

# User participation in decision-making – a qualitative intervention study on mental health professionals’ experiences

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*Ethical approval:* The study was granted ethical approval by the Regional Ethical Review Board: 2012-198-310.

## Abstract

**Purpose** – *The purpose of this study was to describe mental health professionals’ experiences of changes in attitudes towards, and knowledge about, users of mental health-care recovery and decisional participation in clinical practice after an educational intervention.*

**Design/methodology/approach** – *Users of mental health care want to participate in decisions regarding their own mental health care. Shared decision-making as a method is coherent with recovery orientation in mental health services and results in better-informed patients and fewer conflicts regarding decisions. A qualitative intervention study was designed to evaluate changes in attitudes and knowledge about mental health recovery in Sweden. Nine participants were interviewed, and the data were analysed by content analysis.*

**Findings** – *Three categories were generated from the analysis: Increased theoretical knowledge, changing attitudes about practical approaches and the significance of social factors in recovery.*

**Originality/value** – *When shared decision-making is to be implemented in mental health, professionals need to gain knowledge about recovery and need to adopt changed roles as health professionals. Educational interventions therefore seem necessary if such changes are to happen.*

**Keywords** *Mental health, Shared decision-making, Recovery, Educational intervention*

**Paper type** *Research paper*

## Introduction

There is a need for developing interventions that strengthen the opportunities for users of mental health care (hereafter referred to as “users”) to be empowered and to play an active part in decisions regarding their treatment and everyday life situation (Stiggelbout, 2012). The user’s right to participate in the planning of their own treatment is important and is legally required in Sweden (National Board of Health and Welfare, 2018) and in several other countries, both in psychiatric care and in other domains of health services (Härter *et al.*, 2017).

Users want to participate in decisions (Dahlqvist Jönsson *et al.*, 2015), and studies have shown that mental health professionals (MHPs) are aware of this (Chang *et al.*, 2021). In a recovery-oriented system, shared decision-making is considered as a central component (Slade *et al.*, 2012; Slade, 2017). *Recovery* refers to a personal way of living a satisfying, hopeful, and contributing life even within the limitations caused by a psychiatric illness (Anthony, 1993). Shared decision-making is an interactive process between at least two individuals (patient and professional) in which information and opinions are shared, the patient’s preferences and the professional’s responsibilities are discussed and finally the two parties agree on a course of action (Towle and Godolphin, 1999). In terms of psychiatric

rehabilitation, shared decision-making has been identified as an important component in the process (Drake *et al.*, 2010), and this is strengthened by users' own experiences (Chambers *et al.*, 2014) that include participation, hopefulness, identity, meaningfulness and empowerment (Slade, 2009). A recent study by Hamann *et al.* (2020) highlighted that even severely mentally ill patients benefit from using shared decision-making.

It is important to educate MHPs about recovery-oriented systems so that they can become a practical reality (Jørgensen, 2020). Randomized controlled trials have shown that skills training in shared decision-making for professionals improves observed and patient-experienced shared decision-making (Geiger *et al.*, 2017). Although shared decision-making is identified as an important component for recovery (Huang *et al.*, 2020), shared decision-making is not routinely implemented. Identified barriers for this are both on the individual level (MHPs and users) and on the organisational and system levels (Dahl Steffensen *et al.*, 2017; Légaré *et al.*, 2017).

A coordination planning document is to be produced when a user has needs for support and has the rights to receive care. One of the major components in such a document is that the user is supposed to actively participate in the planning and decisions being made. A coordination planning document is established. In the context of a major national effort in Sweden to develop working methods around users' rights to participation and to coordinate the planning of their care and efforts, a pedagogical intervention was carried out with professionals, persons from the user organisations and users' relatives. The training was developed from existing knowledge about shared decision-making and recovery-oriented practice by a research team in Sweden.

