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Legitimizing the knowledge of mental health service users in shared decision making

*Promoting participation through a web-
based decision support tool*

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Abstract:

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Aim: The overall aim of this thesis was to explore the manner in which user knowledge and user perspectives can be included and supported in shared decision making (SDM) in mental health services.

The thesis consists of four studies. Study I explored what needs service users identify to participate in deliberative processes and decision making in their care. Study II examined how a decision support tool (DST) for SDM can be designed to enhance service users' ability to have active and meaningful roles in SDM. Study III investigated barriers and facilitators associated with the implementation of a web-based DST designed to provide a concrete structure to support SDM. In study IV, a theoretical analysis was performed to elucidate the barriers associated with user knowledge being expressed and legitimized in decision-making processes.

Methods: A key feature of the project involved a process of exploring decisional and informational needs and of developing, testing and implementing a DST for SDM. Qualitative data have been collected through focus group and individual interviews with service users and service providers, usability testing with service users and checklists.

Findings: The findings show a number of characteristics specific to the mental health service context that need to be considered when developing support for SDM. Decisions were often complex and found to encompass a number of life domains. Issues related to social context and individual recovery highlighted the necessity to include the knowledge perspectives of service users throughout decision processes. In response, phases for *preparation* and *follow-up* was emphasized in the DST. The results indicate that supportive structures are required for service users to express their knowledge perspectives and for providers to include them in their decision-making. Moreover, existing barriers related to organizational structures and to power differentials need to be addressed.

Conclusions and implications: A DST specifically designed for the mental health context, that methodically invites service users to participate in each phase of the decision-making process might function as a guiding structure to validate service users as knowledgeable agents.

Keywords: User knowledge, SDM, Shared decision making, User involvement, User participation, Mental health services, Psychiatry

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This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Grim, K., Rosenberg, D., Svedberg, P., & Schön, U-K. (2016) Shared decision making in mental health care: A user perspective on decisional needs in community-based services. *International Journal of Qualitative Studies on Health and Well-being*, 11(1), 1-8.
- II Grim, K., Rosenberg, D., Svedberg, P., & Schön, U-K. (2017) Development and usability testing of a web-based decision support for service users and health professionals in psychiatric services. *Psychiatric rehabilitation journal*, 40(3): 293 – 302.
- III Schön, U-K., Grim, K., Wallin, L., Rosenberg, D., & Svedberg, P. (2018). Psychiatric service staff perceptions of implementing a shared decision making tool. A process evaluation study. *International journal of qualitative studies on health and well-being*, (13)1, 1-12.
- IV Grim, K., Tistad, M., Schön, U-K., Rosenberg, D. (2019) The legitimacy of user knowledge in decision-making processes in mental health care. An analysis of *epistemic injustice*. Submitted to *Journal of Psychosocial Rehabilitation and Mental Health*.

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Contents

Preface	11
Introduction.....	12
A growing recognition of user-knowledge.....	12
A lingering gap between policy and practice	13
The promise of shared decision making.....	14
Decision support tools for facilitating SDM.....	15
The context of the present study.....	16
Choice of terms in relation to the context.....	16
Rational.....	18
Overall and specific aims.....	19
Contextualizing SDM in the present research.....	20
Supporting relational autonomy	20
Recognizing barriers and facilitators to identify solutions.....	21
Theoretical concepts and frameworks.....	24
A model for practice as a conceptual framework.....	24
Theoretical frameworks as tools for conceptual clarification	25
Levels of participation	25
The legitimacy of expert knowledge	27
Emancipatory knowledge through reflective learning.....	28
A theoretic framework of <i>epistemic injustice</i>	29
A positive and dynamic perspective on agency	30
Methods	32
A participatory, evolving design	32
Overview of study designs, methods, participants and data analyses	34
Settings, sampling and participants	35
Study I.....	35
Study II	36
Study III.....	36
Study IV.....	37
Data collection.....	37
Focus group and individual interviews.....	37
Usability testing.....	38

Checklists.....	38
Extracting data for a theoretical analysis.....	39
Data analysis	39
The inductive procedures.....	40
Study I.....	40
Study II	41
Study III.....	41
Study IV.....	41
The field notes	42
Ethical considerations	43
Results.....	45
The value of user knowledge in continuous assessment and decision making.....	47
Diverse understandings of the values, prerequisites and barriers of SDM	47
Understanding and learning by testing, practicing and reflecting.....	49
Service users' perspectives on information and decisional needs – Study I	50
Addendums to the original model of Elwyn et al.....	51
Further adaptations in response to the mental health context.....	51
Developing decision support designed to strengthen active service user participation - Study II	52
Service user views and experiences.....	52
Service provider perceptions	53
Revisions made in response to views of respondents and testers	53
Service providers' perceptions in the implementation of SDM using a decision support tool (DST) - Study III.....	54
Perceived barriers to implementation	54
Perceived benefits of the DST	55
Prerequisites for successful implementation.....	55
Investigating the barriers involved in user knowledge being expressed and legitimized - Study IV	56
Testimonial injustice – having ones accounts unduly devalued	56
Participant-based injustice - not being invited as a collaborator	57
Hermeneutical injustice - not having resources for or control over interpretations	58
Discussion.....	60
Making explicit multiple mechanisms of covert power	61
False consensus due to conceptual unclarity	62
A logic of care as a barrier to partnership.....	64
Low trust in ability, agency and insight.....	65
The value of exploring assumptions underpinning practice.....	68

The DST as a tool for discovery	68
Supporting the legitimization and inclusion of user knowledge in decision-making processes	70
Methodological considerations.....	71
Strengths and limitations in relation to trustworthiness of findings	71
Reflexivity when studying the familiar – an account of self- monitoring in the role as an ‘insider’	73
Conclusions and implications	75
Suggestions for future research	76
Sammanfattning (in Swedish).....	78
Syfte	78
Metod	78
Resultat.....	79
Slutsatser	79
Acknowledgements.....	81
References.....	83

Abbreviations

DST	Decision support tool
EBP	Evidence-based practice
FGI	Focus group interview
SDM	Shared decision making
PCC	Person-centered care

Preface

Today, it is 6 years ago that I was invited to be a research assistant in an interdisciplinary research group devoted to promoting user participation and recovery orientation in mental health service delivery. The group had recently launched a project to support the implementation of shared decision making (SDM) in the Swedish mental health service system.

Previously, I had been engaged in the education and development section of The Swedish National Association for Social and Mental Health (RSMH), a context in which I first was introduced to the concept of *recovery*. In addition, it was there I first realized how personal experiences of illness could be recognized as a valuable source of knowledge and increased understanding - for professionals, for people with similar experiences and for oneself.

This thesis explores the possibilities for service users to be perceived and to perceive themselves as having valid and meaningful knowledge in decision-making processes.

Facing and coping with mental health problems might imply a plethora of experiences affecting people at every dimension of their life and personhood. As when any adversity strikes, when control is lost of what is known and what is safe, the challenge becomes to regain control and to make life work. Much of the knowledge on just this - what it takes to make a persons' life work - naturally lies with the person. And while professionals possess much knowledge on how to regain health and function, living and dealing with illness are not only a matter of surviving but also of thriving. Certainly, what gives a person joy in life is a matter of personal perspectives.

People who have travelled the road from acute crisis towards recovery recognize curves, bumps and occasional roadblocks as natural, inextricable elements in the process. However, many express that if the knowledge they had acquired from struggling with illness and from information-gathering practices had influenced decisions to a greater extent, the road from crisis to having a functioning and meaningful life would probably have been a bit shorter and less bumpy. Today, the notion of including this personal knowledge perspective in collaborative dialogue together with professionals is recognized as an inalienable part of qualitative service provision, even if the *how* in relation to this matter is still somewhat unclear. This *how* is the starting point of this thesis. The aspiration is to contribute to some roadwork ahead.

Introduction

A growing recognition of user-knowledge

During the past few decades, there has been an increased focus on user involvement within the planning and delivery of health care and social support service delivery. This development, occurring in several countries internationally, has a number of roots related to social changes and flows of ideas including the emphasis on social justice and the emergence of strong disability consumer movements during the 1960s and 1970s and, more recently, the orientation of welfare institutions towards market principles emphasizing consumer choice, autonomy and empowerment (Beresford, 2002; Vedung & Dahlberg, 2013). An ideological shift from professional control towards more active service user roles associated with rights as well as responsibilities has occurred. Service users of health-care and social services progressively expect to be active participants in the formation of their care and support. Thus there is a growing call for services to ensure transparency and accountability in the care and support delivered (Juhila, Hall, Günther, Raitakari, & Saario, 2015; Vedung & Dahlberg, 2013).

This interest in user involvement has been coupled with a scientific awareness of the importance of valuing the perspectives of service users' experiential knowledge in treatment and care and has generated a need for a modification of how decisions are made (Treichler & Spaulding, 2017). The framework of *person-centered care* (PCC) has been increasingly established in various models of care and support delivery, and is embedded in many policy frameworks and strategic plans internationally (Ekman et al., 2011; McCormack & McCance, 2010). Person-centeredness is characterized as “providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (Wolfe, 2001, p. 234).

Recently, a strong demand on welfare institutions and services to be knowledge- or evidence-based has emphasized user participation as an essential element of knowledge production. Service users personal knowledge has been presented as an inalienable component of an *evidence-based practice* (EBP) (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996) and is given an equivalent status as scientific and professional knowledge (Adams & Drake, 2006).

