

Storm, M., Knudsen, K., Davidson, L., Hausken, K., & Johannessen, J. 2011, "Service user involvement in practice: The evaluation of an intervention program for service providers and inpatients in Norwegian Community Mental Health Centers.", *Psychosis*, vol. 3, no. 1, pp. 29-40.

Storm, M., Hausken, K., & Mikkelsen, A. 2010, "User involvement in in-patient mental health services: operationalisation, empirical testing, and validation", *J Clin Nurs*, vol. 19, no. 13-14, pp. 1897-1907.

Streiner, D. & Norman, G. 2008, *Health Measurement Scales. A practical guide to their development and use.*, 4 edn, Oxford University Press, Oxford.

Stringer, B., Van Meijel, B., De Vree, W., & Van der Bijl, J. 2008, "User involvement in mental health care: the role of nurses. A literature review", *J Psychiatr Ment Health Nurs*, vol. 15, no. 8, pp. 678-683.

Sundet, R. 2010, "Therapeutic collaboration and formalized feedback: using perspectives from Vygotsky and Bakhtin to shed light on practices in a family therapy unit", *Clin Child Psychol Psychiatry*, vol. 15, no. 1, pp. 81-95.

Tambuyzer, E., Pieters, G., & Van, A. C. 2011, "Patient involvement in mental health care: one size does not fit all", *Health Expect*.

Tempfer, CB. & Nowak, P. 2011, "Consumer participation and organizational development in health care: a systematic review", *Wien Klin Wochenschr*, vol. 123, no. 13-14, pp. 408-414.

The Norwegian Directorate of Health 2006, *[User participation - mental health. Goals, recommendations, and initiatives in the escalation plan for mental health]*.

Thompson, A. 2007, "The meaning of patient involvement and participation in health care consultations: A taxonomy", *Soc Sci Med*, vol. 64, pp. 1297-1310.

Tobin, M., Chen, L., & Leathley, C. 2002, "Consumer participation in mental health services: who wants it and why?", *Aust Health Rev*, vol. 25, no. 3, pp. 91-100.

Tritter, J., Koivusalo, M., Ollila, E., & Dorfman, P. 2010, *Globalisation, markets and healthcare policy: redrawing the patient as consumer.* Routledge, New York.

Tritter, JQ. 2009, "Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world", *Health Expect*, vol. 12, no. 3, pp. 275-287.

Tritter, JQ. & McCallum, A. 2006, "The snakes and ladders of user involvement: Moving beyond Arnstein", *Health Policy*, vol. 76, no. 2, pp. 156-168.

Trivedi, P. & Wykes, T. 2002, "From passive subjects to equal partners: qualitative review of user involvement in research", *Br J Psychiatry*, vol. 181, pp. 468-472.

Tuseth, A. 2007, "[When the client controls the treatment]", *Tidsskr Norsk Psykol*, vol. 44, no. 10, pp. 1218-1219.

Tuseth, A., Sverdrup, S., Hjort, H., & Friestad, C. 2006, *[To ask whom it conserns]*, Regionsenter for barn og unges psykiske helse, Oslo, Norway.

Tutton, EM. 2005, "Patient participation on a ward for frail older people", *J Adv Nurs*, vol. 50, no. 2, pp. 143-152.

Van Audenhove, C. & Vertommen, H. 2000, "A negotiation approach to intake and treatment choice.", *J Psychother Integr*, vol. 10, no. 3, pp. 287-299.

Wait, S. & Nolte, E. 2006, "Public involvement policies in health: exploring their conceptual basis", *Health Econ Policy Law*, vol. 1, no. Pt 2, pp. 149-162.

Walker, H. J., Armenakis, A. A., & Bernerth, J. B. 2007, "Factors influencing organizational change efforts - An integrative investigation of change content, context, process and individual differences", *Journal of Organizational Change Management*, vol. 20, no. 6, pp. 761-773.

Wood, J. & Wilson-Barnett, J. 1999, "The influence of user involvement on the learning of mental health nursing students.", *NT Research*, vol. 4, pp. 257-270.

Woodward, VM. 1998, "Caring, patient autonomy and the stigma of paternalism", *J Adv Nurs*, vol. 28, no. 5, pp. 1046-1052.

World Health Organisation 1978, *Declaration of Alma-Ata*, World Health Organisation, Geneva.