Educational interventions that include shared decision-making in a recovery-oriented practice need to be further developed and evaluated, and there is a need of further research regarding MHPs and how they can work with shared decision-making in practice (Haugom, 2020). The aim of this study was to describe MHPs' experiences of changes in attitudes towards, and knowledge about, recovery of users of mental health care and decisional participation in clinical practice after an educational intervention addressed to professionals as well as users and their relatives.

## Methodology

A two-day educational intervention was performed in the spring of 2014 on five different occasions in Sweden including a total of 87 persons. People attending worked with users in psychosocial or inpatient psychiatric services, service users or users' relatives. They were all persons who might be involved in coordinated planning from different aspects, such as users, professionals and relatives. The purpose was to educate about coordinated planning, recovery-oriented practice, the fundamental principles of shared decision-making in psychiatric care and how to use shared decision-making as a tool in practice in such a context.

The educational intervention involved a group of researchers and users and consisted of traditional lecturing about the subjects, group discussions, practical exercises and role-playing (Table 1). Those participating were encouraged to explore their own conception of recovery, identifying the pros and cons of involving users in decision-making processes and developing ways of applying perspectives of recovery in their own workplaces.

For the professionals attending, there were assignments to do and implementation guides to use in practice at their workplaces. The participants were also given the opportunity for online tutoring, one to one, given by the educational team afterwards.

## Participants

The inclusion criterion for this study was: professionals working with users in psychosocial or inpatient psychiatric services that had participated in the educational intervention, and

**Table 1** Programme of the educational intervention (course syllabus, CEPI 2014)

<i>Day 1</i> Shared decision-making in a recovery-oriented practice	<i>Day 2</i> To promote shared decision-making
<ul style="list-style-type: none"> <li>■ Introduction and information</li> <li>■ Ethical values discussion</li> <li>■ Basic principles of recovery in psychiatric care and nursing</li> <li>■ Factors that promote recovery</li> <li>■ Group discussions about recovery and CSP (coordinated service plan)</li> <li>■ Common discussion about recovery and CSP</li> <li>■ Shared decision-making</li> <li>■ Preparing for homework and ending the day</li> </ul>	<ul style="list-style-type: none"> <li>■ Introduction and information about day two</li> <li>■ Practical information about shared decision-making</li> <li>■ Short movies</li> <li>■ What kind of support do you need in the decision-making process</li> <li>■ Group discussions about decision-making</li> <li>■ Common discussion about how to move on</li> <li>■ Review of the homework</li> <li>■ Ending the education and preparing for the homework regarding implementation</li> </ul>

the exclusion criterion was: persons attending the educational intervention but not having a professional role with users, for example, users themselves and user relatives. Out of the five different educational intervention occasions, one group was chosen for this study. There were 22 attending on the chosen occasion and 6 were excluded (5 users and 1 relative) because of meeting the exclusion criterion. All 16 remaining were accepted to be part of the study and 9 were interviewed. They represent professionals from both psychosocial and inpatient psychiatric services (Table 2). There were no drop outs in this study.

The participants were asked personally to participate in the qualitative study. They were informed that the research was about shared decision-making, and prior to the interviews the participants were sent a letter with information including an informed consent form to be signed and returned to the researcher. Immediately prior to the interviews, the researcher also requested a verbal confirmation to ensure voluntary consent.

The participants were given the opportunity to choose the time and day, within two months after the training, for the interview, and because the interviews were carried out by telephone the participants were also able to choose where the interview should take place. The participants were alone in the room when the interview was conducted.

**Table 2** Demographic data of the participants ( $n = 9$ )

	No.
<i>Age (mean)</i>	46 (37–64) years
<i>Sex</i>	
Men	3
Women	6
<i>Years in profession</i>	
6–10	1
11–15	3
16–20	1
21 or more	1
<i>Experience of education in shared decision-making</i>	
Yes	2
No	7
<i>Experience of education in recovery</i>	
Yes	4
No	5

## Study design

A qualitative approach, with semi-structured interviews from an interview guide, developed by the researchers, was used. To focus on attitudes towards and knowledge about recovery, the questions were developed so as to correspond to the aim of the study. Six basic open questions formed an interview guide for the interviews which are as follows:

Interview guide:

Since the educational intervention, I would like you to tell me if you experienced changes in your attitudes or your daily work regarding mental health recovery. I'm going to ask you questions about how you experienced situations before the educational intervention and how you managed them, and then I will ask you to explain how you now, after the educational intervention, experience and handle these situations.