In the mental health field, these frameworks of PCC and EBP have been equally highlighted, and the value of user knowledge and user choice has been increasingly reinforced in the growing body of research on recovery that has begun to guide mental health systems internationally during the past three decades.

From this research, a framework of *recovery* has been developed according to which the holistic nature of mental illness is underlined, promoting more emphasis on the situated, experiential knowledge of service users (Onken, Craig, Ridgway, Ralph, & Cook, 2007; Schön, Denhov, & Topor, 2009; Slade et al., 2012). The recovery perspective thus involves a shift of focus away from symptom reduction towards aspects of wellbeing related to hope, self-esteem and sense of control over one's life (including symptoms), and social-connectedness (James & Quirk, 2017; Onken et al., 2007; Slade, 2009).

A lingering gap between policy and practice

However, despite demands for care- and support delivery to be evidence-based, person-centered and recovery-oriented, the source of knowledge that has been given the least attention in research and service development is that of the experiential knowledge possessed by service users and patients (McLaughlin, 2011). While service user participation is emphasized in political and ideological goals, the scientific knowledge is limited as to how care and support services are to achieve these goals. A frequently noted barrier to honoring experiential knowledge is that it may challenge professional authority, traditional roles and working methods that, in the past, have not involved service users in decision making (Strøm & Fagermoen, 2014). In the field of mental health services, this problem has been identified to be particularly pertinent (Morant, Kaminskiy, & Ramon, 2015; Ramon, Brooks, Rae, & O'Sullivan, 2017; Stacey et al., 2016; Stovell, Morrison, Panayiotou, & Hutton, 2016; Treichler & Spaulding, 2017; Woltmann & Whitley, 2010). In addition, even though many providers recognize experiential knowledge perspectives as valuable for decisions on the care and support of the individual as well as for service development, it is still unclear *how* this service user experience is to be incorporated into the welfare systems (Strøm & Fagermoen, 2014). Accordingly, this increased focus on involvement and co-production still exists within a context where service users often feel they are not consulted and feel marginalized when it comes to decisions about their lives (Stacey et al., 2016).

Transforming the principles emerging from research on recovery and service user participation into concrete routines and methods is therefore described in research literature and in policy, national guidelines and legislation as an urgent matter (Korsbek & Tønder, 2016; Morant et al., 2015).

The promise of shared decision making

At the level of individual care and support, the model of shared decision making (SDM) has increasingly been highlighted in response to the challenges reported above, and is recommended as a concrete method for accessing users' knowledge and experiences. SDM is widely recognized as an essential element of PCC (Matthias, Salyers, Rollins, & Frankel, 2012) and in the field of mental health it is recognized as a model for participation complementary to the recovery philosophy (Adams & Drake, 2006; Morant et al., 2015).

SDM consists of an interactive process in which service users and providers collaborate to make decisions. The key components of SDM include providers and service users' participation at all stages of the decision-making process, including information exchange, deliberation (discussing options in relation to service user values and preferences) and arriving at a decision on the next step of care and treatment (Chong, Aslani, & Chen, 2013). It assumes that both members have relevant knowledge to contribute to the process: Providers have up-dated information regarding for example diagnoses, course of illness, care and support interventions and evidence-based knowledge on possible benefits and adverse effects of various interventions. Service users are experts on their own values, preferences and goals and have experiential knowledge from living with illness and from previous interventions of care and support (Adams & Drake, 2006). In addition, service users today have greater general access to various sources of information (Järkestig Berggren, 2015).

In accordance with the description above, SDM conceptualizes both the provider and the service user as carriers of equally valuable knowledge, between whom information is shared bilaterally and joint decisions are reached. (Goscha & Rapp, 2015).

It is noted how SDM might be particularly suited for the mental health context since these types of illness often lead to disturbances in many of the essential processes of personhood and life experience (Chan & Mak, 2012) and since the uncertainty of intervention outcomes underscores the role for the experiential knowledge perspective of the service user (Deegan, Rapp, Holter, & Riefer, 2008; Matthias et al., 2012; Morant et al., 2015)

However, SDM has predominantly been implemented in somatic care and is still, despite the emergence of promising findings, largely lacking in the field of mental health (Stovell et al., 2016; Woltmann & Whitley, 2010).

The international studies that have been performed on SDM in mental health care show a significant effect on treatment-related empowerment, service user satisfaction, increased knowledge of illness and improved clinical outcomes (Delman, Clark, Eisen, & Parker, 2015; Duncan, Best, & Hagen, 2008; Fisher, Manicavasagar, Kiln, & Juraskova, 2016; Hamann, Cohen, Leucht, Busch, & Kissling, 2005; Stovell et al., 2016; Woltmann & Whitley, 2010).

Basic prerequisites for successful implementation have been identified as involving providers' attitudes and ability to promote increased user participation, service users' willingness and abilities to actively participate in decisions, and access to additional information and decision support that might facilitate the SDM process (Hamann, Kruse, Schmitz, Kissling, & Pajonk, 2010; Loh et al., 2007; O'Connor et al., 2007; Stovell et al., 2016). Accordingly, facilitating SDM requires addressing issues of *attitude, skills, and supportive structures*.

Decision support tools for facilitating SDM

Employing supportive structures typically involves the use of decision support tools (DST:s) which is widely recognized as a major prerequisite for putting SDM into practice (Rystedt, 2011; Slade, 2017; Woltmann, Wilkniss, Teachout, McHugo, & Drake, 2011). DST:s are designed to improve decision quality by providing information, clarifying alternatives and helping service users to elicit and communicate their preferences regarding the benefits and risks of each option so that choices can be made more in keeping with their individual needs, values and circumstances (Elwyn et al., 2012). DSTs come in different formats including brochures, websites or applications, and can be either generic or condition-specific (Slade, 2017).

Studies investigating the effects of applying DSTs in different formats to support SDM in mental health care report on a range of benefits including improved communication and decreased misalignment of information priorities of service users and providers (Barr, Forcino, Mishra, Blitzer, & Elwyn, 2016), improvement of decisional comfort of both service users and providers and improved decision-making process without taking extra time (LeBlanc et al., 2015). Studies investigating how different types of DSTs can contribute to participation have shown the advantages of DSTs in formats that support partnership and interactivity between staff and the service user in comparison with formats that provide one-way communication and information (LeBlanc et al., 2015). Studies on existing DSTs designed for the mental health context show positive effects in increasing service user participation, satisfaction, knowledge and reductions in decisional conflict (Bonfils et al., 2016; LeBlanc et al., 2015; Loh et al., 2007).

However, despite these promising findings, DSTs are still largely lacking within mental health services (Barr et al., 2016). In evaluations of implementation endeavors of DST:s, barriers have been related to technological difficulties, increased staff burden and poor fit with service structure (Bonfils et al., 2016).

The context of the present study

The current research, completed within a national research project, “Participation and Recovery Oriented Services” (PAROS), has had a specific focus on developing support for service users to be active participants in SDM in the context of mental health care in Sweden. The PAROS research group is multidisciplinary with expertise in social science, nursing and psychology.

In Sweden, there are two primary actors in the mental health system: social psychiatry, based in the municipal social services and county-based outpatient psychiatry. The social psychiatric services support people with mental health problems with residential support, occupational- and social activities, habilitation, rehabilitation and case management. The psychiatric services offer medical treatment, psychotherapy and specialized psychiatric treatment. Because of this division of responsibility, there is a continuing challenge in Sweden to coordinate these two service providers so that they may offer collaborative services for the many clients that have complex needs that transcend any one actor (Schön & Rosenberg, 2013).

Choice of terms in relation to the context

Choosing the correct term to describe people receiving mental health care has involved a complex and often ideological discussion (Simmons, Hawley, Gale, & Sivakumaran, 2010). In this thesis, the term *service user* will be employed when referring to individuals who receive care or support from mental health services. Other common terms for individuals receiving mental health care and support are *patients* (within psychiatry) and *clients* (within community support). Because this thesis concerns individuals using services from both these domains, a generic concept was required and has thus been settled upon as being provided by the term *service user*.

In the same way that terms for individuals and groups using these services vary, the terms differ for the illness/ill health or problem. In this thesis, the terms *mental illness* and *mental health problem* will predominantly be employed. On some occasions, when referring to the mental health conditions specifically within the psychiatric health care context or the diagnostic framework the terms *psychiatric condition* or *psychiatric diagnosis* will be used.

As for individuals providing the various types of service of interest in this thesis, the terms *staff* and *providers* will be used as generic terms referring to people with a variety of occupations, such as psychiatrists, nurses, psychotherapists, case managers, residential supporters and occupational therapists. These two terms will be used interchangeably to provide a more varied and readable text.

When referring to the services, the terms *mental health care* and *mental health services* will predominantly be employed. When referring to the interventions delivered, the terms *care and support* will be used as a joint concept

with partially overlapping denotations. In this context, *care* includes psychiatric treatment interventions (e.g., medication or psychotherapy) and *support* refers to interventions such as residential support and case management.

Given that the institutions making up the Swedish mental health system are officially described in terms of *psychiatry*, the terms *psychiatry* or *psychiatric* will be used when referring specifically to services within the Swedish setting.

Rational

Against the background outlined above, there is an urgent need to explore and understand how this ‘meeting between experts’ which SDM implies, should be realized.

As noted, while imbalances of knowledge validation and power are recognized as barriers to participation in many domains of care and support, several studies have reported how greater levels of disempowerment, stigma and coercion in mental health settings may amplify barriers to service user participation (Hamann, Bühner, & Rüschi, 2017; James & Quirk, 2017). In accordance, mental health service users usually express that their knowledge is not being requested or considered in decision-making processes (Goscha & Rapp, 2015; Morant et al., 2015; Ramon et al., 2017).