World Health Organisation Regional Office for Europe 1994, *Declaration on the Promotion of Patients' Rights in Europe*, WHO Regional Office for Europe, Copenhagen.

World Health Organisation Regional Office for Europe 1996, "The Ljubljana Charter on reforming health care", *BMJ*, vol. 312, pp. 1664-1665.

Appendices

Appendix 1 Topic guides

Topic guide for interviews with users in study 1 and 2:

What do you understand by the term user participation?
(What is it and how would you define it?)

Have you experienced user participation? How did you experience this?

Is user participation important? Why?

When you are in a treatment situation in mental health care/participate on a system level:
What makes you feel good or bad?

What does it take to have influence on your own treatment/in the boards or committees
where you participate?

Have you experienced that the influence you have had on your treatment/in the boards or
committees where you participate have provided any results? How?

Have you ever experienced not to be able to have influence? How?

What could be positive in user participation?
What could be negative in user participation?

What are the advantages or possibilities related to user participation in mental health care?
What are the challenges or hindrances related to user participation in mental health care?

How have you experienced user participation related to the treatment you have received in
this hospital/your participation on a system level?
What attitudes towards user participation du you feel the professionals at this hospital have?

If users are to participate – how should this happen?
What can be done to increase user participation in mental health services and in this
hospital?

Topic guide for interviews with professionals in study 1 and 2:

What du you understand by the term user participation?
(What is it and how would you define it?)

What is the value of user participation?

How can you notice the effect of user participation?

User participation in mental health services:
What are the benefits from user participation in mental health care?
What are the challenges or hindrances related to user participation in mental health care?

How du you feel about the fact that user participation in mandatory in health care?
Can it be too much user participation?

Is mental health services organised for user participation?
Can user participation change the mental health services?
What can be done to enhance user participation in mental health services?

How would you describe the culture for user participation in your unit?

How do you feel user participation should be conducted?
What does it take to give users influence on their treatment and life?
What does it take to give users influence on decisions made in the administration/organisation?

Which expectations do you have towards user participation in your future work in this hospital?

Appendix 2 Questions

Questions to participants (professionals) in study 3

1. Does your unit have a complaints procedure for users?
Yes/No/Don't know

2. If yes, is this procedure easy to use – is it in plain language and user friendly?
Yes/No/Don't know

3. Are users told they have a right to see and/or correct their records?
Yes/No/Don't know

4. Are users informed about the facts about confidentiality and privacy regarding information contained in those records?
Yes/No/Don't know

5. Have you heard or read anything about consumer involvement and participation in the provision of mental health services?
Yes/No

6. In most cases, where does the responsibility for deciding the goals of treatment usually lie?
Entirely the user/Mostly the user and the mental health worker a little/Half the user and half the mental health worker/Mostly the mental health worker and the user a little/Entirely the mental health worker.

7. Do you tell users what goals are intended to be accomplished by the treatment?
Yes/No

8a. Does your unit solicit input from users for the planning of mental health services?
Yes/No/Don't know

8b. Does your unit solicit input from user organisation for the planning of mental health services?
Yes/No/Don't know

9. Does your unit routinely conduct user satisfaction service on the service it offers?
Yes/No/Don't know

10. Are users involved in the hiring decisions of your unit's staff?
Yes/No/Don't know

11. Are users invited to participate in staff training meetings at your agency?
Yes/No/Don't know

12. Has your unit ever asked users to act as teachers at staff training events?
Yes/No/Don't know

13. Does your unit sponsor events/forums that educate users about their rights and entitlements?
Yes/No/Don't know

14. Should users be involved in the evaluation of their presenting problems?
Always/Usually/Sometimes/Never

14a. Should users be involved in the diagnosis of their presenting problems?
Always/Usually/Sometimes/Never

15. In your opinion, should users contribute to the writing of their notes and records?
Yes/No

16. In your opinion, should users be involved in the planning of their own treatment?
Yes/No

17. How would mental health service change if users were employed by that service?
Improve a lot/Improve a little/No change/Worsen a little/Worsen a lot

18. In your opinion, what are the most important reasons when users of mental health care don't want to be involved? (Tick one or more)
- Too vulnerable
- Lacking in self-confidence
- Lacking in ability or knowledge
- Lacking in motivation
- Lack of trust in the ability of the services to provide help
- Not wanting to have any further contact after getting better
- Other reasons (place to write comment)