Before we begin the interview, I want to remind you that this is voluntary and that you have the right to end the interview whenever you like to without explaining why.

### Aim

The aim of this study was to describe MHPs' experiences of changes in attitudes towards, and knowledge about, users of mental health-care recovery and decisional participation in clinical practice after an educational intervention which was addressed to professionals as well as users and their relatives:

1. Could you describe/explain how you experienced the recovery process before the educational intervention?

How... Why...

2. What effect has the educational intervention had on your experiences with the recovery process?

What... Describe...

3. Before the educational intervention, how did you experience responsibility regarding recovery?

The user [...] The professional [...]

4. Since the educational intervention, how do you experience roles and responsibility regarding recovery?

The user [...] The professional [...]

5. Before the education, what kinds of roles did you feel that significant others and other individuals played for the user?

Tell me more [...] Experiences [...] Describe [...]

6. Since the educational intervention – how do you experience the roles of significant others and other individuals for the user?

Tell me more [...] Experiences [...] Describe [...]

Prior to the study a pilot interview was carried out to test the interview guide (Polit and Beck, 2012). Data from the pilot interview were analysed by content analysis, and the results indicated that the interview guide worked well. Results from the pilot interview were not included in this study.

The interviews were audio recorded and lasted 34–77 min (mean = 48 min). During the interviews, comments and observations from the researcher were written down.

## Analysis

The data were analysed, coded and discussed according to manifest content analysis (Graneheim and Lundman; 2004; Graneheim *et al.*, 2017). The interviews were transcribed verbatim in Microsoft Word, and the data were then analysed and coded by one of the researchers and discussed with two of the other researchers. Saturation was considered to have been reached after the ninth interview. To gain an overall sense of the transcripts, the interviews were read several times and meaning units were identified. The meaning units were then condensed to obtain the essence of the text without affecting its meaning. The condensed text was abstracted into codes, namely, words or short sentences, to facilitate sorting and maintaining order in the analysis. Codes with a similar content were put together in sub-categories. After a process of division and sorting among the sub-categories, three categories and eight sub-categories were identified (Table 3). The original interviews were listened to repeatedly during the analysis process to ensure that the essence of the material was not affected or changed. By using content analysis, it was possible to draw conclusions and to present a result that is based on the participants' experiences (Table 4, examples from the analysis).

All of the authors, except one, were involved in both the educational intervention and the analysis of the data. The one who was not involved in the educational intervention was involved in the analysis of the data. The team consisted of three female and four male authors, including two doctoral students and four clinical researchers. All of the authors are trained in qualitative research.

## Ethical considerations

The study was granted ethical approval by the Regional Ethical Review Board: 2012-198-31Ö. All participants completed a consent form.

## Results

The analysis resulted in three categories – *increased theoretical knowledge*, *changing attitudes about practical approaches* and *the significance of social factors in recovery*.

**Table 3** Results presented in categories and sub-categories

Category	Sub-category
Increased theoretical knowledge	Increased understanding of the definition of recovery for MHPs Recovery as a non-linear process
Changing attitudes about practical approaches	The concept of recovery means support Efforts to allow users to take responsibility for themselves Allowing users to assess their situation
The significance of social factors in recovery	Shared decision-making as a model to increase participation in practice Greater awareness about network collaboration MHPs require more involvement of significant others

**Table 4** Example from content analysis based on Graneheim and Lundman (2004) and Graneheim *et al.* (2017)

Meaning unit	Condensed meaning unit	Code	Sub-category	Category
P4 Now with this new term that I've learned // . . . // recovery was a new term for me. . .	Recovery was a new term	Recovery new term	Increased understanding of the definition of recovery for MHPs	Increased theoretical knowledge

Each category consisted of several sub-categories. In the results presented below, each sub-category has examples of quotations from the participants. Each quotation is marked by a specific participant number.