As suggested in past research, increased knowledge is required about the barriers made up by explicit and implicit power structures in mental health settings and of the prerequisites and tools that strategically legitimize user knowledge and support service user participation and SDM in mental health care and support (Ramon et al., 2017; Stacey et al., 2016). It is also noted that more knowledge is required on the preferences of mental health service users around decision making and the skills required for participating in SDM (Goscha & Rapp, 2015).

Because the acknowledgement of the service user as a carrier of meaningful knowledge and equal collaborator is a prerequisite for SDM, gaining clarity as to the specific mechanisms at play regarding this issue is vital to effectively tailor further efforts of method development and implementation that seek to close the gap between principles and practice.

In accordance, the main concern of this thesis is to examine more closely those determinants that relate to the complex issue of user knowledge being expressed, validated and considered in decision-making processes.

In order to explore how increased inclusion and influence of user knowledge in decision making can be supported, this issue will be approached from two perspectives, specifically the provider perspective and the user perspective.

Overall and specific aims

The overall aim of this thesis is to explore how user knowledge and user perspectives can be included and supported in SDM in mental health services.

The specific aims were:

1. To explore what decisional and information needs service users express to be able to participate in deliberative processes and decision making regarding their care and support
2. To explore how a decision support tool (DST) can be designed to strengthen service users in having active, valid and meaningful roles in decision-making processes
3. To describe and analyze facilitators and barriers associated with the implementation of a tool designed to provide a concrete structure for supporting deliberative processes and SDM
4. To gain a fuller understanding into the complexities and barriers associated with user knowledge being expressed and legitimized in decision-making processes in light of the theoretical framework of epistemic injustice

Contextualizing SDM in the present research

In this section, some critical concerns about the current focus on individual choice will be discussed in relation to the concept of SDM. This description is followed by a brief account of some identified determinants for implementation that have been selected to provide relevant background-information for the current study.

Supporting relational autonomy

A concern sometimes raised in regarding the prevalent focus on user choice is that an overly narrow focus on self-agency, which can be perceived as a reflection on the current emphasis on the power of the individual, might limit the scope of the recovery perspective. It is suggested that collective approaches, in which family and the wider networks of the person may be included in collaboration, need to be supported (Onken et al., 2007).

Some researchers voice concerns that the recent shift of focus previously described, away from a collective struggle for redistribution of power and social policy change to individual citizens' freedom of choice involves a transference of responsibility from the public to the individual citizen. Increasingly, "citizens are offered / required to make different types of "choices" (Eriksson, 2015, p. 16, author's translation). Within this discourse, social problems tend to be understood in reference to individualistic explanatory models rather than structural models, placing higher demands on personal responsibility for one's own wellbeing and lowering responsibility on the collective and the state (Eriksson, 2015). It is noted how this focus on individual freedom of choice also has implications with respect to responsibility in that users' views on inadequacies in care or support may be perceived as consumer complaints rather than as citizen opinions (Mol, 2008).

When viewing SDM in relation to these concerns it is important to underscore the term *shared* in the concept. Indeed, as asserted by Elwyn et al. (2012), (a group of researchers prominent in developing tools and interventions to support SDM), the method "depends on tasks that help confer agency, where agency refers to the capacity of individuals to act independently and to make their own free choices" (p. 1362). However, they emphasize that even though SDM rests on the guiding ethical principle of individual self-determination as a desirable goal, supporting self-determination does *not* imply that

people are abandoned. According to them, SDM recognizes the need to support autonomy by building relationships and respecting both individual competence and the interdependence of others. In describing this dialectic interaction, they apply the term *relational autonomy* and assert how “we are not entirely free, self-governing agents but that our decisions will always relate to interpersonal relationships and mutual dependencies” (Elwyn et al., 2012, pp. 1361-1362).

Within a recovery-oriented framework, in which increased value is placed on personal knowledge, resources and strengths of the service user, the role of the provider shifts from “authority to coach offering specialist knowledge” (Morant et al., 2015, p. 1007). The decision-making processes thus becomes an “open experiment between two co-investigators”(Deegan & Drake, 2006, p. 1636). Morant et al. (2015) highlights how such dialogic interactions may support service users’ in developing their understanding of their mental ill health and its management over time, so that they may become increasingly empowered to participate as equal partners in decision making. Accordingly, they note how SDM promotes agency and self-management and thus “has the potential to be not just a means of deciding on treatment, but an important part of treatment itself” (Morant et al., 2015, p. 1007).

Accordingly, many studies underline the importance of fostering a trusting relationship and genuine ongoing partnership as a fundamental element of SDM (Duncan et al., 2008; Eliacin, Salyers, Kukla, & Matthias, 2015a; Fisher et al., 2016; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009; Woltmann & Whitley, 2010). While emphasizing the values of a good therapeutic relationship, it is, however, noted how a key tenet of SDM is that of actual sharing of decisional power as well as of sharing risk and responsibility (Treichler & Spaulding, 2017).

Recognizing barriers and facilitators to identify solutions

In order to accomplish the move to SDM in mental health care contexts, it is suggested that it is necessary to identify barriers that may relate to providers, to service users and the mental healthcare system (Holmes-Rovner, Adams, Ashenden, Schauer, & Del Vecchio, 2010).

It is highlighted that the context of mental health care is associated with several specific barriers and challenges for implementation (Morant et al., 2015; Ramon et al., 2017). Some, in particular note how acknowledging power and scrutinizing the ways in which power operate across all aforementioned levels (provider, user, system) is specifically important in the mental health context in order to overcome barriers to achieve SDM (Kaminskiy, 2015; Stacey et al., 2016).

As regards structural issues, service users as well as providers commonly identify a number of obstacles for successful implementation. These obstacles relate to issues of limited resources such as time constraints, lack of training for providers and service users, to heavy work load for staff, high turnover, financial constraints and low staff investment (Duncan et al., 2008; Fukui et al., 2016; Shepherd, Shorthouse, & Gask, 2014; Stovell et al., 2016). In response to the frequently voiced concerns about time limitations, it should be noted that several studies show how increased levels of SDM do not lead to an increase in consultation times. (Duncan et al., 2008; LeBlanc et al., 2015).

Despite the promising findings outlined in the introduction, the relative paucity of robust clinical evidence has been identified as a barrier to implementation (Fisher et al., 2016). However, recovery-oriented researchers point out that increased empowerment should not be ascribed value only in so far as it facilitates outcomes such as symptom reduction or lower costs. In agreement, reviews on outcomes of SDM report that even though easily measurable evidence is not yet robust, many service users, providers, and other stakeholders support SDM as an important pathway to recovery (Duncan et al., 2008; Stovell et al., 2016).

A frequently emphasized barrier to SDM is the shift in roles required from the traditional, paternalistic modes of interaction (Morant et al., 2015; Ramon et al., 2017). In addition, it is noted how the lack of a collectively accepted definition of SDM makes it difficult for both providers and service users to understand the implications of SDM in relation to their roles and their modes of interaction (Ramon et al., 2017; Slade, 2017).

While studies exploring attitudes among providers show how providers commonly are supportive of the principles of SDM and usually acknowledge how the model improves the therapeutic relationship and user empowerment, it is frequently pointed out how providers have difficulties in differentiating it from their current practices (Elwyn et al., 2012; Ramon et al., 2017).

Providers often indicate insufficient insight, capacity and determination as critical obstacles to SDM (Hamann et al., 2009; Shepherd et al., 2014; Younas, Bradley, Holmes, Sud, & Maidment, 2016). In acknowledgement of these concerns, criticism is sometimes voiced that SDM fails to capture issues related to professional accountability and the complexities involved in sharing risk and responsibility with service users (Hamann & Heres, 2014; Légaré, Ratté, Gravel, & Graham, 2008). Typically providers perceive that SDM is not applicable in cases when the incorporation of user perspectives is not considered to reflect the *best clinical choice*. Concerning medical treatment, the potential risk of non-adherence is commonly mentioned (Ramon et al., 2017).

Contradicting these apparent risks however, studies show that there is no evidence about professional accountability in regard to increased levels of SDM that lead to any severe consequences (e.g., in response to non-adherence of medical treatment) for service users (Ramon et al., 2017; Velligan, Roberts, Sierra, Fredrick, & Roach, 2016).

Many studies comparably, report positive findings in response to concerns about capacity, insight and determination. Several publications have reported that a majority of people with mental health issues express a wish to be involved in decision-making processes (Chan & Mak, 2012; De las Cuevas et al., 2011). Similarly, there is evidence supporting the ability of mental health service users to be actively involved in decision making. Research shows that the vast majority, even of those with severe disorders, demonstrate capacity of understanding treatment choices and making rational decisions comparable with the general population (Carpenter et al., 2000; Chong et al., 2013; Grisso & Appelbaum, 1995; Stroup et al., 2005; Wong, Clare, Holland, Watson, & Gunn, 2000).

Nevertheless, other studies have shown that people with severe mental illness are more likely to have impaired decision-making capacity (Wang et al., 2017). It is worth noting, however, that practicing SDM is shown to increase decision-making capacity. It is therefore emphasized that posing capacity as a prerequisite to SDM might unfoundedly limit users' possibility to influence decisions (Larkin & Hutton, 2017).

