User Involvement in Mental Health and Substance Abuse: Myth or Reality?

Exploring the Role of User Involvement in Clinical Pathway Development

Margrethe Aaen Erlandsen

Thesis submitted as a part of the Master of Philosophy Degree in Health Economics, Policy and Management

Faculty of Medicine
Department of Health Management and Health Economics
Supervisor: Trond Tjerbo

UNIVERSITY OF OSLO

May 2017
User Involvement in Mental Health and Substance Abuse: Myth or Reality?

Exploring the Role of User Involvement in Clinical Pathway Development
User Involvement in Mental Health and Substance Abuse: Myth or Reality?
Exploring the Role of User Involvement in Clinical Pathway Development

Margrethe Aaen Erlandsen

http://www.duo.uio.no

Print: University Print Centre, University of Oslo
Abstract

User Involvement in Mental Health and Substance Abuse: Myth or Reality?

Exploring the Role of User Involvement in Clinical Pathway Development

User involvement is a statutory right on both individual level and system level in Norway. There is broad consensus regarding the benefits of involving users in the development of health care policies and services. However, evidence of the relationship between user involvement and improved outcomes is weak, and little research has been done to find the best ways of involving users in health care decisions, especially when it comes to users who abuse substances.

The Directorate of Health is currently in the process of developing models for clinical pathways in mental health and substance abuse treatment. Based on the recommendation to include users at all levels of the pathway development and implementation process, this case study aims to explore how user representatives influence the process, and describe in what manner other participants of the planning process perceive their influence. Research question: How can we understand the role of user involvement in clinical pathway development for mental health and substance abuse?

Semi-structured interviews were conducted with 7 respondents, all members of the multidisciplinary pathway working groups, and were analyzed by means of content analysis. The results revealed that user involvement in the development of clinical pathways for mental health and substance abuse is perceived to be of instrumental significance for all respondents. A combination of methods of user involvement, rather than just a single method, may be decisive for its perceived success. It is recommended to further research the effects of user involvement on policy development, and also to examine the role of user involvement in the first line services.
Acknowledgements

Completing the master thesis has been a challenging and a rewarding process. First of all, I would like to give my sincere thanks to the informants for kindly taking time out of their busy day to contribute to the thesis.

My acknowledgement also goes to my supervisor Professor Trond Tjerbo at the Department of Health Economics and Health Management, for guiding me through the process. Thank you for all valuable inputs and feedback along the way.

I would also like to thank my fellow students and friends for their support and encouragement through the master thesis process.

Finally, I am especially thankful to my family for their never ending support. My deepest gratitude and love goes to my parents who have provided me with countless opportunities and for which I am eternally grateful.

Margrethe Aaen Erlandsen,
Oslo, May 2017
# Table of contents

1.0 Introduction .................................................................................................................. 1
  1.1 Research question ........................................................................................................... 2

2.0 Background ..................................................................................................................... 4
  2.1 User involvement ........................................................................................................... 4
    2.1.1 A framework for user involvement in mental health .............................................. 5
    2.1.2 Reviewing the literature on user involvement ....................................................... 7
  2.2 Defining the case ........................................................................................................... 10
    2.2.1 What are clinical pathways? .................................................................................. 10
    2.2.2 Clinical pathways in mental health – potential benefits and barriers ................. 11
    2.2.3 User involvement in mental health pathway development .................................. 13

3.0 Theory ............................................................................................................................ 15
  3.1 An instrumental perspective ......................................................................................... 15
    3.1.1 Hypothesis ............................................................................................................. 16
  3.2 Institutional myths ........................................................................................................ 17
    3.2.1 Hypothesis ............................................................................................................. 19

4.0 Methodology .................................................................................................................. 20
  4.1 Objectives perspective and mode of enquiry .............................................................. 20
  4.2 Study design ................................................................................................................ 20
  4.3 Method of data collection and analysis ...................................................................... 21
  4.4 Quality criteria ............................................................................................................. 23
    4.4.1 Validity ................................................................................................................ 23
    4.4.2 Reliability and transparency ................................................................................. 24
    4.4.3 Ethical considerations .......................................................................................... 24

5.0 Results ........................................................................................................................... 26
  5.1 User involvement as a means to achieve better quality on health services ............ 27
1.0 Introduction

User involvement has been a statutory right on both individual level and system level in Norway since the Patient Rights Act was passed in 1999. Today, there is widespread consensus regarding the benefits of involving users, families and caregivers in the planning and design of services and health policies (Morena and Moriana, 2016). The current emphasis on user involvement has arisen from various reasons, including the perceived remoteness and unresponsiveness of services to the needs and wishes of users, as well as an increasingly diverse and discerning public and the demands of various user groups (Hickey and Kipping, 1998). However, evidence of the relationship between user involvement and improved outcomes is weak (Fudge et al., 2008). Additionally, little research has been done to find the best ways of involving users in health care decisions (Nilsen et al., 2006 and Van Wersch & Eccles, 2001), and there is especially a knowledge gap on the subject of involving people who abuse substances in policy and program development (Ti et al., 2012). There is evidence to suggest that professionals are generally supportive of user involvement, however, there are also discrepancies between expressed support and actual practice (Tait and Lester, 2008).

One might argue that user involvement in mental health and substance abuse care is more crucial than in somatic care. Psychiatric diagnoses and methods are based on rather weak scientific evidence, and compared to for example surgery, psychiatry is “floating” (Mjaaland, cited in Skogstrøm, 2017, p. 11). Mental health problems manifest themselves in different ways for different people, which is why conversation with the service user is necessary in order to give a diagnosis and find appropriate treatment options. Furthermore, for mental health and substance abuse patients, there is usually no quick fix for a specific problem or diagnosis. Treatment often involves changing behavioral and thought patterns, having implications for the rest of their lives, and not just one specific problem or diagnosis. Due to the assumed importance of user involvement in mental health and substance abuse, but
also the inconsistencies in the literature, it would be relevant and interesting to explore how the concept is applied and perceived by those working with it.

Commissioned by the Department of Health and Care Services, the Directorate of Health is currently in the process of developing models for clinical pathways in mental health and substance abuse treatment. The plan is that they be implemented during 2018. The literature provides few guidelines on strategies for development and implementation of clinical pathways in mental health, but Denton et al. (1999) recommends that “consumers, carers and other relevant stakeholders must be involved at all levels of the pathway development and implementation process through local consumer representatives and groups”. In the pathway development currently ongoing in the Directorate of Health, user representatives are involved as part of the multidisciplinary working groups consisting of group leaders from the Directorate, health professionals from both primary and specialist care, and user representatives.

1.1 Research question

This thesis’ objective is to find out how user involvement is applied in the development of clinical pathways for mental health and substance abuse, and explore the views, attitudes and opinions of members of the working groups on the concept. The clinical pathway development provides as a case of mental health policy development, and sets the framework for investigating this topic. The aim of the thesis is to explore how user representatives influence the process, and describe in what manner other participants of the planning process perceive their influence. With this, I might be able to uncover the true role of users, and whether they are able to achieve genuine user involvement in the form of user influence. When exploring the concept of user involvement, an instrumental and an institutional perspective within organization theory will be utilized to shed light on the findings. Is user involvement part of the formal structure, applied in order to achieve better products, or is it applied superficially through a pressure from the environment, functioning merely as “window dressing”? 
Consequently, the research question for this thesis evolves as the following:

*How can we understand the role of user involvement in clinical pathway development for mental health and substance abuse?*
2.0 Background

2.1 User involvement

Users may here be defined as “people who need, seek or receives help from the health and welfare system” (Andreassen, 2005, p.21). The term “user” also includes those who receive health care against their will. In addition, family and relatives are initially seen as resource persons for the user, but “when relatives, because of their close relationship with the user, also need to use health services, or the user is not able to attend to their user rights, they must also be considered users” (ibid). In this sense, the term “user” is comparable to those health professionals traditionally have called “patients” and social workers have called “clients”.

“User involvement” is a term used about many different methods that are applied in order for the health and welfare system to listen to users’ experiences and allow users’ perspectives to influence the design of health services (Andreassen, 2005). User involvement is a statutory right in Norway, and so it is not something that the public service can choose to deal with or not (Helsedirektoratet, 2006, s. 8). It is useful to divide between user involvement on individual level, and user involvement on system level. The former refers to the individual’s rights and opportunities to influence their own course of treatment, allowing for increased autonomy and control over their own life (Helsedirektoratet, 2006, p. 8). It touches upon the health and social care’s methods and the professionals’ approach to the people they meet as helpers. User involvement on system level points to the fact that the involvement concerns the system around the individual help relations, the health and welfare design and framework conditions, and the health and social policy (Andreassen, 2005). At the system level, user involvement means that the users are included in an equal partnership with public services, and are actively participating in the planning and decision making from start to finish. Users and representatives of user organizations are elected to various committees and councils. The representatives will contribute with their knowledge to professionals, administration and
politicians in the planning, design and operation of an improved service (Helsedirektoratet, 2006, p. 8).