19. How would mental health service change if users were involved in the planning and/or delivery of those services?
The service would be much better / the service would be somewhat better / no change / the service would be somewhat worse / the service would be much worse

20. In your opinion, if users were involved in planning and/or carrying out the mental health service, how would the service develop? (Tick one or more)
- Upgrading of services and delivery
- Less burnout and stress for providers of those services
- More chance that users would benefit from those services the first time round
- Less chance of the "revolving door" syndrome, where users keep returning with the hope of finding help
- Downgrading of services and delivery
- More burnout and stress for the providers of those services
- That users would only be regarded as tokens by the professionals
- That users would not understand the language used, and therefore find it difficult to give any input
- Other developments (open space for writing comments)

21. Does the unit have a users' committee?

Yes/No/Don't know

22. Does the unit have representatives or spokespersons on behalf of the users?
Yes/No/Don't know

23. How would you describe the unit's general attitude towards user participation?
Very poor/Quite poor/So-so/Quite good/Very good

24. In your opinion, do users understand the information you give about their illnesses and treatment opportunities?
Yes/No

25. Do you have enough time to ensure users' participation?
Yes/No

26. In your opinion, are next of kin in general sufficiently involved?
Yes/No

27. How would you describe the collaboration with next of kin in general?
Very poor/Quite poor/So-so/Quite good/Very good

28. Do you inform users about relevant self-help groups and user organisations?
Yes/No

Questions to participants (patients) in study 4
Main outcome measures

Treatment Alliance Scale (TAS)

1. I work well with my therapist

2. I feel that my therapist has a good understanding of my problems

3. I feel that the therapist listens to my problems

4. I think my therapist will be available if I need him/her

5. I feel that my therapist wants me to partake fully in my treatment

6. I feel that my therapist wants to help me

7. I feel like an active participant in my treatment

8. I feel respected by my therapist

9. My therapist and I agree on what has to change in order to conclude my treatment

10. I think my treatment will be successful

All questions are answered by ticking one box from 0 to 6 where 0 is "False" and 6 is "Completely true"

Client Satisfaction Questionnaire (CSQ)

1. How would you rate the quality of service you received?
Excellent
Good
Fair
Poor

2. Did you get the kind of service you wanted?
No, definitely not
No, not really
Yes, generally
Yes, definitely

3. To what extent has our program met your needs?
Almost all of my needs have been met
Most of my needs have been met
Only a few of my needs have been met
None of my needs have been met

4. If a friend were in need of similar help, would you recommend our program to him/her?
No, definitely not
No, I don't think so
Yes, I think so
Yes, definitely

5. How satisfied are you with the amount of help you received?
Quite dissatisfied
Indifferent or mildly dissatisfied
Mostly satisfied
Very satisfied

6. Have the services you received helped you to deal more effectively with your problems?
Yes, they helped a great deal
Yes, they helped somewhat
No, they really didn't help
No, they seemed to make things worse

7. In an overall, general sense, how satisfied are you with the service you received?
Very satisfied
Mostly satisfied
Indifferent or mildly dissatisfied
Quite dissatisfied

8. If you were to seek help again, would you come back to our program?
No, definitely not
No, I don't think so
Yes, I think so
Yes, definitely.

Questions to participants (patients) in study 4 Participation and Motivation

*Questions marked with * are about Motivation. All other questions are about Participation.*

1. I am treated with respect by my therapist and others I have contact with regarding my treatment.

2. I feel that my therapist and I are equal and co-operating partners.

3. I feel that I am being heard during my treatment.

4. The treatment I receive is based on a reciprocal dialogue.

5. The therapist is interested in hearing my opinion.

6. I have much influence on the choice of treatment approach.

7. I worry that the therapist will make decisions without consulting me.

8. I receive good information about the possible treatments for my problems.

9. I receive good information about my mental health problems.

10. It is very important for me that my mental health problems improve.*

11. I want to make a large effort to improve from my mental health problems.*

12. I am very motivated for the treatment of my mental health problems.*

13. I feel that it is quite all right to disagree with my therapist.

14. I feel that the treatment will be helpful.

All questions are answered by ticking a box between 0 and 6 where 0 is "Totally disagree" and 6 is "Totally agree".