Service users commonly indicate relational, attitudinal aspects as the most crucial for their knowledge and perspective being considered in decision making (Eliacin, Salyers, Kukla, & Matthias, 2015b; Fossey, Harvey, Mokhtari, & Meadows, 2012; Woltmann & Whitley, 2010) In view of providers' concerns that service users often do not wish to be active agents in SDM, it is true that users of mental health services often tend to experience insecurity regarding their own knowledge and therefore take a passive role as recipients of the knowledge and competence of others (Duncan et al., 2008; Eliacin et al., 2015a; Woltmann & Whitley, 2010).

Theoretical concepts and frameworks

Service user influence and SDM are features of a value-based practice, emanating from strengths-based theories and empowerment (Drake, Deegan, & Rapp, 2010; Matthias et al., 2012). As regards mental health practice, SDM is a natural element of a recovery-oriented system (Matthias et al., 2012; Onken et al., 2007; Slade et al., 2012). The present project has its origins in in these theoretical perspectives of empowerment and recovery orientation, perspectives that have provided guidance in choices of research questions, methods and data analysis of results.

Some key underpinnings of the frameworks of PCC and recovery have been noted in the introduction, (e.g., the core values of autonomy and self-determination, the strengths- and resource-based perspective and the conceptualization of the user as a competent knowledge bearer). These basic assumptions have provided a viewing platform for the present study and will, as such, be relevant for the understanding of important aspects of the results that carry implications on notions of roles, knowledge and desirable outcomes of interventions.

The review of selected theories and frameworks presented below will start with an outline of the conceptual model for SDM as developed by Elwyn et al. (2012), that were applied in the development of decision support. Next, since the rebalancing of power is central to the idea of SDM, some concepts and frameworks on power, relating to issues of agency and knowledge will follow. These have provided particularly pertinent conceptual tools for illuminating the qualitative findings on study-participants perspectives and reflections in relation to user knowledge and SDM.

A model for practice as a conceptual framework

In the development of decision support within the present study, an existing model for SDM developed by Elwyn et al. (2012) for SDM in general health care was adopted as a conceptual framework, so that its possible transferability and adaptability to the context of mental health services could be explored.

The aim of the model is to assist providers in integrating SDM and decisionsupport into their practice. The model has three steps: i) introducing choice, ii) describing options and iii) helping patients explore preferences and

make well-founded decisions. The model rests on supporting a process of deliberation defined in terms of considering information about the possible benefits and adverse effects of different options, exploring and respecting *what matters most* to the person they concern and supporting people to express their preferences and views during the decision-making process. The deliberative process is described as both iterative and recursive and encompasses collaborative work with professionals as well as with people from the individual's wider networks, work that is performed inside as well as outside the frames of clinical encounters (Elwyn et al., 2012).

Theoretical frameworks as tools for conceptual clarification

As previously reported, a problem frequently mentioned as a barrier to implementation of SDM involves the lack of a generally accepted understanding of the concept of SDM (Ramon et al., 2017). It is noted how disparate stakeholders (policymakers, service providers, service users) all support the idea of SDM and how the concept of SDM can therefore be described as *polyvalent* (Slade, 2017). Being charged with positive values (such as autonomy and self-determination) “it commands superficial agreement and apparent consensus” but might conceal “incompatible assumptions and expectations” (Slade, 2017, p. 147). This surface consensus then obscures issues of conflict: for instance, problems might arise when ethical values relating to autonomy collide with risk and responsibility (Slade, 2017).

The results of this thesis demonstrate a multitude of complicated, sometimes conflicting, aspects of SDM that require conceptual clarification. Some of the theoretical frameworks presented below, such as *Arnstein's ladder of participation* and the theory on *epistemic injustice*, may be particularly useful for this purpose.

Levels of participation

Arnstein's ladder of participation (1969) is frequently used as a theoretical tool to assess service user influence for different levels of participation (from passive participation to active involvement) (McLaughlin, 2009). Despite that the model has been criticized for having a too unilateral perspective of power and that it disregards issues relating to variations among individuals in relation to capacity for participation (Collins & Ison, 2006), the model is still often used by providers involved in influence work, and by researchers to illuminate and monitor levels of participation. In this study, Arnstein's model is applied to help clarify levels of service user influence in decision-making processes,

but also to shed light on the discrepancy of perceptions among various stakeholders found to be prevalent with respect to the concepts of service user participation and SDM.

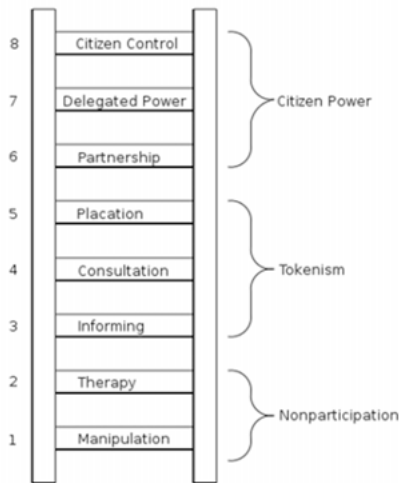


Figure 1. Arnstein's ladder of participation as a framework to clarify and evaluate levels of citizen power and influence

The model illuminates the significant differences between empty rituals of participation and activities for which service users have actual influence over decision processes. The two first rungs concern manipulation and therapy and do not, in reality, involve participation at all. Steps 3 - 5 entail actions to involve individuals in planning, but that often might be performed as *tokenistic* or *decorative* acts, rather encompassing actual power to influence events. For example, on the *consultative* level, service users are welcome to express their views, and even if these views are regarded as important since they provide knowledge to staff on the service users' perspectives of their situation, the service users do not necessarily have any influence or control over how this knowledge is applied in actual decision making.

The collaborative features of SDM, in which provider and service user are conceptualized as equally valuable sources of knowledge, are located on the three upper rungs of Arnstein's ladder where the views of the service user have real influence over decisions. On this level, providers and service users enter a partnership involving dialogue, mutual trust and shared decisions and desired outcomes are systematically centered on service user preferences, values and goals (Deegan & Drake, 2006).

The lower rungs of Arnsteins' ladder illustrate how occurrences of what seem to be sharing of power are in reality tokenistic strategies performed to placate those with less power. By drawing attention to the important phenomenon that some theorists call *the area of non-decision making* (Bachrach &

Baratz, 1963), it is evident how people in true possession of power can manipulate and limit the field for real influence to *safe aspects*. For example, by formulating what is on the agenda for interactions, it is possible to control which options are open for discussion (Kaminskiy, 2015).

The legitimacy of expert knowledge

While the area of non-decision making concerns power that is hidden from the disadvantaged stakeholders, some theorists describe dimensions of power that are even more insidious in that they involve influencing how people perceive themselves and their capacities and, in consequence what they believe they need and prefer. Philosophers such as Foucault and Freire have explored this form of power in the context of repressive cultures and self-stigma (Foucault, 1982; Freire, 2018). At this level of power, the legitimacy of expert knowledge is internalized, and no conflict arises because people do not question certain circumstances and their subordinate roles in knowledge transactions. In the realm of health care and social support, the notion of *compliance* might be understood as such internalized submission (Hörnqvist, 2012).

Dominance of the biomedical model of mental illness and a deficit-focused, disease-targeting model of mental health service are noted to conceal alternative explanations (Morant et al., 2015), to downgrade the value of experiential user knowledge and consequently to obstruct the recovery-oriented ideals of empowerment (Ramon et al., 2017).

In noting the intimate relation between knowledge and power, as asserted by Foucault (Börjesson & Rehn, 2009), the expert language used by professionals might be relevant to consider in this context, as knowledge is closely linked to language and information. In their review on power theory, Börjesson and Rehn suggest that the use of expert vocabulary, although inaccessible to laymen, is normally considered justified because experts need it in order to make precise analyses and descriptions. However, it is sometimes noted how the experts' access to professional terminology also lends them access to power that is not always justifiable (Börjesson & Rehn, 2009).

In her analysis of this phenomenon, Järvinen points to the *Janus-face of power* operating in certain welfare institutions that provide what she describes as a “range of interventions consisting of treatment, fostering and control” (Järvinen, 2006, p. 74, author's translation). Similarly, Foucault applies the concept of *pastoral power* when describing why people are sometimes willing to relinquish decisional power in faith of the compassion and expertise of the professional (Foucault, 1982). Together, these concepts bring to light the complexities involved in detecting and opposing power that is incorporated into professional knowledge and, in addition, is interwoven with help and benevolence.

The power to classify and categorize – constructing clients and problems

In reaction to this legitimacy ordinarily bestowed to experts and expert-language, an emancipatory interest of knowledge is promoted in the field of social work, a knowledge perspective that is closely linked to the acknowledgement of service users as resources in knowledge production. From this perspective, knowledge per se, as well as how knowledge is used entails aspects of power and has effects on the individuals that the knowledge is intended to support. Some theorists, for example, draw attention to the ways in which users are categorized into different client/user/patient groups and that this is a manifestation of the power of defining the problems to be managed (Blom, Morén, & Nygren, 2013; Cohen, 1985). Certain sets of values, beliefs and taken-for-granted assumptions at work in a welfare institution are said to be strongly linked to the power position of the professional (Järvinen, 2006). Emerson and Messenger refer to the professional as the official *troubleshooter* and mediator in determining the nature of problems (Emerson & Messenger, 1977). They point out how the way in which something is named as a problem has implications, prefiguring some solutions and removing others and how people and problems are typically constructed in the light of available remedies. Naturally, the prevalent medical conceptualization of problems, as noted above, influences the view on what is to be done to solve the problems.