User involvement on system level may for this reason also be called collective user involvement or representational user involvement (Andreassen 2005). Representational, in that spokespersons, or user representatives, are acting on behalf of the user group. Collective, in that it concerns processes where the health and welfare system’s user groups are involved in some form of collective action, or interaction with the system. User representatives act on behalf of the user group, and promote collective interests – they do not (or should not) act as private individuals to promote self-interest. In this context, “user organizations” is a term for organizations that represent, and is the voice of, people who are users of health services (Ibid). Users may be represented both by users (or former users) themselves, and by their relatives.

2.1.1 A framework for user involvement in mental health
As shown, user involvement is a stated goal, but often lack a clear definition, and the term has been used to describe a variety of initiatives. It can also be justified in various ways. In policy documents user involvement is often presented as a quality issue, necessary to make service improvements. However, other analysts provide explanations from several philosophical and political perspectives, such as consumerism, democracy and citizenship, and the rise of patient pressure groups (Fudge et al., 2008). In order to contribute to greater clarity around the concept, Hickey and Kipping (1998) identified three main rationales for involving users in decision-making, and stated that the rationale will determine the approach to user involvement taken, with subsequent implications for the extent to which users can be involved in decisions. The first rationale is the desire to provide a service that is more responsive to the needs and wishes of users, with a subsequent consumerist approach to user involvement. The second rationale is the right users have to be involved in decisions that will affect them, and the third is the therapeutic value that being involved in decision-making can have for people with mental health problems, both of which suggest a
democratization approach. The consumerist approach is concerned mainly with increasing the users’ amount of choices when deciding upon a service, as well as increasing the responsiveness of the service to the consumer. The democratization approach actually involves users in the decision-making process. The difference in power in decision-making between the two approaches can be highlighted by referring to service users as consumers for the consumerist approach, and as citizens for the democratization approach. As a consumer one becomes the judge of the benefits of a service, but still accepts the service ideology and is merely an evaluator of the output, while as a citizen however, one actually decides the content of a service.

Based on these two approaches to user involvement, Hickey and Kipping (1998) developed a “participation continuum” (figure 1). The first two positions, “information/explanation” and “consultation”, are associated with the consumerist approach to empowerment, because they do not transfer any decision-making power to the user. The last two positions, “partnership” and “user control”, are associated with a democratization approach because power is shifted from the policy makers or service provider to the service user.

Figure 1: Participation continuum

<table>
<thead>
<tr>
<th>Information/explanation</th>
<th>Consultation</th>
<th>Partnership</th>
<th>User control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumerist</td>
<td></td>
<td>Democratization</td>
<td></td>
</tr>
</tbody>
</table>

The first position involves providing users with information and explanation, but not actually include them in the decision-making process. The second position involves policy makers/service providers seeking the views and opinions of the service users, but deciding themselves whether or not these are considered in the decision-making process. The third position involves redistributing power following negotiations between the users and policy makers/service providers, so that decisions are made jointly. The last position involves
redistribution of power so that the users make the decisions, and decides whether or not to involve other people in the decision-making process (ibid).

This framework assumes that some initiatives that are referred to as user involvement, does not actually give users any decision-making power, and is thus not genuine user involvement, which is achieved when you have user influence. A variety of constraints to user involvement exist, which inhibit the redistribution of power between policy makers/service providers and users (Hickey and Kipping, 1998). The users themselves may be the source of constraint, depending on what impact their mental health problem has on their decision-making ability. Some users at some stages in their illness may therefore be unable to move far along the continuum. Lack of commitment from the organization is one of the most important constraints to user involvement, which needs to be a “core value” of the organization, and not just something that is forced upon it. The same goes for the professional culture, which has a long history of the notion that the professional knows best. If the professional holds assumptions that patients are unable to hold valid opinions, then genuine user involvement will be severely restricted. Finally, there are attitudes held in the wider society towards people with mental health problems, about their continually irrationality, which encourages the belief that they are incapable of giving a valid view. These attitudes are a major influence in determining the extent to which users can be involved in decision-making (ibid).

2.1.2 Reviewing the literature on user involvement

As mentioned, there is widespread consensus regarding the benefits of involving users, families and caregivers in the planning and design of services and health policies (Morena and Moriana, 2016). In fact, the importance of user involvement at all levels of the health services is widely recognized (Nilsen et al., 2006). As Harrison and Mort (1998, p. 66) put it: “Being in favor of more user involvement is rather like being against sin; at a rhetorical level, it is hard to find disagreement”. According to Nilsen et al. (2006), involving users in health care may lead to policy, research, practice and patient information that include users’ ideas
or addresses their concerns. Input from users in planning of health care may lead to more accessible and acceptable health services, and improve health and quality of life. User involvement can also be viewed as a goal in itself by encouraging participative democracy, public accountability and transparency (ibid). In addition, people with mental health problems are among the most socially excluded within any society, and as user involvement can be empowering, it may therefore encourage greater social inclusion (Tait and Lester, 2005).

However, research find little or weak evidence of the relationship between user involvement and improved outcomes (Fudge et al., 2008, Rutter et al., 2004, Van de Bovenkamp and Trappenburg, 2009 and Conklin et al., 2012). Uncertainty of outcome is compounded by uncertainty about the process (Rutter et al., 2004); as mentioned earlier the term user involvement describes a variety of initiatives, ranging from a consumerist approach to a democratization approach. According to Conclin et al. (2012, p 161) “the absence of clear definitions, operationalization and reporting of specific outcome measures is problematic for purposes of evaluation as well as for the development of policy informed by evidence on the effects of public involvement (on process, output and outcome)”. They found in their systematic review, limited evidence of longer-term impact of user involvement in health-care policy – that is, “were participants’ preferences “match” policy or service preferences, the users’ requests are more likely to be met and thereby demonstrate the impact of involvement on policy or practice” (ibid, p. 162). They did find some evidence for the developmental role of user involvement, such as enhancing awareness and understanding, but less evidence for instrumental benefits. Nevertheless, they concluded that the emphasis placed on assessing outcomes or impact of user involvement risks overshadowing the normative value of user involvement as intrinsically good because it is a deliberative democratic process. Rutter et al. (2004) found in their case studies on user involvement in the planning and delivery of mental health services, little evidence that power sharing was taking place, or that involvement had progressed on the continuum beyond consultation to partnership. They also found that managers focused
upon the process of user involvement, and were more satisfied than users with the degree of participation offered to service users, while users were more concerned with the outcomes of involvement, and therefore expressed greater levels of dissatisfaction. Van de Bovenkamp and Trappenburd (2009) found in their literature review, no empirical evidence to support the assumption that user involvement would enhance the quality of guidelines in guideline development. Moreover, their review showed that users experience several difficulties in the participation process. Based on these results, they concluded that the plea to actively involve users in the guideline development process should be reconsidered.

While the evidence of user involvement on the effect of the planning and design of health services and health policies is limited, it is still reinforced in political guidelines and health legislation as a statutory right. Some researchers state that users should be involved in all stages of policy development, but acknowledge the difficulties and limitations of current methods (Van Wersch and Eccles, 2001, Nilsen et al., 2006 and Ti et al., 2012). In addition to constraints related to organizational and professional culture, there are barriers and limitations related to the financial and time costs of properly implemented user involvement, as well as concerns over representativeness, particularly for users who are “too well” or “too articulate” to represent the general user views (Tait and Lester, 2005). It is found that users who are included in guideline development contribute infrequently, and have problems with the use of technical and medical language (Van Wersch and Eccles, 2001), as well as fitting into management structures and struggle against professional authority (Rutter et al., 2004). People who abuse substances are restricted from involvement especially because of high levels of stigma and discrimination (Ti et al., 2012). Nilsen et al. (2006) found in their systematic review, that there is not only a lack of research that investigates whether user involvement achieves their potential and said benefits, but also a lack of research that investigates which methods of user involvement are most effective in this. They stated that users might not find it meaningful to function as user representatives because their opportunities for input and influence are minimized, and that there is a need for more research that investigates methods for overcoming such barriers to user involvement. Van Werch and Eccles (2001) explored four different methods of user
involvement in guideline development, and found that none was ideal and, even if optimized, each alone would be likely to remain limited. Their research concluded that experience on how to best involve users was limited, and that there is a need for further work on how best to achieve it. They suggest that future guideline development groups should consider, and report on, using more than a single method of user involvement. Ti et al. (2012) revealed in their literature review, a consistent knowledge gap in the subject of user involvement of people who use drugs in the areas of policy and program development, and states that future research should seek to further explore and document this.