### *Increased theoretical knowledge*

The participants were previously acquainted in various ways with the theories about recovery that were presented at the educational intervention, but they had now developed their knowledge further about recovery and what this means.

*Increased understanding of the definition of recovery for mental health professionals.* For those who were already familiar with the term it was a reminder, and they gained greater knowledge about the concept. For some of the participants the term “recovery” constituted new knowledge, and it emerged that knowing that the use of the concept of recovery also provided hope to users was important:

P7 The recovery process isn't a concept that I've previously been in contact with at work. It's a new term for me.

P6 A hope that it is possible (recovery) and that maybe we can convey this hope. Now we have the knowledge//. . //yes, we can convey hope. That's important I think.

*Recovery as a non-linear process.* The participants had gained greater theoretical knowledge about the fact that recovery is a unique, non-linear and individual process. The participants spoke of previous experiences of a great focus on getting the person “healthy” and “well” again from the MHPs' perspective, after an episode of mental illness. The educational intervention helped them to understand that recovery from mental illness is an individual process and not the professionals' definition of being well or not well:

P2 in plain terms, recovery for me, it becomes something that's very individual. Because everybody recovers in different ways, I think [. . .].

Participants discovered that recovery did not entail always progressing by moving forward all the time. Recovery was mentioned as an individual journey, without a specific destination or date of arrival, and furthermore that recovery takes time:

P7 I got help to put (the recovery process) into words, and I was also confirmed in thinking that it's // . . // like a long journey.

*Concept of recovery means support.* The participants talked about experiencing an eye-opener in theoretical terms and realising that they sometimes had been over-involved in giving too much support, and being over-protective in the past, because they were taught to do so in their prior education and learning. The educational intervention had made the participants aware of the amount of care and support that some individuals need to be as independent as possible:

P3 The intervention is supposed to be, I'll support you. I'll come with you to the door at the job centre.

The participants expressed that they now were aware that individuals in a recovery process might need extensive interventions or services in various forms, for a limited period, but in the end, the MHPs might not even be a part of the person's life anymore because there is no need for them to be:

P1 Giving support is just one part of recovery, but in the end, we might not even need to be there and might not even need to give any support at all.

### *Changing attitudes about practical approaches*

MHPs experienced and became aware of how their practical work could or may change after the education intervention.

*Efforts to allow users to take responsibility for themselves.* The fact that the users should be involved in their care was known to the participants, but the educational intervention made it clear that the users should be even more involved in the process than they were before:

P4 you have to work harder to get to know where the person is heading.

Since the educational intervention, reflections were shared about how the professionals generally had contributed to the individual being afraid of taking responsibility. The participants were empowered in how to communicate with and support the users to take responsibility in their lives, not by forcing them, but by actively supporting them:

P5 Giving back responsibility in a smart way, by only making small demands and letting them take part and believing that their opinions and thoughts are good.

*Allowing users to assess their situation.* The participants expressed that they, and other professionals around them, had worked in such a way that the user became powerless. They were now empowered regarding the importance for the user being involved in decisions, for example, in terms of treatment, and if the decisions do not turn out as the user wishes then this could be a useful learning experience for the user.

The educational intervention led to a deeper understanding about how they had previously been acting too protectively towards the users, in particular concerning allowing them to make their own mistakes. Traditionally it was deemed bad practice if a user is allowed to make a mistake or to fail in some way if the MHP could anticipate this result:

P5 No, I think that you want to [...] protect them from failure; you think that making mistakes is a setback.