Some theorists emphasize the fact that professionals most often are unaware that documentation involves ‘constructions of the second order’, but that they perceive their documentation as factual reports (D. E. Smith, 1978). They note how professionals generally choose among an infinite amount of information what is relevant to document, and make certain interpretations of phenomena that could be interpreted from a variety of other perspectives (Holstein, 1992). In view of these phenomena, the importance of including service users’ own descriptions of what is occurring is stressed, so that knowledge is created on which the perceptions of users affect how people and phenomena are perceived, categorized and described (Svensson, Johnsson, & Laanemets, 2008).

Emancipatory knowledge through reflective learning

Many theorists promoting the emancipatory interest of knowledge, (as referred to above), stress the link between values, knowledge and actions and underscore the need for practitioners to scrutinize what interests and motivations drive the production of knowledge as well as how the knowledge is applied. Manley and McCormack (2003) draw on the ideas of Habermas to assert that while technical and practical knowledge is crucial to practice, it is on the level of emancipatory knowledge, involving a combinatory function of understanding and change, where awareness is directed towards the power embedded in practice and in social interactions, that social transformation can be

achieved. In referring to thier study, Smith (2016) accentuates how this emancipatory approach is particularly important in the transition towards person-centeredness, by noting that it “is not just a technical approach to health service delivery but an authentic moral and ethical recognition of the rights of the individual” (K. Smith, 2016, p. 1). Smith highlights the link between reflective practice, person-centeredness and practice development. She describes how deliberate reflection on practice may further practitioners understanding of their own beliefs, attitudes, values and motives and stimulate them “to question the taken-for-granted assumptions (and the sometimes hidden power) that underpin practice” (K. Smith, 2016).

A theoretic framework of *epistemic injustice*

Recently, the theoretic framework of *epistemic injustice* (Fricker, 2007) has been suggested as a tool for the kind of deliberative reflection as advocated above. During the current project, a need was recognized, that of gaining further insight into service users’ difficulties in voicing their needs and concerns to providers and, even more notably, for service providers to validate and consider user knowledge perspectives in decision. In response to the literature drawing attention to the epistemic aspects of the dynamics involved in accessing and actively making use of user knowledge in mental health care, this theory was applied in data analysis to further explore mechanisms at play in the interactions between service users and providers.

As previously noted, service users commonly voice their concerns about epistemic disadvantages as being key barriers to the implementation of SDM, an issue that is emphasized in the current literature as an urgent matter for further inquiry and deeper understanding (Crichton, Carel, & Kidd, 2017; Goscha & Rapp, 2015). So, while it could be argued that applying an *injustice framework* to empirical data might involve biased presumptions of injustices, the framework is indeed chosen to study the mechanisms involved in epistemic interactions from the particular perspective of these concerns.

The concept of epistemic injustice, originally coined by Fricker, points to a kind of injustice done to persons in their *capacity as a knower*, in which thier ability to take part in epistemic practices, such as giving knowledge to others (testifying) or making sense of her experiences (interpreting), is weakened. As suggested by this description, Fricker identifies two such wrongs: *testimonial injustice* and *hermeneutical injustice*. *Testimonial injustice* is the injustice a speaker suffers when a hearer assigns his or her testimony a level of credibility that is unduly low. This deflated credibility is often due to the speaker being a member of a negatively stereotyped group, which causes the hearer to view his or her accounts and arguments as less competent and sincere and thus less trustworthy. *Hermeneutical injustice* occurs when there is a gap in shared conceptual, interpretative resources that puts a person at a disadvantage when try-

ing to make sense of his or her experiences. When shared modes of interpretation, such as concepts, ideas and narratives are absent or inaccessible, people are deprived of the capacity to use and develop the shared descriptive labels essential for mutual understanding of the phenomena they experience.

In recent years, many theorists have developed Frickers' twofold framework and have offered both critique and expansions on the nature and extent of epistemic injustice (Anderson, 2017; Hookway, 2010; Pohlhaus Jr, 2017). One such extension found to be relevant for the present study is the concept of *participant-based injustice* (Hookway, 2010). This concept describes how being an equal communicator requires not only that a person's accounts are assessed with due credibility, but that the person is afforded with due acknowledgement as a contributor in "knowledge-gathering practice" and a capable "collaborator in shared inquiry, that is, as someone who can ask pertinent questions and recognize relevant information in problem-solving inquiries" (Kwong, 2015, p. 339).

A positive and dynamic perspective on agency

To conclude, in view of the structural components of the mental healthcare system which are often described as major barriers to PCC and SDM, by service users as well as providers, a theoretical perspective on the interaction between agency and structure might be worth considering. Such a perspective might also be worthwhile when discussing the possible conflict of values presented in the background to this study (i.e. between autonomy and safety), and the concern of losing focus on the wider structural societal issues of democracy when focusing on the empowerment of the individual.

In social theory, there has been an ongoing discussion on whether free will and agency creates social structures or whether it is the structures that define and regulate agency. Modern theorists (e.g., Clegg, Giddens and Archer) offer a more dynamic perception (Börjesson & Rehn, 2009; Giddens, 1979; Kaminskiy, 2015), noting the multifaceted and dynamic aspects of culture and drawing attention to what Giddens describe as the "fundamentally recursive character of social life, and ... the mutual dependence of structure and agency (Giddens, 1979, p. 69). Giddens highlight how the modern everyday life is perfused with knowledge and information, providing resources that may increase the possibility for agency of individuals (Giddens, 2003). Giddens emphasizes the concept of *knowledgeable agency*, which will be applied in discussing the results of the current thesis. He asserts how knowledge plays a central role in the formation of structures in that it provides the basis on which agents, with increased knowledgeable capacities, perceive, understand and transform the rules around them. (Giddens, 1979).

According to this perspective, increasing degrees of control at the individual level might affect macro and meso levels of power and (at least to some

extent) serve to “transform the structural and cultural conditions that impinge upon them” (Archer, 2012, p. 31).

This dynamic and positive perspective on agency is also relevant to consider when discussing the tendency of many mental health service users to take on a passive role in decision making. In her analysis of power for SDM in the context of psychiatric medication management, Kaminskiy acknowledges how passivity and low levels of agency are indeed effects of dominating prevalent structures (i.e., diagnostic categories, epistemic injustice and medicalization). At the same time, however, she notes how “the dynamic and intersecting aspects of structure and the potential for agency” needs to be acknowledged and further explored (Kaminskiy, 2015, p. 30). This perspective contrasts with the fatalistic view of agency as proposed by Bourdieu’s *habitus* (learned dispositions, skills and ways of acting) according to which passivity is structural since choice has no meaning to those without access to the resources needed to make meaningful choice (Kaminskiy, 2015).

Methods

In this chapter, an outline of the context and trajectory of the research project as well as settings, participants and methods for data collection is presented. Subsequently, the various analytic procedures with their respective methodological approaches will be detailed to provide the possibility to follow the logic underlying the analytical processes of the various data sets generated throughout the research project.

A participatory, evolving design

A key feature in this project relates to exploring aspects of participation and SDM in the development of a web-based DST that enables service users to take an active role in deliberative processes together with service providers. This process has called for several phases of exploring, developing, testing and evaluating, and during its course, a variety of methodological approaches have been applied. Since a primary aim of the SDM project was to create an application that corresponds to the specific needs of mental health service users in their interaction with service providers, research procedures were chosen that allowed for development processes to be open and iterative, where people from the target groups - both service users and providers - were involved as informants and testers in each step of the development process (Hekler et al., 2016). Thus, even though the concepts of *user perspective* and *user knowledge* normally are employed with reference to *service users* in this dissertation, it should be noted that potential users of the DST also include providers. In the explorative phase, before initiating the development process, service user panels were consulted. These panels consist of individuals who have received training in basic research techniques and in how to consult with researchers on projects. The panel members contributed with user perspectives and offered opinions that were considered in the formation of the research design and interview-guides.

I myself have long and diverse experience of mental illness and mental health service use myself and as such, my own 'insider' position can be perceived as contributing to this participatory design. Engaging people with their own service user experience in various roles in research processes is a growing phenomenon and it is increasingly emphasized how service users have the po-

tential to contribute with their experimental knowledge perspective throughout the research process (Fricker, 2007; Kara, 2013; Littlechild, Tanner, & Hall, 2015; McLaughlin, 2009). In the discussion's chapter, I devote a section to reflexivity in which I account for the ways in which my insider perspective has contributed in the various stages of the research project as well as the ways in which I have tried to avoid it causing unwanted bias.

Within the outlines of the predefined design of the project, choices have continuously been made, regarding specific design techniques, methods for analysis and samples of participants. Findings from each consecutive phase have guided the process forward in the specification and formulation of aims of the subsequent phases and in the choices of methodologies and participants most appropriate regarding these aims. The findings from study I - III inspired study IV, which was a theoretical exploration on the complexities involved in legitimizing service users as knowledgeable agents.