There is evidence to suggest that professionals are generally supportive of user involvement, however, there are also discrepancies between expressed support and actual practice (Tait and Lester, 2008). Soffe et al., (2004) sought in their survey to examine clinical psychologists’ views regarding service user involvement in mental health services. Although they found that the majority of clinical psychologists were supportive of it, there was variability in the extent of involvement at differing levels within mental health systems and structures. This implies that there is a mismatch, or a decoupling, between what professionals say and how they act in mental health systems.

2.2 Defining the case

When exploring the role of user involvement in mental health and substance abuse, the development of clinical pathways will provide as a case that sets the framework for this.

2.2.1 What are clinical pathways?

There are multiple definitions of a clinical pathway, as well as multiple alternative terms used in the literature, such as critical pathway, integrated care pathway, care map, protocol, guideline and many more. De Bleser et al. (2006) found 84 different definitions used in studies published about the concept clinical pathways. Such a variation in terms and definitions can lead to confusion and also makes empirical testing problematic. For this
reason, there are a few studies to be found aiming to develop a definition of the concept, and Kinsman et al. (2010) used three of these to derive the following criteria of a clinical pathway: 1) It is a structured multidisciplinary plan of care; 2) it is used to channel the translation of guidelines or evidence into local structures; 3) it details the steps in a course of treatment or care in a plan, pathway, algorithm, guideline, protocol or other “inventory of actions”; 4) it has timeframes or criteria-based progression; and 5) it aims to standardize care for a specific clinical problem, procedure or episode of healthcare in a specific population. After testing these criteria, the authors agreed that an intervention was defined as a clinical pathway if it met the first criteria and any three of the remaining four (Kinsman et al., 2010).

Clinical pathways are most commonly used in surgical and medical areas where treatment and procedures are standardized, and their use in mental health is so far limited (Emmerson et al. 2006, Jones, 1999, Vanhaecht et al., 2006). A comprehensive Cochrane review (Rotter et al., 2010) found that clinical pathways are associated with reduced in-hospital complications and improved documentation. It also found that most studies reported a decreased length of stay and reduction in hospital costs, but the variation in study designs prevented statistical pooling of these results. Another systematic review (Deneckere et al., 2012) found that care pathways have the potential to support inter-professional teams in enhancing teamwork.

2.2.2 Clinical pathways in mental health – potential benefits and barriers

Implementation of clinical pathways in mental health have the potential for improving quality of care and the utilization of resources, improving coordination between those involved with the patient, minimizing delays, and reducing variation in treatment (Emmerson et al., 2004). In addition, they may provide as a useful tool for communicating with patients and their families (Jones, 2000). According to Green (2008), quality of care will improve due to the promotion of best practice, and the fact that pathways allow for ongoing clinical audit. When benchmarks of best practice are based on latest research and
guidelines, clinical pathways should not prevent development of better practice. Mjaaland (2017, cited in Skogstrøm, 2017, p.12) argues that the attempt to achieve standardization and structure in mental health may be wise, for example in creating checkpoints during the course of treatment, in order to reveal whether or not there is progress. She also argues that standardization will give less room for personal guesswork when it comes to diagnosing in psychiatry.

However, the literature also highlights potential problems and challenges with implementing clinical pathways in mental health care, including the problems with defining the start and end of an episode of care (as is the case with some long-term or relapsing conditions), standardizing packages of care for complex disorders (as is the case with most mental disorders), and the high levels of individual variations within the same diagnose (Evans-Lacko et al., 2008). In mental health, contrasting to physical health, there are limits to diagnostic precision, as well as some overlap of treatments from one condition to another. It has therefore traditionally been perceived that “the innate variability within each person would color his or her response to treatment such that no adequate average plan could be devised and operated with sufficient clinical integrity” (Green, 2008, p. 233).

Critics may also point to the resultant loss of individual creativity for clinicians. Compared to some medical conditions and surgical procedures, there is a need for more individual customization in mental health care, as patients with the same diagnose may have different needs. However, Green (2008) argues that this apparent negative is reduced when observing the impact of interventions upon similar groupings of patients, results in learning. In a pathway, any deviation from standard guideline should be documented and reasoned for, thus promoting attention to the individual patient, as well as clinical and organizational learning.

The perceived success of clinical pathways in mental health naturally depends on the grounds for implementing them. In Norway the overarching goals are increased user involvement and user satisfaction; good, coherent and intersectoral pathways of care; security and predictability for patients and their relatives; to avoid unfounded waiting times;
equality of treatment regardless of municipality of residence; and better care for physical health and habits of lifestyle (Helsedirektoratet.no).

2.2.3 User involvement in mental health pathway development

Denton et al. (1999) acknowledged in their article that the literature provides few guidelines on strategies for development and implementation of clinical pathways in mental health, and thus came up with some recommendations. Among others, their recommendations included that consumers, carers and other relevant stakeholders must be involved at all levels of the pathway development and implementation process through local consumer representatives and groups. Other authors also acknowledge the importance of involving service users in the development process. Jones (2006), in his study of a clinical pathway for schizophrenia, acknowledged that a major limitation of the study was the absence of service users from the development phase of the pathway. He recommends that future research specifically identify this group to find out their views on what interventions should be included in order to make their admission more purposeful (Jones, 2006, p. 26). Green (2008) talks about how clinician and user partnerships are essential for the success of the pathways. Users and their relatives provide valuable information about the pre-illness stage, and a benchmark for progress towards recovery. According to Green (2008), users should be involved in developing a flexible pathway with a range of choices for patients and clinicians to explore together.

In the pathway development currently ongoing in the Directorate of Health, user representatives are involved as part of multidisciplinary working groups, consisting of group leaders from the Directorate, health professionals from both primary- and specialist care, and user representatives. In relation to Hickey and Kipping’s framework, both of the terms “consultation” and “partnership” have been used to describe this approach, even though consultation is a model in which professionals retain control of both the process and outcomes of user involvement, while partnership implies similar status, shared power and some equality of influence over both the agenda and the outcomes of shared decision.
making (Rutter et al., 2003). The former represents a consumerist approach and the latter a democratization approach, implying that the rationale for involving users in this case is unclear.
3.0 Theory

The conceptual perspective to shed light upon the research question is chosen from organizational theory, that is, perspectives that explain how one may look upon organizations, their members, and organizational processes. I will present two perspectives, namely an instrumental perspective and an institutional perspective. The main difference between these perspectives is that an instrumental perspective looks at organizations as tools for leaders, whereas institutional perspectives are open to the idea of an institutionalized environment, focusing on the values and norms present in an organization and its environment (Christensen et al., 2007). The approaches further differ in their understanding of what logic of action make up the basis for the behavior of the organization’s members, and in their view of organizational change, which will be explained more in depth.

3.1 An instrumental perspective

The underlying logic of action in an instrumental perspective is a logic of consequence, based on a means–end rationality, where one choses to execute the action with the most desirable effects (Christensen et al., 2007). The management acts rationally, in that they perform thorough analytical assessments of consequences for all of the alternatives they face, and make rational choices between them. The available alternatives are assessed in terms of the impact they have on the selected goals. It is expected that the chosen measures will have an effect on actual behavior in the organization. Both goals and the chosen means to achieve them are founded on a clear knowledge base (ibid). Organization and reorganization is seen as a choice that reflects goals and expectations of the stakeholders (Roness, 1997, p. 63). Organizations can thus be understood as tools or instruments for achieving certain goals. The organizational structure creates rationality through channeling behavior and resources towards predetermined goals. This means that organizing gives foundation for problem solving and capacity for action beyond what the management and members otherwise could have done on their own (ibid).
Change from an instrumental perspective will occur as a rational adjustment to new goals, or to shifting external demands (Christensen et al., 2007). Thus, reorganization will occur if a new management enters with different goals, or if the sitting management changes its existing goals. Reorganization will also occur if there is new content in the knowledge base on effects of organizational structures and how they can be put into practice (Roness, 1997, p. 64). The management will try to reduce the distance in the relationship between desirable state and status quo, and to the degree that they perceive organizational structure and the organizing of change processes to be important factors, these will be attempted changed (ibid).

However, different individuals or groups within an organization can be committed to different goals and interests, and the organization or its individual parts must relate to other organizations that may have other goals and interests (Christensen et al., 2007). From this negotiation-based instrumental perspective, organizations can be understood as coalitions, where each actor acts in an instrumentally rational way, is motivated by interests, and can also enter into coalitions with actors outside the organization. Conflicts of interest between organizations can be dealt with through negotiation where actors can arrive at a compromise between different interests, which in turn will provide the basis for a rational choice where there is full knowledge about the alternatives and consequences (ibid). The result of the negotiation process reflects the amount of resources and power the different actors possess.