The participants' roles as nurses, contact persons or in other positions as rehabilitators gave them an important role in relation to the clients. The participants spoke of this role as a difficult balance with the risk of becoming a "parent" to the user. They expressed that they now knew that no matter what situation was at hand, their job was to help and support, not only when there was an on-going positive process but also when failures occurred in daily life:

P7 You never know until you've tried // . . . // we don't want to support individuals so that they don't dare to try because of fear of doing wrong. Out of fear of making mistakes.

*Shared decision-making as a model to increase participation in practice.* The educational intervention gave solid knowledge about shared decision-making and what participation means in practice in shared decision-making. The participants became aware that if they were to allow the user to be a decision maker, they themselves would have to take on a new role as professionals. They had to allow the user to choose by informing about alternative decisions and then discussing the consequences of different decisions. Prior to learning about shared decision-making as a model, the participants were aware of having controlled users, not only in their everyday living with daily choices but also regarding care and rehabilitation interventions such as treatment methods and activities:

P4 If you say that you're working with these processes, and by that, I mean that you have to help them be aware and present them with visions about the future so that they can make a choice between them.

The participants were reinforced in their ambitions of helping the user to become a decision maker and thought that shared decision-making, as a model for participation and decision-making, would support them in working with user participation correctly:

P8 I've been strengthened in//. . //participation for the individuals and that they are to take part when decisions are made. I can argue more convincingly for that now.

### ***The significance of social factors in recovery***

This category concerns the participants' knowledge about social factors in everyday life and their meaning for the user's recovery process.

*Greater awareness about network collaboration.* The participants expressed that they had become more aware that MHPs and other professionals must learn to find ways to collaborate and to complement each other. The social services from the municipality, the psychiatric and health-care services from the health authorities, other professional competences and significant others together have an important role for the user and have a responsibility to collaborate in the user's care. The participants also gained greater awareness about social factors. Collaboration between social services and health care thus becomes more important in such a situation:

P2 Because I believe there's a lack of knowledge. I think that if we could collaborate and complement each other in a better way//. . //and take it from here where the psychiatric services stop. Then we could do a better job for the individual.

*Mental health professionals require more involvement of significant others.* During the educational intervention, the participants learned that the user's *significant others* were more important in the recovery process than the participants had previously believed. Inviting significant others to give and receive information and communication together with the users could have a positive impact on the recovery process. The significant others could have a role both in terms of supporting the user and of being someone who could "raise a red flag" if the user needed such support:

P1 Well, it's always important to think of using significant others as a resource.

The participants had realised during and after the educational intervention that it was part of their job to support the person in contacting family and to support them in keeping in contact:

P2 We could bring the relatives in much more around the individual and strengthen the user in doing that.

## **Discussion**

The aim of this study was to describe MHPs' experienced changes in attitudes towards, and knowledge about, users' recovery and decisional participation in clinical practice after an educational intervention, and the main result highlights a strengthened recovery orientation.

The educational intervention included not only traditional lecturing but also users as instructors. In addition, people attending were a mixed group of professionals, users and users' relatives. It is conceivable that the mix of these people and instructors might have contributed to the participants' opportunities to get new perspectives, as reflected in the results. This could be in line with what [Haugom et al. \(2020\)](#) calls for in research regarding the fact that MHPs need to be trained in recovery, to be reminded and to gain more knowledge about the recovery process.

The results indicate that if shared decision-making is to be incorporated in mental health care and services, awareness about recovery orientation is needed. In addition, the attitudes towards recovery must become a common value and approach for MHPs. This includes both cultural and ethical challenges, which has also been highlighted by [Slade \(2017\)](#). [Huang et al. \(2020\)](#) identified challenges concerning how shared decision-making has not been routinely implemented, and they demonstrated barriers to the individual as

well as at system level. Our results revealed that the MHPs talked about realising that the users need to be more involved in the planning of their care, and how MHPs need to take on a new role as professionals working *together with* the user and not working *for* the user. On the system and organisational levels, the MHPs wished for more involvement of significant others, which means new tasks for MHPs. The MHPs realised the importance of collaborating with, for example, the municipality and the psychiatric services to make supplementary types of interventions available for the users.