Overview of study designs, methods, participants and data analyses

Table 1. *An overview of the study designs, methods, participants and data analyses for the four studies of this thesis*

	Study I	Study II	Study III	Study IV
Design	Explorative qualitative	Explorative qualitative - iterative multi-phase design	Process evaluation	Explorative, qualitative theoretic analysis
Participants	Adult service users with a psychiatric diagnosis and with experience of mental health service use. (n = 22*) Male = 5 Female = 17	Adult service users with a psychiatric diagnosis and with experience of mental health service use (n=6, all female) Providers of mental health services (n = 95) Male = 25 Female = 67 Community support-workers (n = 33) Nurses (n = 19) Social workers (n = 11) Occupational therapists (n = 1) Psychologists (n = 7) Psychiatrists (n = 6) Case managers (n = 11) Section managers (n = 3) Project manager (n = 1) Employment coordinator (n = 1) Therapists (n = 2)	Providers of mental health services (n=92) (same as study II)	Adult service users with a psychiatric diagnosis and with experience of mental health service use. (n = 23) = the sample from study I and one respondent from study II Male = 5 Female = 18 Providers of mental health services (n=31) (Same as the respondents in interviews in study II and focus-group-participants in III) Male = 9 Female = 22
Data collection	3 semi-structured focus group interviews	Individual video-recorded 'usability testing' sessions using 'think aloud protocol' (n = 5) with semi-structured interviews Video-recorded semi-structured interview with a service user (female). Individual interviews with two providers (female) Checklists/protocol from two pilot tests using a prototype in role-playing with cases. (with providers)	Self-reported checklists Four semi-structured focus group interviews (n = 29 of the total 92 participants)	Data previously collected in study I - III: Three semi-structured focus group interviews from study I Individual interviews with one service user and two providers from study II Four semi-structured focus group interviews with service providers from study III
Data analysis	Abductive content analysis -Initial inductive approach - Succeeding deductive approach: A categorization matrix was developed from Elwyn's three domains - Concluding inductive approach	Deductive content analysis was performed on usability testing and the complete interviews. A matrix was developed using pre-existing usability constructs Inductive content analysis was performed on individual interviews and data from checklists/protocols	Abductive content analysis Qualitative data analyzed by inductive content analysis and by deductive analyses employing a blueprint for process evaluation developed by Moore et al (2015)	Abductive content analysis Qualitative data collected in the previous studies were studied collectively in a secondary, primarily theory-driven analysis focusing on epistemic injustice.

*Among these 22, 2 persons had the perspective of being a relative in addition to own service user-experience

Settings, sampling and participants

As illustrated in table 1, a wide variety of samples of participants were recruited for the included studies. Consistently, sampling techniques for these studies had been designed to maximize diversity of perspectives, views and ideas (Kvale & Brinkmann, 2009). In Sweden, two primary actors make up the mental health system: social psychiatry (based in the municipal social services) and county-based specialized psychiatry (including inpatient and outpatient treatment). Coordination of medical and social interventions, across organizational borders, is required by law (Socialstyrelsen, 2011) [National Board of Health and Welfare]. The included units belonged to different organizations and with varied functions. Formal decisions are not made to the same extent in the municipal social services (primarily offering support and coordination) as in outpatient psychiatry (which provides treatment and makes diagnoses and assessments from which decisions on social insurance and sick leave are based). It is noted how these social psychiatric services, are often challenged by a psychiatric medical model that is dominant in the psychiatric services (Rosenberg, 2009). As such, the services included in the present study can be said to reflect the complexity of today's mental healthcare system in Sweden.

Study I

Study I served as an exploratory analysis on information and decisional needs of service users. The participants were recruited to form a purposive sample through service user panels and activity centers at three sites in three municipalities in Sweden. One of these municipalities is mid-sized and two are larger. The inclusion criteria were adults with a psychiatric diagnosis and with personal experience of using mental health services. Participants were recruited to form a heterogeneous sample as to sex, age, experience of mental illness, service use and experience of organized user influence work. Hence, individuals were recruited with a wide variety of different though sometimes overlapping psychiatric diagnoses (such as anxiety-, affective- or psychosis-disorders or neuro psychiatric disorders) and service user experiences. Some of these participants had considerable cognitive challenges related to neuropsychiatric conditions or to schizophrenia or schizophrenia-like conditions. Ages ranged from 19 - 63. Of the three focus groups, two were consisted of members of service user panels. The third group included people who were recruited through two community-based activity services and one activity center run by a nonprofit service user organization: The Swedish National Association for Social and Mental Health (RSMH). The service users making up this group had little or no experience of acting as service user representatives in any organized form.

Study II

As was the case for study I, accessing a broad range of illnesses and service use experiences was desired for the usability testing of the first paper prototype performed in study II. Thus, the participants that were purposely recruited for this study formed a sample with a variety of diagnoses and experiences. The participants (all women) were recruited through phone calls and notices of interest sent by e-mail to a number of community services and service user-organizations. According to previous research, 80% of all usability problems are detected with as few as four to five participants (Virzi, 1992) and therefore a sample of five participants was considered sufficient for this endeavor. Two of these participants had considerable cognitive challenges related to their psychiatric diagnoses.

Purposive sampling was similarly conducted when recruiting the two service provider respondents for individual interviews, also performed in study II. These interviews were conducted to obtain further guidance in the prototype development, and because the DST was developed as a generic tool to be implemented in various mental health services, provider perspectives and views on contextual factors from diverse settings that could potentially affect the use of the DST were deemed relevant. Accordingly, the two recruited service providers worked in different care settings and in different professional roles.

Finally, in study II, three pilot tests were performed with groups of staff members of community services located in two mid-size municipalities.

Study III

The remainder of the data collection process was conducted within the framework of a process evaluation of a comprehensive implementation endeavor performed in six mental health service units located across three counties in Sweden.

To investigate and incorporate the required coordination between the mental health service settings in the development of support for SDM, units from county council-based outpatient psychiatry together with units of municipal social support were included in an extensive implementation study. Accordingly, two of the six units chosen were municipal social services offering residential support services and case management and four were outpatient psychiatric services offering medical treatment, therapy and home visits. Four of the participating units were recruited from urban areas with about 200 000 inhabitants and two units were recruited from rural areas with 14 000 to 40 000 inhabitants. Half of these units were in areas with a socially vulnerable population and a high proportion was foreign-born residents.

Participants consisted of all staff who provided mental health care and support in the six units included in the study. These participants covered a wide

range of professional perspectives. Table 1 presents information on staff characteristics. For the four focus group interviews (FGIs) conducted, in which in-depth knowledge was sought on the experiences of staff regarding the completed implementation activities and the use of the DST, those staff members that had taken part in the implementation project were invited to participate. Profession-wise, this subgroup of participants provided an acceptably representative sample of the entire group.

Study IV

For this study, material collected from all individual interviews and FGIs in study I - III was used.

Data collection

As demonstrated in table 1, data had been collected using several methods. In the various phases of research, qualitative data had been gathered through FGIs with groups of service users (study I) and service providers (study III), individual interviews with service users and service providers (study II), usability testing with service users with 'think-aloud' protocol (study II) and pre-constructed checklists (study III). Data collected from individual interviews and FGIs in study I-III were later used for a secondary analysis in study IV.

Focus group and individual interviews

In study I, three FGIs were conducted with service users and in study III four FGIs were conducted with service providers. This method was used to obtain data that might be generated by individual respondents and by the interactions between respondents in a group setting. The method is especially suitable when participants might feel more at ease when discussing sensitive issues if they are with others with similar experiences, as was assumed to be the case for our service-user participants (Patton, 2002). A specific aim of most data collection processes that took place in this study was to generate ideas for prototype development, and because focus group interviewing is also recommended when creative thinking is required, this was conceived of as an appropriate method (Patton, 2002).

Individual interviews were conducted with two service providers and one service user during the design phase when further insight was sought of service user and service provider perspectives and experiences of decision-making procedures and of contextual variations of such procedures in mental health service settings. In these interviews service designers participated to make full use of their expertise in thinking about design solutions (Hekler et al., 2016).

All the interviews were semi-structured. Interview guides were pre-developed with open-ended questions to explore the views and experiences of the respondents on the issue in focus in the respective study. As for interviews and FGIs performed in the process of developing and testing the DST (study I and II), questions were constructed to assess issues of information priorities and needs for support in decision-making processes. In the process evaluating the implementation effort, the interview guide focused on experiences of the implementation activities and on the use of the DST, but also on barriers and facilitators to implementation (study III). Field notes were taken during and after each interview to capture the researchers' impressions and immediate reflections, as well as to provide context and support the interpretation of the transcripts (Fossey, Harvey, McDermott, & Davidson, 2002). All interviews were audio-recorded and transcribed verbatim by the present author (Patton, 2002).

Usability testing

After constructing the first paper prototype, service users acted as testers and informants by participating in usability test sessions using think-aloud methodology (study II). This methodology is increasingly employed in health care and allows potential end service users to participate in designing materials and websites that are both comprehensible and engaging (Giguere et al., 2014). The aim here was to test the prototype with target service users to elicit comprehension and usability. Participants were presented with the prototype and asked to recall a situation that called for decision making apropos care or support. While working through the prototype, they were prompted to think aloud and verbalize their thoughts and give feedback on such aspects as clarity, relevancy and difficulties. At the end of the session, they were asked open-ended questions about suggestions for improvement and focused on issues of usability and feasibility (van Someren, Barnard, & Sandberg, 1994).

The sessions were videotaped with the camera directed on the DST prototype and the hands of the participants to capture words and actions related to completing the DST. Concurrent field notes were taken to capture the researcher's impressions. A semi-structured interview based on a reflective process and following principles to produce comprehensive think-aloud protocols was conducted at the end of each session (van Someren et al., 1994).

Checklists

During testing and the implementation process with service providers, reported in study II and III, qualitative data were also collected through checklists to map the conditions for implementation of the SDM intervention and capture staff compliance with the content of the implementation program. The checklists were preconstructed by the researchers to capture aspects relating

to context, fidelity, dose delivered and reach (Moore et al., 2015). The checklists were completed by the researchers in connection with the meetings with staff during the implementation process.