3.1.1 Hypothesis

From an instrumental perspective, one would expect that user involvement be seen as a means in a development process where all stakeholders are represented and should negotiate their views, and where the chosen solution reflects the power relationship between the stakeholders, in order to achieve the overarching goals of clinical pathways.
3.2 Institutional myths

Whereas the underlying logic of action in an instrumental perspective is a logic of consequence, the underlying logic of action in an institutional perspective is a logic of appropriateness, where one acts in accordance with one’s experience of what feels fair, reasonable and acceptable in the environment one works within. When it comes to the view on organizational change, from an institutional perspective, organizations will be more robust and change will occur slowly through gradual adjustment, or through long stable periods interrupted by radical breaks (Christensen et al., 2007).

In an institutional perspective, a key conception is that organizations operate within institutional environments where they are confronted with socially created norms for how they should be designed and how they should function. Organizations must try to incorporate and reflect these norms outwardly, even if they do not necessarily make the organization’s activities more effective (Christensen et al., 2007). The reason for this is that organizations need legitimacy from the environment to survive – they cannot survive “merely” by striving for efficiency. Socially created norms in institutional environments are called myths (ibid). A myth can be understood as a legitimate recipe for how one should design the various parts of the organizational arrangement. The recipes are based on the prevailing norms and values that exist within the organization’s institutional setting. Organizations attempt to adopt various elements of such patterns to appear innovative, modern and efficient (ibid).

Myths are then adopted into the organization. There are various motives that lead members of organizations trying to adopt such recipes. DiMaggio and Powell (1983) distinguish between three reasons for adopting organizational recipes; coercive pressure, that stems from political influence and the problem of legitimacy; mimetic pressure, that stems from standard responses to uncertainty; and normative pressure, associated with
professionalization. An organization may coercively adopt certain recipes via laws or regulations, without having any other choice. In situations of uncertainty, organizations may mimetically adopt recipes in an attempt to imitate other organizations that are perceived as successful. Finally, an organization may adopt recipes based on a normative pressure, because of common norms, values, knowledge and networks that are held by various professional groups within the organization or its environment.

Adoption of the recipes by the organization is not synonymous with implementation, that is, these recipes do not necessarily get a governing effect on the actual activity within the organization. When these recipes are attempted implemented, the myth perspective highlights three possible expectations for what will be the outcome; quick coupling, rejection or decoupling. Quick coupling presents an optimistic scenario, where the recipe is implemented relatively quickly, and will give the expected positive effects. Rejection presents a more pessimistic scenario, where the organization is able to resist reforms that are attempted implemented, but revealed as incompatible and unsuitable within the complexity of the organization. Decoupling is most typical for the myth perspective, and presents the view that modern organizations must deal with the dilemma of being efficient on the one hand, which often requires adhering to tried-and-tested solutions; and adopting recipes perceived to be modern at the time on the other hand, not least because these recipes have the potential to give the organization external legitimacy (Christensen et al., 2007). When an organization face conflicting demands, it tends to meet some demands by way of talk, and others by way of action. Brunsson (2002) defines incorporated inconsistencies like that “hypocrisy”. He argues that hypocrisy is “often an important and even necessary ingredients in any modern organization that wants to act according to current demands for rationality, decency and fairness, while also efficiently generating coordinated action”. Thus, talk and actions of an organization may operate seemingly independent of one another. In other words, talk does not necessitate action. This phenomenon is called “decoupling”. Decoupling is the creation and maintenance of gaps between formal policies and actual organizational practices (Brunsson, 2002). It enables
organizations to gain legitimacy with their external members while simultaneously maintaining internal flexibility to address practical considerations (ibid). From this perspective, myths or recipes are ideas that function as a kind of “window dressing” intended to convince the environment that the organization is modern and efficient, without actually having to change very much on the inside (Christensen et al., 2007).

3.2.1 Hypothesis

From a myth perspective, one would expect that user involvement as a method in the development of pathways, may be motivated by similar processes that have taken place in the development of health care in other countries, or by norms, regulations, or guidelines. Either way, adopting this method can be seen as a way to legitimize the process of pathway development for mental health. Further, from a myth perspective, one would expect that user involvement as a method is subjected to decoupling.

It is interesting to take a closer look at the distinction between the instrumental and the institutional perspective. The instrumental perspective reflects organizations and their members as fundamentally rational, acting based on a logic of consequence. The institutional myth perspective on the other hand, reflects organizations and their members as acting based on a logic of appropriateness, striving to achieve legitimization from its environment. These perspectives seem to represent contrasting views resembling counter poles, but the distinction may not be as sharp as assumed in theory. There is empirical research suggesting that the possible outcomes of adopting an organizational recipe outlined here, does not embrace the totality of possible outcomes. Based on this, a number of theorists have argued that one should also take long-term effects of adoption under consideration, as well as how organizations translate and process these recipes (Christensen et al., 2007). The applicability of the chosen theoretical perspectives, and the hidden blurred lines between them, will be further discussed.
4.0 Methodology

4.1 Objectives perspective and mode of enquiry

This study is an empirical descriptive study. Descriptive studies aim to “describe systematically a situation, problem, phenomenon, service or program, or provide information about for example the living conditions of a community, or describe attitudes towards an issue. (...) The main purpose is to describe what is prevalent with respect to the issue or problem under study” (Kumar, 2014, p. 13). The phenomenon in this study is user involvement in the development of mental health clinical pathways, and the aim is to describe how user representatives influence this process, as well as the attitudes to user involvement of different stakeholders, and thus how we can understand the role of user involvement in this. Descriptive research is also called exploratory research, and it is needed when little is known about the subject of study (Fawcett and Downs, 1986).

The thesis takes form as a qualitative study. The qualitative approach follows an open, flexible and unstructured approach to enquiry. It aims to explore diversity and describe feelings, perceptions and experiences. Findings are communicated in a descriptive and narrative manner, placing no or less emphasis on generalizations (Kumar, 2014, p. 14). Qualitative studies are well suited to describe phenomena in context and provide an interpretation that leads to a greater understanding of the phenomenon. They will always take into account the context that forms the framework for the phenomenon being studied (Justesen and Mik-Meyer, 2012, p. 16-17).

4.2 Study design

The thesis is a study of user involvement in the initial development phase of clinical pathways for mental health and substance abuse. Thus, it falls under the category of single case studies. There are many definitions of case studies, however, the “central tendency among all types of case study, is that it tries to illuminate a decision or set of decisions: why
they were taken, how they were implemented, and with what result” (Schramm, 1971, cited in Yin, 2014, p. 15). Gerring (2007) defines it as “the intensive study of a single case for the purpose of understanding a larger class of cases”. The selected case becomes the basis of “a thorough, holistic, and in-depth exploration of the aspect(s) that you want to find out about” (Kumar, 2014, p. 155). According to Yin (2014) the case study method is best applied when research addresses descriptive or explanatory questions and aims to produce a first-hand understanding of people and events. Research questions seeking to explain some present circumstance, e.g. “how” or “why” some social phenomenon works, are especially relevant. The case study has the advantage of an exploratory nature, and is a useful design when the focus is on “exploring and understanding, rather than confirming and quantifying” (ibid).

In selecting the case, a typical-case approach has been undertaken, meaning that the case is selected on “the assumption that it is typical of cases of a certain type and therefore a single case can provide insight into the events and situations prevalent in a group from where the case has been drawn” (Kumar, 2014, p. 155). In this thesis, the assumption is that the user involvement in the initial development phase of clinical pathways in mental health and substance abuse is a typical case of user involvement in mental health policy development, and may thus provide insight in this more general phenomenon.

4.3 Method of data collection and analysis

The main method of data collection was the performance of interviews. These were semi-structured, which means there is a guide in which the themes and a number of key issues are defined in advance. The interviewees are all asked the same open questions, but there is room to deviate from the guide and ask follow-up questions if the interviewee brings up unexpected but interesting topics, and the interviewer is also able to ask supplementary sub-questions where the interviewee provides inadequate responses (Justesen and Mik-Meyer, 2012). The semi-structured interview method is suitable for studies in which the researcher both wants to adopt an exploratory approach that generates new knowledge
and to stimulate interviewees’ reflections on the planned themes and key issues (ibid). However, there are potential pitfalls in choosing this method. First of all, the quality of interaction between interviewer and respondent is likely to affect the quality of the information obtained. Also, because the interaction in each interview is unique, the quality of the responses obtained from different interviews may vary significantly. Secondly, the quality of the data generated is affected by the experience, skills and commitment of the interviewer, implying a risk if the interviewer is new to the method. Thirdly, a researcher’s bias either in the framing of questions and/or in the interpretation of responses obtained is always possible (Kumar, 2014, p. 183).