Shared decision-making was described by the participants as support for the participants to work on decision-making together with users in a structured way. Shared decision-making as a model would thus help MHPs to implement participation together with users. The participants mentioned that shared decision-making entails that the MHPs are “responsible” for presenting the possibilities and options that lie ahead for the user. [Slade \(2009\)](#) described how the MHP’s role in shared decision-making in practice is to present options to a person based on experience and knowledge.

The participants spoke of being aware that users should be more involved in decision-making and should become more responsible for their daily lives. [Castro et al. \(2016\)](#) described how, if empowerment is to be implemented, both patient participation and patient centredness are necessary. [Le Bouillier et al. \(2015\)](#) highlighted that important components of personal recovery are autonomy and decision-making.

The educational intervention helped the participants to understand that it was an extensive task to invite users to take responsibility for themselves and to become a part of their own decision-making. [Gyamfi et al. \(2020\)](#) also showed that MHPs need to respect users’ rights and to involve them in decisions concerning their lives. It is necessary to develop more educational interventions regarding shared decision-making for MHPs, which has also been highlighted by [Haugom et al. \(2020\)](#) whose MHP participants thought they were using shared decision-making in their practice but they were not working fully in accordance with the method.

There was also a greater awareness among the MHPs that they often had focused on trying to protect users from failure, and the participants expressed how they previously had been over-protective regarding users by trying to prevent them from making mistakes. A similar process is presented by [Chang et al. \(2021\)](#), who describes the importance of encouraging users to make their own decisions.

The study by [Haugom et al. \(2020\)](#) also highlights that there is a need for more comprehensive shared decision-making training, which includes a focus on values, attitudes, shared decision-making in clinical practice and communication skills. The results of this study encourage sustained educational interventions that should combine the transfer of values as well as practical skills. The participants expressed that they previously had worked in such a way that the user became powerless, and they had become aware of the fact that they had to change some of their approaches to their work, so that the users could believe in their own abilities.

### ***Limitations and strengths***

At first glance, the data collection may seem a bit outdated because it was collected in 2014, and this could therefore be perceived as a limitation. However, there have been no major changes in the organisation of the Swedish health-care and mental health-care system since 2014, and a recently published study ([Chang et al., 2021](#)) has highlighted that the results in this study seem as relevant now as they were in 2014.

The generalisability is limited as a consequence of the method and the small sample of participants. Also, the total of nine participants can certainly be seen as a vulnerable aspect of this study because important experiences may have been missed. On the other hand,

they represented a variety of characteristics and experiences, and the interviews analysed last indicated a certain degree of redundancy and thus sufficient saturation was assumed to have been obtained.

## Conclusion

The findings of this study highlight that there is a need for these kinds of educational interventions among MHPs, and there is a need for practical support and guidance in how to create a situation where MHPs and users can work together and share decisions. The educational intervention presented here shows that MHPs gained a wider understanding of the need to empower users and to give them the opportunity to take a central part in their own recovery.

When MHPs promote opportunities for users to become part of a decision-making process, it is not only about taking part in decisions, but it is a wider and deeper understanding that every person, no matter what illness or absence of illness they have, should be seen as an individual human being with equally common rights as others. The MHPs must learn to take a step back, allowing the person to take a step forward, but at the same time not abandoning them. The MHP must put extensive effort into supporting and guiding the person to be able to take part in decisions regarding their own care. It is not just a matter of changing one's perspective on decision-making, and in the end it is about professionals giving space, working extensively and guiding the individuals to learn how to be involved in decisions and how to take responsibility for themselves. However, it is important to reveal the outcomes of results regarding shared decision-making from the perspective of the users, which is being done in Sweden in an on-going study by [Sandlund \(2019\)](#).

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