Extracting data for a theoretical analysis

The conclusions from studies I - III suggested a focus on the attitudes towards user knowledge that seemed to affect the SDM process and became a focus of inquiry in the fourth study. A barrier to user participation that appeared throughout the processes of implementing SDM, was the low extent to which user knowledge is expressed, requested and considered in decision-making processes. This observation inspired us to develop additional knowledge by approaching data with a theoretical focus that involves issues of user knowledge and aspects of attitudes, power and agency in relation to SDM.

Hence, the dataset for study IV was drawn from the qualitative phases of studies I - III. The data were rich in comments, from both service users and providers, reflecting insufficiencies and challenges in the kind of epistemic partnership that SDM requires. Consequently, the empirical basis for this analysis was made up from excerpts extracted from all interview transcripts and field notes relating to epistemic issues. In table I, information is provided of the data sets generated in the consecutive stages of developing and implementing support for SDM. These data sets were selected for a secondary analysis in study IV.

Data analysis

Qualitative content analysis has been applied to the data. Data have predominantly been approached abductively, incorporating both inductive and deductive methodology at different stages of analysis (Graneheim, Lindgren, & Lundman, 2017). Suggestedly, an abductive approach of moving back and forth between concrete descriptions and theoretic understanding is appropriate when the goal is to create knowledge about social processes in terms of motives, actions and understandings of various actors.

For all interviews and FGIs, participants had been selected to cover a broad range of perspectives and had been asked a variety of open-ended questions. The inductive approaches allowed the analysis to be structured in a way that captured this complexity (Hsieh & Shannon, 2005), rendering a broad and inclusive understanding of the participants' experiences and avoiding the risk of forcing data into codes or categories based exclusively on pre-existing models and theories (Graneheim et al., 2017) or on the analytical preconceptions of the researcher (Hsieh & Shannon, 2005).

In the deductive stages, pre-existing models and frameworks were allowed to assist in clarifying the data. Relevant concepts derived from well-validated

models or established theoretical frameworks served as orienteering concepts to enable the researchers to identify more subtle features of the data and perceive content on levels of interpretation and abstraction that might not have been recognized in the inductive analysis (Braun & Clarke, 2006). In addition, they were chosen to serve as basic frameworks from which to explore possibilities for conceptual extensions.

More than one researcher from our research group took part in all of the analysis processes. Throughout the processes, findings have been discussed within the research team to refine and clarify categories in the data.

Because the inductive stages of analysis were performed in a similar way in the four studies, this section will continue by providing a description of the inductive procedure that applies to all inductive phases in the analysis processes. Next, a detailed description of the analysis procedures performed in each study is given.

The inductive procedures

For the inductive procedures, the data were analyzed following the procedure of inductive analysis outlined by Hsieh & Shannon (2005) and (Elo & Kyngäs, 2008). The analyses started by reviewing the data repeatedly to achieve a sense of the whole. Next, data were read word by word to derive codes by marking words, sentences and phrases that seemed to capture key thoughts or concepts. Once the data were entirely coded, texts were approached by making notes of impressions and thoughts in an initial analysis. Labels for codes were formulated that appeared to be represent more than one key concept and these codes were used to make up initial coding schemes. Thereafter, the codes were sorted into categories based on how the codes were related and connected. Finally, the categories were used to help organize and group codes into meaningful clusters.

Study I

Because knowledge is limited on service users' preferences relative to decision making and of support required for participating in SDM (Goscha & Rapp, 2015), the project began with an open-ended explorative approach to capture various experiences on different issues related to decision-making processes.

Accordingly, data from the initial FGIs of service users in study I were initially approached inductively (see description above). Next, inductively derived codes were placed into a matrix based on the three domains of SDM defined by Elwyn et al. (2012) (Hsieh & Shannon, 2005). Key concepts from the SDM model were identified as coding categories and then given operational definitions determined by descriptions provided in reference to the model. The purpose of this strategy was to explore its potential for organizing

the data and to what extent the model could be applied to the context of mental health. Finally, codes that did not fit the matrix were used to compose new categories, an approach that served to conceptually extend Elwyn's model and to broaden the understanding of SDM in the context of mental health services.

Study II

Study II involved a usability testing phase focusing on issues of usability and feasibility.

In the first step, log files generated by field notes taken during the usability sessions with service users and the transcripts from the recordings were approached inductively, following the steps as described above. In the next (deductive) step, data were mapped onto a preconstructed matrix where key usability constructs identified in previous usability studies were employed as coding categories (Chrimes, Kitos, Kushniruk, & Mann, 2014)

Qualitative data from individual interviews with two providers and one service user obtained in study II were approached purely inductively, in correspondence with the above descriptions.

Study III

Study III entailed an implementation evaluation that generated qualitative data from FGIs and education sessions with providers. The implementation program included the education of local facilitators and staff who were working with the DST, continuous facilitation and follow-up seminars. Similar to study I, data analysis started with an inductive, data-driven approach involving open-ended explorative analysis of qualitative data from FGIs and the checklists (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). In the next step, inductively derived codes were placed into categories based on the process evaluation components from Moore et al. (2015). This strategy facilitated the assessment of fidelity and the quality of the varying aspects of implementation that served to clarify causal mechanisms and identify contextual determinants associated with variation in outcomes (Moore et al., 2015).

Study IV

In study IV, the sets of empirical data that had previously been approached with diverse focuses for examination in the various stages of developing and implementing support for SDM were approached in a secondary, primarily theory-driven analysis centering on *epistemic injustice*.

As noted, it could be argued that applying an *injustice framework* to empirical data might entail value-laden presumptions of injustices that could bias the analysis. However, because themes reflecting epistemic challenges were

prevalent in the data, this framework was chosen to study the dynamics involved in epistemic interactions from this perspective.

For the analysis of study IV, all texts were read several times to get a sense of the whole. Next, words, sentences and phrases that seemed to relate to knowledge sharing and knowledge valuation in decision-making processes were marked to form preliminary codes (Elo & Kyngäs, 2008). The preliminary codes were then compared based on differences and similarities and sorted into preliminary categories (Graneheim et al., 2017).

Unlike purely inductive or deductive research processes, which can be characterized as linear in the sense that they follow strict procedures, abductive processes can be described as more cyclic or spiral-like (Blaikie, 2007), a depiction that is particularly illustrative of the subsequent analysis process performed in this study. Accordingly, a period followed, of moving back and forth between data and theory and viewing them in light of each other. Concepts from the theory were found to contribute to the identification and naming of additional codes and in the clustering of codes. An unconstrained matrix was constructed, to allow for categories to be created within its bounds that were not assembled directly from theoretical concepts (Erlingsson & Brysiewicz, 2017), but where theoretical concepts guided the discovery of categories and contributed to the naming of some of the categories.

The field notes

The field notes that were taken during data collection contained descriptive information on patterns of activity among the participants when, for example, reflecting on or testing the DST, and of interactions between them when, for example, discussing or working in role-play. In addition, they contained reflective information (e.g., ideas, questions, concerns, and other related thoughts) that came to the researchers' mind during activities of data collection. In addition to supporting the reflective attentiveness of the researchers, these notes aided in the interpretation of the transcripts (Fossey et al., 2002) by, for example, capturing and reminding us of the reflective, tentative atmosphere that was typically prevalent, and the often explorative mode of communicating, working and replying among the participants.

Ethical considerations

Ethical issues were considered in accordance with the applications for the studies, which have been approved of by the Regional Ethical Review Board in Umeå (study I - Dnr: 2012-198-31), the Regional Ethics committee based at Uppsala University (study II) and the Ethics Committee at Uppsala University (study III - Dnr 2015:218). The project follows ethical principles for social and medical research according to the Declaration of Helsinki and international guidelines. Participants signed written consents before the interviews.

For mental health service users, taking part in research might entail both positive and negative implications. In the following account, possible benefits are discussed alongside an account of the ways in which possible risks have been assessed and countered (Ritchie, Lewis, Nicholls, & Ormston, 2013).

One possible risk to consider is that service users might experience the process of sharing experiences of contacts with providers as sensitive given that they are reliant on these services for their care and support. Thus, in all focus groups with service users, researchers took care to describe the manner in which the material would be anonymized and presented, so that service users could feel safe that their decision to participate (or to not participate) would not affect their future care or support.

Participation in the study might involve personal benefits for the individual respondent, even though such value cannot be predicted or presupposed. However, from previous experiences of conducting interviews with both service users and providers of mental health services, respondents have usually perceived the discussions as interesting and rewarding, even from a personal view. The purpose of the interviews was to embrace and take advantage of the experiential knowledge of the respondents. Being recruited as knowledge bearers might be regarded as something positive, especially for service users for whom this might be an affirmative and empowering experience. Ultimately, the aim of the project is to improve safety and quality of care and support. As such, the results of the project are expected to provide benefits for the target groups as a whole.

For example, talking about experiences of mental health care and support may trigger painful memories of times when illness has been severe or of contacts with providers where one has felt powerless or disrespectfully treated. Another risk of conversing with someone who has an attitude of genuine listening, who creates an atmosphere of confidentiality and who poses open questions about experiences of care and support for mental illness may prompt

respondents to reveal parts of their history that they, after the interview, feel that they would have wished to keep for themselves. To minimize these risks, it was important to provide information in a proper and careful manner about the purpose and procedure of the interview. In addition, it was important for us as interviewers to be responsive and alert when sensitive information was shared (Kvale & Brinkmann, 2009). The FGIs were conducted by individuals with considerable experience of interviewing people of the same target group.