In qualitative research, respondents are sampled purposefully, and not randomly, meaning that individuals are selected because it is assumed that they can provide the best information. Respondents in this study were chosen solely by virtue of being members of a multidisciplinary working group, and consisted of three user representatives, two group leaders and two health professionals. The sampling strategy can therefore be seen to have elements of a maximum variation sampling strategy, meaning that a small number of respondents have been chosen that maximize the diversity relevant to the research question. The strategy is used when one wants to understand how different groups of people view a specific topic, so one samples a wide range of perspectives to capture the broadest set of information and experiences (Kuper et al., 2008).

The interviews conducted were audio recorded and then transcribed before they were analyzed by means of content analysis. The analysis of the interviews was conducted in parallel with the performance of interviews. This way, it was possible to adapt the content of the interview guide in order to retrieve the most relevant and interesting information for the next interviews. Content analysis is a technique used to sort data into categories that emerge during analysis (Fawcett and Downs, 1986). The researcher tries to reveal general or typical patterns in the data material by reading it repeatedly. These patterns are then coded, meaning that a larger part of the transcription is summarized and simplified. Codes
may be keywords or symbols that describe the relevant part of the data, and these may be strictly descriptive, but also interpretative, which means that they express the researchers interpretation or understanding of the content (Grønmo, 2007). Coding of the material may then help to categorize the content. A category may be seen as a collection or a class of phenomena with certain qualities (ibid). The categories that emerged during the analysis were named in relation to the chosen theoretical perspectives, in order for the categories to be relatable to established concepts.

### 4.4 Quality criteria

#### 4.4.1 Validity

Validity is about the extent to which the study’s findings actually shed light on the research question, that is, whether we measure what we say we will measure (Justesen and Mik-Meyer, 2012). One often distinguishes between internal and external validity. Internal validity exists in an explanatory or causal study if the observed effects of the independent variable on the dependent variable are real, and distinguished from spurious correlations. Internal validity is thus less relevant for descriptive or exploratory studies, where one is not seeking to establish a causal relationship (Yin, 2014, p. 46). External validity can be explained as the ability to generalize the study’s findings to other groups and settings beyond those in the current study (ibid).

Some argue that case study research does suffer from problems of representativeness because it includes only one or a small number of cases, and thus cannot claim to make any generalizations to a population beyond cases similar to the one studied (Gerring, 2007 and Kumar, 2014). In other words, case study research is generally weaker when it comes to external validity than other research designs. However, the internal validity is correspondingly higher, as it is often easier to establish the accuracy of a causal relationship relating to a single case than for a larger set of cases (Gerring, 2007). Others may argue that there is another form of generalization that constitutes the goal of case studies. Yin (2014)
says that for case studies, having some theory or theoretical propositions will play a crucial role in helping to generalize the lessons learned from the study. This role of theory is characterized as *analytical generalization* (Yin, 2014, p. 40). It differs from *statistical generalization*, where an inference is made about a population on the basis of empirical data collected from a sample of that population. Analytic generalization on the other hand, compares the results of a case study to a previously developed theory. Case studies are generalizable to theoretical propositions and not to populations. In this sense, the case study does not represent a "sample", and in doing a case study, the goal will be to expand and generalize theories – analytical generalization – and not to enumerate frequencies – statistical generalization (ibid). This thesis’ aim is to generalize the results of the interviews to an instrumental and an institutional perspective within organization theory, in order to find out whether these perspectives can be used to explain the role of user involvement.

### 4.4.2 Reliability and transparency

The quality criterion of reliability is about demonstrating that the operations of a study – such as the data collection procedures – can be repeated under the same conditions, with the same results. It refers to how well the study’s methodology is defined, and how well the procedures are documented (Yin, 2014, p. 49). Reliability is associated with reducing *bias*, and insuring that the research is influenced as little as possible by contextual factors such as the researchers role and subjectivity. Bias refers to “any imbalance or coloration of the study’s findings due to the actions of the researcher or the actual design of the study” (Justesen and Mik-Meyer, 2012, p.38). To ensure a high degree of reliability and transparency, it has therefore been attempted to thoroughly document and justify the chosen methods, as well as reflect upon the role that the researcher’s own position and experiences play in the study.

### 4.4.3 Ethical considerations

Both oral and written informed consent was obtained from the respondents before interviews were conducted, and they were assured the opportunity to withdraw from the
study at any point. Respondents were informed that anonymity was guaranteed, and that direct or indirect personally identifiable information would not be disclosed in the thesis, or stored after submission. This guarantee was given in order for respondents to be able to speak as freely as possible, and meant that it was not applicable naming user organizations or working groups that the respondents were employed in. The study was reported to and approved by the Norwegian Data Protection Officer.
5.0 Results

The results from the semi-structured interviews are presented in the following chapter. The analysis of the interviewees’ responses resulted in some categories. These categories are compiled in order to provide a rich and profound understanding of this thesis’ topic and research question:

*How can we understand the role of user involvement in clinical pathway development for mental health and substance abuse?*

In order for the categories to be relatable to already established concepts, they are named in relation to the chosen theoretical perspectives, which is an instrumental perspective and a myth perspective within institutional theory. The first category is called “User involvement as a means to achieve better quality on health services”, under which one will find quotations that support this rationale for user involvement. Subcategories have been applied to distinguish between quotations regarding the role of user involvement in the pathways on “individual level”, and the role of user involvement in the making of the pathways – on “system level”. The second category is called “User involvement as a means to legitimize the process”, under which one will find quotations that support the view that legitimization is the rationale behind user involvement. The subcategory “Decoupling vs. implementation” has been applied, under which one will find quotations supporting or contradicting that user involvement is subject of decoupling.

Table 1: Categories derived from content analysis

<table>
<thead>
<tr>
<th>User involvement as a means to achieve better quality on health services</th>
<th>User involvement as a means to legitimize the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual level</td>
<td>System level</td>
</tr>
</tbody>
</table>
5.1 User involvement as a means to achieve better quality on health services

5.1.1 Individual level

Respondents had an instrumental view on user involvement on individual level, that is, the individual user’s possibility of participating in decisions about their own health care. This was seen as a necessary means in order for the treatment and therapy to be of best possible quality. The group leaders both emphasized how users should be involved in order to set appropriate goals for treatment:

Group leader 2: Treatment goals become more realistic, because the emphasis is on the patient’s goals and not the clinician’s goals.

Group leader 1: ...the question “what is important to you”? Not “how are you”, but “what is important to you”. Because very often, it is something else that is important to users than what the professionals think.

Other respondents focused on how users must be involved in their own process of change in order for it to be successful. They emphasize that making own decisions lead one to being more motivated towards pursuing those decisions.

Professional 1: Those users saying, "treat me", those who are passive recipients, they achieve little change. And mental illnesses are to a large degree about changing behavioral patterns. And you won’t be able to do that without being actively participating.
Professional 1: You can calm psychotic symptoms with medication, but you cannot get them employment, a better life, without putting in effort, and without them actually wanting it. So you have to (involve them in their own treatment.)

Professional 2: User involvement is extremely important, especially in this group of patients, because it is not just about one specific diagnose, it is actually about their whole lives. (...) We’re actually trying to get them on board with a process of change, and that change can only be carried out by the patients themselves, but we act sort of as mentors and advisors in this process (...) so that the user have the best possible foundation for making their decisions.

User representative 3: I believe that all recovery, or all development depends on your own engine. User involvement for me is all about the professional being able to start my own engine. When you get to decide something yourself, you will be more motivated, right. Then there is a greater chance that the result will be better, because you are involved in it yourself.

5.1.2 System level

On system level, users are involved in the development of health services. Involving user representatives in multidisciplinary working groups is the main method of user involvement in the initial phase of developing clinical pathways. All respondents gave statements supporting the view that they see this as a means for improving the quality of the result:

Group leader 1: I think that it is not possible to pursue quality improvement without involving users. It is simply not possible. We get a much better result if we involve users from day one. (...) It is the users who know what is most important to improve.
Group leader 2: It is they (the users) who are the main recipients of the services. And they know to a greater degree than others where the shoe pinches. (...) We need their correction, or their views.

Professional 1: (Users are involved) primarily to achieve good clinical pathways, good plans. It’s not because it is supposed to be politically correct and fair that they should be represented, the point is they will help ensure that this will be a good pathway.

Professional 2: We who possess professional expertise, we know a lot about how things can be done, but we do not know very much about what it’s like to sit in the other chair. So involving users that ask us to stop, ask us to consider, ask us to see things from different angles, is actually essential for this to be something that the users actually want to use.

User representative 1: It’s an advantage to know where the shoe pinches, when one is making a shoe (laughs). So, we can say something about where the weaknesses are and how things are perceived when one is standing in the middle of it.

User representative 2: I think you get a more user-friendly end result. Also, I think you get a result that is much easier to sell. It can be such a simple thing like language. Should we use technical terms in a pathway, or should we use language that everyone understands, in the patient’s health services?

User representative 3: ... they (the bureaucrats) see that they get a lot out of it, and that we deliver. (...) We have a different kind of knowledge, we have a different expertise. And that is needed.

The group leaders did also ascertain that it is the Directorate of Health that has the responsibility to make any final decisions.
Group leader 1: *Ultimately, it is the Directorate’s responsibility to decide what it says in the end.*

Group leader 2: *It is a democracy, and surely we want their perspectives and opinions, but ultimately, we decide on the formulation.*

However, this statement from a user representative indicates that the views of all stakeholders are seen as equally important. This respondent does not assume that user involvement is only successful when users get to decide what the result will be like, but rather see it as a means of achieving successful collaboration.

User representative 2: *User involvement is not about having me decide how everything will turn out. User involvement is about working together and collaborating to get the best possible end result.*

And the following statements from one of the group leaders and one of the user representatives say something about the power relationship within the working group, and that the user representatives does actually possess some power over professional representatives when it comes to negotiation. This contrasts to the traditional view on users as disadvantaged and less articulate.

Group leader 1: *They are heard equally, an perhaps even more so, than the others in the group, and impact to a greater degree on the end product.*

User representative 2: *... and we actually have quite a great impact. Whether we put a stamp on it or not, I think is of great importance. It is much more important to get our approval than to get the psychologist’s approval.*
User representative 2: \(\text{...when they set the meetings so that us user representatives are able to attend, but whether the psychologist is available or not is less important. That is, we can manage without a psychologist, but we cannot manage without the user representatives.}\)

Finally, some quotations refer to an increasing use of “professional user representatives”. This suggests an instrumental approach to user involvement, because professional user representatives can seemingly contribute on a more appropriate and beneficial level.

Group leader 2: \(\text{I, who also have a long experience in the treatment sector, have been part of a lot of user involvement that may not have been very appropriate. For example, if someone is using drugs, they are mostly concerned with their own navel. So our experience with user representatives within different pathways is that they are professional, in that they also have the ability to look at things a little more from above, and have a more principal view on user involvement as well. They are more able to draw experiences from many, rather than just themselves.}\)

Professional 2: \(\text{I personally feel that the users we have now are better educated, or better trained in the role they should have. And I think it is simply because, we have more experience, we know more about user involvement and how to use it more properly than we did 7-8-9 years ago.}\)

User representative 3: \(\text{But they also expect us to have a lot of knowledge about how it actually is out there. And eventually, they actually also expect that when we convey that knowledge, it should be evidence-based. So it will become more and more demanding for us, or there will be demanded more from us.}\)
5.2 User involvement as a means to legitimize the process

Some respondents acknowledge that user representatives are involved in the development of pathways in order to legitimize the process. Legitimization seems to be based both on a coercive pressure, that is, political guidelines that secure the right for users to be involved in the planning of health care services, as well as a normative pressure, that is, common norms, values and knowledge held or engaged by professionals. The respondents said the following about the rationale for user involvement:

Professional 1: The rationale is political guidelines that the patient should be involved to a greater degree.

Professional 2: ...and it is given high priority throughout, and that is also because it is a political guideline that we have.

User representative 1: We can only hope that they understand that the quality will be better. But it may also be because it is politically imposed to involve users. So I reckon maybe it is something in between.

User representative 2: Alibi. Yeah, but that is straight talking. We are alibis. The Minister of Health said, “we must involve users in order to give this legitimacy”. (...) I am not sure that the end result will turn out so differently because we are involved, but the fact that we are (gives legitimacy to the process).

User representative 2: It is all about legitimacy, about giving this legitimacy. And it is the users that I am representing who will be referred to the pathway. It will be a pity for the Minister of Health, should he try to sell in this brilliant solution, and us users say that it is absolutely hopeless. Then he will struggle, because... he does have a vision about “the patient’s health service”.
User representative 3: *The reason they chose to involve us users is because there are such clear political guidelines for it (...).*

### 5.2.1 Decoupling vs. implementation

The user representatives gave some statements indicating a decoupling when it comes to user involvement in general, and not related to the current pathway development process. When they talked about this, they referred to processes in the past, or processes not related to the development of clinical pathways.

User representative 1: *Often we are not taken in early enough in the process, so a lot of the decisions are already made, and those matters that are important to us are already decided upon. And we arrive there in the end of the process because they are required to have users involved, but we don’t get any redemption at all. So then you kind of sit there like a hostage.*

User representative 2: *So, we just write “user involvement” with the appropriate number of frequencies within a public document, and then the services (supposedly) get better.*

User representative 2: *If this is the patients’ health service – the patient should be in the center it is often said. But there is never a patient in the center. Because it is always the framework for the services, that are in the center.*

User representative 3: *Yes, I think that Norway is, as a welfare system, an amazing country on paper. But we are also struggling to get what is written on paper implemented through the system and into the first line to the service user.*

However, the following quotations indicates that user involvement, especially in clinical pathway development, is more implemented, and less decoupled than user involvement on
system level was some years ago. These quotations are an indication of the process that has led to a change in how user involvement is being applied.

Professional 1: Before, there was often one user involved, it was like - "we need to have a user representative". So there was one included, who represented, and sat in meetings with a bunch of professionals, alone. And it’s hard to speak up in this kind of setting. Whether it is a patient, a relative – they don’t have the same confidence and talent, as do trained professionals. So to raise their voice in such an assembly is difficult, and it is easier if you are not alone. So there should be at least two user representatives. And in our group there are three. And they are very articulate and active people.

Group leader 2: Changing the system takes time. Change in itself takes time. And off course, it is one thing what we who sit in this glass house are saying, but it is really about the extent to which it is implemented, and a mixture of carrot and stick must be used.

User representative 3: ...and it (user involvement) has eventually become very established and rooted in the Directorate of Health’s culture and foundation. They are really starting to get the hang of it now, with user involvement. So it would be quite unthinkable for them to do something like this without involving us. It is our experience in everything they do, at least in the field of mental health and substance abuse, that we are very well established when it comes to user involvement, no doubt about that.

Several respondents gave statements indicating that user involvement in clinical pathway development is actually fully implemented, in that users are involved on the same grounds as professionals. These quotations provide a picture of the working groups as equal
partnerships where user representatives are just as important and involved as the rest of the group:

Professional 1: They are on board on the same level as all the professionals, they attend all meetings and their voices are heard just as much.

Interviewer: Do you feel that you have been involved into the process early enough this time?
User representative 1: Yes, I think so. And since I have also been a representative in the user council, we have been very well informed about the clinical pathways, and the planning before working groups were formed. So I feel that we are well established in this.

User representative 2: ...I also feel that it is an equal collaboration...

User representative 2: I don’t feel like we are getting special treatment because we are users, and if we did I think I would have been pissed. Yeah, but it is about taking people seriously.

User representative 3: ...it has always been our goal that our knowledge would be equated with the professional knowledge. And I think we’re about getting there, in this group, because we are starting to get responsibility. It has actually come to the point where me and the other user representative have been like – oh shit, this is almost a little scary (...) because now we have finally achieved equality, and being equal also means that we have to be responsible.

User representative 3: In those cases where we push hard, we are used to being heard a lot. (...) and we do recognize the suggestions and things we have said, we recognize those things in the documents that are being formed.
6.0 Discussion

The findings may shed some light on the research question: How can we understand the role of user involvement in clinical pathway development for mental health and substance abuse? Two hypotheses have formed the basis for exploring this topic. From an instrumental perspective, it was expected that user involvement be seen as a tool in a development process where all stakeholders are represented and should negotiate their views, and where the chosen solution reflects the power relationship between the stakeholders. If one looks at the Directorate of Health, their members, and processes from an instrumental perspective, as fundamentally rational, one would see how user involvement is a method applied in order to engage in quality improvement, and develop a product that is useful and desirable for those who are to benefit from it. All of the respondents shared this view on user involvement, whether on individual level or on system level.

From a myth perspective, it was expected that user involvement as a method in the development of pathways for mental health, be adopted through a certain pressure, in order to legitimize the process. Certainly, if one looks at the Directorate of Health and their members from an institutional perspective, as fundamentally rational, one would see how user involvement is a method applied in order to engage in quality improvement, and develop a product that is useful and desirable for those who are to benefit from it. All of the respondents shared this view on user involvement, whether on individual level or on system level.

First of all, user involvement is first and foremost adopted through legislation, and is not something the Directorate can opt out. Both of the health professionals and all three user representatives interviewed, acknowledged that the involvement of users is grounded in political guidelines and legislations. Secondly, norms and values found in various professional groups in the organization and its environment constitutes a normative pressure to adopt user involvement as a method. User involvement is strongly advocated among health professionals in this case, and among the general population, as literature shows. Even though the evidence of the effect of user involvement is weak, it still has an intrinsic value and is a sound democratic principle that benefits from general support. As explained, from
an institutional perspective, the Directorate is dependent on legitimacy from the environment in order to survive. Thus, it faces a pressure to adopt user involvement as a method.

Additionally, through a myth perspective, one would not only expect user involvement to be adopted as a method in the development of clinical pathways in order to give legitimacy to the process and achieve acceptance from the environment, but also to be subject of decoupling when attempting to implement it. However, the findings of this study provide little evidence for the decoupling of user involvement. Had there been a decoupling, user involvement would have been adopted as a formal policy that did not affect to a noteworthy degree the actions and processes going on in the Directorate. This would allow the organization to maintain efficiency in usual practice. The policy of involving users at all levels would then function as “window dressing” intended to gain legitimacy with the members of the external environment. Had this been the case, the user representatives in the working groups would have expressed dissatisfaction with their ability to influence the process of developing clinical pathways. However, they all expressed a high degree of contentment with their involvement in the process from the beginning, and their opportunities to influence decisions. Their experience is that their opinions are heard and considered on the same level as the professionals in the group, if not more.

Whether or not user involvement is adopted through coercive or normative pressure, it seems clear in this case that its use is instrumental, and that those who work with user representatives see the value of it in terms of getting different perspectives into the process, and developing better clinical pathways. The instrumental view on the use of user involvement is not, as this paper have shown, based on a complete knowledge base on the effects of user involvement, as this knowledge base is severely limited. As the instrumental perspective assumes that members of the organizations act rationally, choosing carefully between alternatives with known consequences, one might argue that the assertion of an instrumental view on user involvement is wrongful. I would, however, rather argue that the
distinction between the instrumental perspective and the myth perspective is in reality not as clear as the theory portrays. It is indeed true that user involvement as a formal part of the organizational structure, has been adopted through a coercive and normative pressure, as suggested from a myth perspective. But it is also right to claim that user involvement has been adopted through a rational assumption from the decision makers that its use will lead to better services. These results tell us that making a clear distinction between the instrumental and myth perspective is problematic in reality. Policymaking is often based on assumptions and values, rather than hard facts and evidence, but it doesn’t necessarily mean that different organizational recipes are adopted solely in order to get legitimacy from the environment, and are thus decoupled from the actual practice in the organization. The Directorate of Health has proven that an organizational recipe adopted in the name of legitimization, can indeed be fully implemented in the organizational structure and lead to actual changes in actions and behavior.

One thing that further emphasizes the instrumental rationale of user involvement is the increasing use of “professional” user representatives, which several of the respondents referred to. A few of the respondents talked about how some years ago, it was more common to involve users who were in the middle of mental illness and drug abuse problems. They all described this as less suitable, because these users had difficulties of generalizing their views and opinions, and were less able to see the “big picture”. Today, user representatives are usually out of mental illness and drug abuse, and also educated to a greater degree on what their role as user representatives are. According to the respondents, this provides as a better foundation for appropriately applying user involvement in the development of clinical pathways, because of the more nuanced and reflected views and perspectives the user representatives contribute with, and because it leads to better collaboration and group dynamics. In addition, it might lead to less stigma and discrimination in the working groups, which the literature has shown to be a problem among people who use drugs. However, Cowden and Singh (2007) provide an opposing view on the use of professional user representatives in policy planning and development.
They problematize it, and point to the way in which it is easy for institutions to define “user involvement” through an essentially collaborative arrangement between themselves and groups of “professional users”, and being in control of which users they listen to, and which users they decide to be “too difficult” to incorporate. One respondent in this study, a user representative, did also problematize it when the Directorate of Health hand picked the user representatives they wanted to include in the working groups, and pointed out that it might be better for the issue of representativeness to involve users who were both professional representatives and users who were not:

It’s about representativeness, right. And when you think about it, I have been employed as a user representative for 10 years. This role is off course something that has had an impact on me, I mean, you come in, you’re on a first name basis, you grow into this sort of environment. And there might be some disadvantages with this fact, because you lose this kind of freshness. But at the same time, we who have worked for this long, who are so called professional user representatives, we have also acquired a competence – we are easy to collaborate with because we know the system, we know the guidelines. We are becoming very equal in one way, which has been our goal. Our goal has been that our knowledge be equated with the professional knowledge. (...) So maybe, what one could have wished for, is that there would always be one experienced user representative involved, and also one who was new.

The user representatives interviewed did also present some statements indicating a decoupling of user involvement, not in clinical pathway development, but generally. One respondent said that often they are not included in policy development from the beginning, and therefore are not able to reach through with their opinions. Another said that “user involvement” was just a word used in official documents. The third said that user involvement is good on paper, but we as a country have difficulties getting it implemented through the system and out to the first line. All of these statements indicate that user
involvement has been subject to decoupling in the past, and may still be in some cases. The decoupling theory maintains that attempts to change organizations through new recipes will often be limited to just a linguistic change, so that leaders may talk about user involvement without actually implementing it into new routines and practices (Christensen et al., 2007). Some evidence does suggest that this theory is too simple and does not encompass the possible outcomes of implementation. The choice to use organization theory to shed light on the results was a prerequisite for the assumptions made about the role of user involvement. However, the results of this study indicate that the selected perspectives are not sufficient to explain this phenomenon. According to the findings, one cannot rule out one or the other perspective. Other theories and perspectives could perhaps have complemented the instrumental and institutional perspectives chosen, in order to give a more accurate picture of the role of user involvement.

The virus theory is another theory attempting to look at long-term effects of adopting recipes, and shows that decoupling can be explained through other theories than the myth perspective. It says that new terminology may, over time, also give rise to new routines and practices, in other words, talk and action may be coupled in the long run. The term “virus” is used metaphorically to describe new recipes that come into an organization like a sort of “linguistic infection”, and which usually, after a relatively long period of “incubation”, express themselves in changed routines and practices (Røvik, 2009). This theory may offer an explanation for the increasing instrumental use of user involvement methods over time. One respondent, a user representative, gave quite a descriptive statement regarding the change over the last decade:

*It has been a long way to get where we are today. It wasn’t like this at all, 10 years ago. Initially, when I started working as a user representative, it was like – I was not allowed to be a part of things, and we had to fight for them to open doors and… When we eventually were allowed in, they were often like “oh, so you are the user representative…” (soft, compassionate voice). So we spent a lot of time explaining*
that we did not come to tell our story. We spent a lot of time gaining acceptance for that fact that we possess a competence, that the knowledge we have is in fact a competence. (...) We were soon considered to be too outspoken, too rebellious, too loud... We are much more well behaved today, than what we used to be. But I think that it was necessary in order to get where we are today.

Van Wersch and Eccles (2001) recommended considering, and reporting on, using more than a single method of user involvement, as they found that each method alone would probably be limited. In fact, in this case, involving user representatives in working groups is only one of the methods the Directorate of Health is utilizing. They also have a user council in the field of mental health and substance abuse, consisting of 18 representatives for user organizations, some of them also part of the working groups. They meet 6 times a year, and representatives for the Directorate are part of each meeting in order to report on status and get input from the users. According to the respondents, there is a close collaboration going on with the user council. Here, they have a chance to bring up issues or problems regarding user involvement that might come up during the pathway development process. In addition to this, the Directorate has also employed one user representative in a position at a superior level regarding the clinical pathways, whose job is to safeguard user involvement all throughout the pathways. This person acts as a leader of an expert group on user involvement. A couple of the user representatives interviewed did mention the positive effect of this measure on the process.

This combination of methods of user involvement applied in the clinical pathway process seems to have had a positive impact. All of the respondents expressed satisfaction with how users have been involved in this process, and most of the respondents even expressed how much more appropriate and sensible the use of user involvement has been in this process compared to similar processes a few years ago. This finding may imply that future policy makers may successfully adopt this combination of measures as an instrumental way of applying user involvement. With this said, while this model of user involvement have
proven to be successful in the development process of clinical pathways, it still remains to have user involvement implemented through the system and out to the first line services, which indeed is something that some of the respondents mentioned to be a challenge. One may understand the case of user involvement in developing clinical pathways for mental health and substance abuse in Norway as a success story within user involvement in policy development for mental health. It seems to be a genuine priority seen from the Directorate of Health’s point of view, and user representatives seem to be satisfied with the level of influence they are able to achieve. The basic idea is that the involvement of users lead to better clinical pathways – however, there has been applied no matter of measurement to prove this. There is no way to tell whether the user involvement actually has an impact on the final product result. It would be relevant for future research to address this, seeing as many resources are being spent on the issue. Although, whether or not it does have an impact on the end result does not take away the intrinsic value of user involvement previously mentioned, and the fact that it is a democratic principle, which gives legitimacy to the process.

When looking at these findings in light of international literature found on user involvement, which is inconsistent and skeptical, it may seem like Norway is uniquely successful. This may also be the case, and if so, Norway is not comparable to other countries. It may also be the case that the literature referred to in this thesis is expired. As discussed, the pressure to adopt user involvement has increased, and the implementation process has slowly changed and gone from loosely coupled to almost fully implemented the last decade, as the respondents in this study have talked about. Some of the literature referred to here is in fact more than a decade old. It is natural to think that the same pressure, and the same implementation process has been undergone, also internationally. In so case, it is necessary with new research regarding user involvement in mental health policy making.
6.1 Limitations of study

The method of data collection was based on semi-structured interviews, and so no data triangulation was employed in this study. According to Yin (2014, p. 119-120), the main idea in collecting case study data is to triangulate, or establish converging lines of evidence to make the findings as robust as possible, and the need to do this in case studies far exceeds that in other research methods. By adding one or more methods of data collection, for example observation, the thesis could have demonstrated a higher degree of validity and reliability. The lack of triangulation also applies when it comes to investigator triangulation, and a second researcher to review the data and perform the analysis would possibly have produced more objective results.

Considering the quality of the data generated, there is a chance that the interview situation was affected by the role of the researcher as interviewer. In this study, the researcher performed qualitative interviews for the first time, and was not trained in the method on beforehand, and as mentioned, the quality of the data generated is affected by the experience, skills and commitment of the interviewer (Kumar, 2014, p. 183). The lack of training and experience may also have resulted in framing of questions and/or the interpretation of responses, even though this was deliberately attempted avoided.
7.0 Conclusion

Although research on the topic is inconsistent, the importance of user involvement is widely recognized and is a statutory right in several countries. When it comes to mental health and substance abuse, user involvement can be seen to be especially important, but also especially challenging. Given the gap in the literature on this topic, the objective of this thesis was to explore the role of user involvement in mental health and substance abuse, through the development of clinical pathways in the Directorate of Health. Main findings show that user involvement is applied in the pathway development process due to the legislation that imposes it, but also due to a genuine belief that involving user representatives will result in better clinical pathways that will appeal more to the service users. The application of user involvement has to a greater degree been decoupled from actual practices in the past, and perhaps still in some cases, but findings from this study show that it has become better implemented during the last decade, and in the case of clinical pathway development is perceived as almost fully implemented. It seems that a combination of methods of user involvement, rather than just a single method, may be decisive for its perceived success. It was beyond the scope of this paper to explore the implementation of user involvement through the system and to the first line services, but the findings indicate that this issue is more unclear and challenging. Future research may address this in order to uncover whether the positive development of user involvement has been present also in the providing of health services, and not just in the development of health policies. In addition to this, it would be relevant to examine the actual effects of involving users in policy development, in order to be able to justify it through instrumental reasons, and not just through legitimacy – the genuine assumption that involving users will lead to better services would benefit from evidence, as considerable resources are being placed on this.
References


Appendix 1: Request for participation in study

Forespørsel om deltakelse i forskningsprosjektet
"Brukermedvirkning i utviklingen av pakkeforløp for psykisk helse og rus"

Bakgrunn og formål

Problemstilling: På hvilken måte blir brukermedvirkning ivaretatt under utviklingen av pakkeforløp for psykisk helse og rus?

Utvalget består av representanter fra brukerorganisasjoner i psykisk helse/rus, samt prosjektledere for utvikling av pakkeforløp (eller andre relevante deltagere). Når vedkommende får denne forespørselen, er det fordi navnet deres står oppført som deltaker av en arbeidsgruppe for utvikling av pakkeforløp.

Hva innebærer deltakelse i studien?
Oppgaven er et casestudie og datainnsamling vil hovedsakelig bestå av personlige, semi-strukturerte intervjuer som vil vare i omtrent en time. Verken direkte eller indirekte personidentifiserende opplysninger vil bli brukt i oppgaven. Det vil ikke fremgå hvilken arbeidsgruppe intervjuobjektene er hentet fra, og det vil heller ikke fremgå hvilken brukerorganisasjon intervjuobjektene er ansatt i. Opplysninger innhentet under intervjuet vil bli registrert som lydopptak som slettes etter transkribering.

Hva skjer med informasjonen om deg?
Alle personopplysninger vil bli behandlet konfidensielt. Kun student og veileder vil ha tilgang til personopplysninger, som vil bli laget på privat, passordbeskyttet pc. Deltakere vil ikke kunne gjenkjennes i publikasjon.

Prosjektet skal etter planen avsluttes 15.05.17. Etter dette vil registrerte lydopptak slettes, og personopplysninger anonymiseres.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert.

Dersom du ønsker å delta eller har spørsomål til studien, ta kontakt med Margrethe Aaen Erlandsen, tlf 95228994, e-post m.a.erlandsen@studmed.uio.no eller veileder Trond Tjerbo, e-post trond.tjerbo@medisin.uio.no.

Studien er meldt til Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.
Samtykke til deltagelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

----------------------------------------------------------------------------------------------------------------
(Signert av prosjektdeltaker, dato)
Appendix 2: Interview guide

Nøkkelspørsmål

Hvordan er prosessen med utvikling av pakkeforløpene lagt opp?

- Valg av tilstand/diagnose som skal få pakkeforløp
- Valg av deltakere i arbeidsgruppe
- Hvordan arbeidsgruppen jobber med pakkeforløpene

Hvilket rasjonale legges til grunn for å involvere brukere i planlegging og utforming av pakkeforløp/helsetjenester generelt? (Hvorfor er det viktig? Hva er målet?)

- Bedre tjenester?
- Demokratisk prinsipp?
- Legitimitet?

På hvilken måte blir brukere involvert i planleggingsprosessen av pakkeforløpene? (Hvilke metoder for brukermedvirkning blir benyttet?)

- Konsultasjon?
- Samarbeid?

I hvilken grad føler du/dere at målet for brukermedvirkning oppnås ved å benytte disse metodene?

I hvilken grad mener du/dere at brukerrepresentantene er representative for brukergruppen pakkeforløpet lages for?

Hvordan påvirker brukerrepresentantene prosessen? (Hvilke muligheter har brukerrepresentanter til å påvirke prosessen?)

Hvordan påvirker brukerrepresentantene beslutninger? (Hvilke muligheter har brukerrepresentanter til å påvirke beslutninger?)

Hva er fordelene med å involvere brukere i planlegging? (Hva er fordelene med å bli involvert?)

Hva er ulempene med å involvere brukere i planlegging? (Hva er ulempene med å bli involvert?)

Oppsummering og sluttkommentar
Appendix 3: Approval by the Norwegian Data Protection Officer

Trond Tjerbo
Institutt for helse og samfunn Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår dat: 22.02.2017 Vår ref: 52514 / 3 / AH Døres dato: Døres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 25.01.2017. Meldingen gjelder prosjektet:

52514 User involvement in developing clinical pathways for mental health and substance abuse
Behandlingsansvarlig Universitetet i Oslo, ved institusjonens øverste leder
Døg til ansvarlig Trond Tjerbo
Student Margrethe Aaen Erlandsen

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldeplichtig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med 'forskrifter. Behandlingen av personopplysninger kan settes i gang.


Personvernombudet vil ved prosjektets avslutning, 15.05.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Kontaktperson: Åsne Halskau tlf: 55 58 21 88

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.
Vedlegg: Prosjektvurdering
Kopi: Margrethe Aaen Erlandsen m.a.erlandsen@studmed.uio.no
Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjekt nr. 52514

Formålet til masteroppgaven er å granske utviklingsprosessen for pakkeforløpene i psykisk helse og rus.

Utvalget består av representanter/prosjektledere i brukerorganisasjoner for psykisk helse og rus som deltar i prosessen med å utvikle pakkeforløp. Personvernombudet forstår det slik at dette er ansette i relevante organisasjoner og icke rusmisbrukere/personer med psykiske problemer. Vi legger vekt på det at tautheiskheten ikke er til hinder for rekruering og behandling av personopplysninger i prosjektet.

Utvalget informeres skriftlig og mundtlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

Personvernombudet legger til grunn at forsker etterfølger Universitetet i Oslo sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på privat pc/mobile enheter, bør opplysningene krypteres tilstrekkelig.

Det oppgis at personopplysninger skal publiseres. Personvernombudet legger til grunn at det foreligger eksplisitt samtykke fra den enkelte til dette. Vi anbefaler at deltakerne gir anledning til å lese igjenom egne opplysninger og godkjennes disse før publisering.

Forvekslet prosjektet slutt er 15.05.2017. Ifølge prosjektmeldingen skal innanslede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersona kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkler)
- slette/omskrive indirekte personopplysninger (identifierende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidsssted, alder og kjønn)
- slette digitale lyd-/bilde- og videoopptak