In published articles, the individual data or identities of the respondents are confidential. The data were anonymized and encoded by the researchers before initiation of the analysis. Collected transcribed materials will be stored in security containers at Karlstad University and only researchers in the project will have access to the material. All data are treated confidentially in accordance with the Swedish Research Council (Vetenskapsrådet, 2017) [The Swedish Research Council].

As an additional issue for ethical consideration, Beresford and Croft (1993) point out that people that are requested to share their views, but who have no actual influence on (research) decisions might experience *consultation overload* and a sense that their involvement is merely a *tokenistic* exercise. Because implementation of the final DST might take time, it will also be quite long before they can be presented with any final product. As for the members of the service user panel focus group, they have frequently had roles as active decision makers in various processes such as service user audits and thus this group was not considered vulnerable to such weariness. For the remainder of the participating service users, this risk was counteracted by sending them a copy of the article together with a letter clearly describing how their input had guided the development forward.

As a concluding ethical note in research aiming at supporting service user involvement is to ensure that research processes and outcomes are readily accessible to the target group they concern (Phillips, 2006). In response to this issue, findings will be summarized, translated into plain language (and into Swedish) with no loss of accuracy or precision and disseminated in service user networks and provider and policymaker networks.

Results

The findings of this thesis show how service users and providers express support for the concept of SDM in the context of mental health services. However, while the value of user knowledge and perspectives in decision making is generally acknowledged, our findings show a number of characteristics specific to the mental health service context that need to be considered when developing support for achieving decision processes in which service users are included and legitimized as competent collaborators and carriers of important knowledge.

In response to prerequisites identified for SDM in this specific context, a model for SDM in mental health services was developed that subsequently was incorporated in a web-based DST. This model was based on an existing model created for SDM in general health care (Elwyn et al., 2012), which was adapted and extended to fit the special needs present in the context of mental health services. Decisions related to mental illness were often found to be complex and involve a number of life domains. Thus, issues related to social context and individual recovery pointed to the need to give emphasis to one phase for *preparation* that focused on establishing cooperation and mutual understanding and another phase for clear *follow-up* that allows for feedback and adjustments to the decision-making process.

The findings demonstrated how supportive structures are needed for service users to express their knowledge perspectives and for providers to elicit and include them in their decision-making processes. In accordance, the findings revealed how using a DST can enable an interactive partnership, enhance user participation and include user knowledge in decision making.

Critical issues for practicing and implementing SDM with a DST were successively identified that were related to structural problems (e.g., time limitation and high workload), contextual feasibility issues, cognitive challenges of service users and attitudinal and relational matters in the interactions between service users and providers. Core findings concerning issues of implementation revealed the importance of providing training and facilitation, to ensure managers' commitment to SDM so that sustainable structures are made available and to address staff attitudes that might limit possibilities for user participation.

By employing a highly participatory design in an iterative process of developing, testing and evaluating the DST, problems could be identified that

were systematically addressed in a process of revising both the DST prototypes and the implementation program. Thus, a major finding of this thesis is that in-depth knowledge about barriers and facilitators can be generated in a variety of ways through a development process with a supportive structure involving potential end users.

The development and testing process of the DST resulted in a shared platform for SDM featuring the following elements:

- Web-based – to allow for continuity and deliberation within the structural limitations and constraints of the mental health systems
- Interactivity and transparency – to promote partnership and mutuality
- Eliciting and centering on user-defined needs and goals – motivating agency and promoting person-centeredness
- Flexibility of formats for communication – in response to preferences and cognitive challenges
- Generic – promoting adaptability to different services

The present findings also show the importance of making existing barriers and challenges explicit in relation to power and role expectations in order to recognize and legitimize different forms of knowledge in the decision-making process. In response to these issues, a crosscutting finding of the current research involved the recognition that the research design chosen for developing and implementing SDM with a DST, strongly focusing on having potential end users reflect, test and practice, provided a means to this specific purpose. Such practice helped raise awareness of critical issues primarily related to attitudes and beliefs of service providers as well as service users. In addition, this practice encouraged the participants to discover increased possibilities for service users to be knowledgeable agents in decision making.

In the following, crosscutting findings will be elucidated that relate to the conceptualization of the service user as a carrier of valuable knowledge, the diverse understandings and attitudes of service users and providers and the discovered value of reflective practice as a tool to increase skills and overcome barriers. Thereafter, accounts will be presented of the central findings of each study, following the order in which the studies were performed. These accounts will provide information on the specifics discovered as they pertain to critical issues as well as possible facilitators regarding the knowledgeable agency of service users.

The value of user knowledge in continuous assessment and decision making

The present findings confirmed the indispensable value of the knowledge perspective of service users in decision making. Diverse forms of knowledge possessed by service users were identified. Many service users were experienced users who had a broad experiential as well as theoretical knowledge regarding their mental health problems. From their long experience of living with illness, the service users noted how they had developed self-help and coping strategies. In addition, they expressed how aspects of such personal knowledge should be included in problem analyses because they might affect choices of interventions. Most of the service users were active gatherers of formal knowledge.

Elements and components of care and treatment procedures were often complex and interactive and thus required the continuous evaluation of treatment and care interventions. The need was noted to include the person living with illness in (sometimes tricky) assessments of whether positive experiences were related to interventions or to other life circumstances and whether negative experiences were the effect of illness symptoms or whether they were adverse effects of treatment. Chains of causes and effects were thus often difficult to trace and issues of life context and personal recovery were found to be relevant for decision-making processes, which underscore the importance of valuing the service user's experiential knowledge perspective.

Accordingly, these multifaceted and nonlinear features of illness and recovery described by service users illustrated the importance of decision support to be designed to endorse deliberation processes in which users and providers jointly explore the manner in which different possibilities might lead to different results over time and which allow for continuous reviewing of decisions.

Diverse understandings of the values, prerequisites and barriers of SDM

One recurrent barrier to service user participation that occurred during the implementation of SDM involved the poor extent to which user knowledge is expressed, requested and considered in decision-making processes. In correspondence with previous research findings, service users and service providers described partially overlapping and separate phenomena in describing obstacles for service users to be active participants in decision making. Both service users and service providers reported structural problems (e.g., time constraints and lack of continuity and collaboration) between institutions (Shepherd et al., 2014; Younas et al., 2016). Many service providers noted

(sometimes with frustration) how workflow issues and regulatory frameworks limited the possibility to invite service users as full partners in decision-making processes.

Service users often discussed relational and attitudinal issues with staff and expressed experiences of feeling powerless, inferior, dependent and as lacking judgement. They also suggested that relational and attitudinal aspects were most crucial when considering how their knowledge and perspectives might be taken into account in decision making (Fossey et al., 2012). To them, being met with respect as a worthy interlocutor was considered a basic requirement for genuine dialogue to take place. This finding, pervasive throughout this thesis work, indicated how decision support needs to be designed to endorse a more equal encounter.

Data generated by providers showed that while there was a consensus regarding the ideologically described principles of user participation, numerous thoughts and attitudes were expressed relative to the value and feasibility of SDM in relation to the users of the services included in the studies. Some providers strongly voiced the that they, as professionals, often 'know best' and that service users' insufficient decision-making competence and decisiveness naturally places limitations on user participation. Other providers, however, reported the need for professionals to relinquish some decisional power and to acknowledge and support the role of service users as competent participants in shared deliberation and decision making. For the most part, however, the provider-generated data did not reflect such a dialectic positioning vis-à-vis user involvement, but rather revealed an often prevailing ambivalence and uncertainty associated with their role as professionals as regards balancing conflicting values of service users' autonomy and safety and of allocating responsibility for uncertain outcomes. The comments on service users' influence on decisions were generally tentative and reflective, expressing continuous challenges of assessing situations and adapting their practice to structural obstacles, specific contextual considerations and ethical dilemmas. Many service providers noted service users' vulnerability to stress factors, including information overload, high expectations of proactivity and having to navigate unwieldy and complex systems. Whereas some related such susceptibility primarily to the psychiatric circumstances of service users, others mentioned how interacting with various institutions, regulatory systems and professionals, as well as how valuing and forming decisions upon information from a multitude of sources, would be challenging for any person.

Understanding and learning by testing, practicing and reflecting

These concerns expressed by service providers provided some critical clues to their hesitancy to apply SDM. Moreover, it drew attention to the complex interaction between attitudes and practice. Together, they emphasize the importance of providing continuous facilitation and guidance during implementation as well as hands-on training and opportunities for reflective learning where SDM is practiced in different situations, while considering possible dilemmas related to inviting service users as full deliberative partners.

Consistent with the previous literature, many providers initially expressed that they already worked according to the principles of SDM (Elwyn et al., 2012; Ramon et al., 2017). However, when reflecting on the different steps of the DST, some discovered that their current way of working did not involve the levels of user participation that they had first assumed. These provider-related findings led to the recognition of the structure of decision support (interactive, web-based design) and practice (learning by doing) as central elements of the learning process of providers, and the actual mechanisms by which they could understand and apply the method.

In the four studies, reflection on various specific situations and concrete cases was found to influence staff attitudes towards user participation and to increase their readiness to include user perspectives in decision-making processes. On occasions when service providers carefully reviewed and considered each consecutive item in the DST in relation to either real life cases from their own work-life experiences (in interviews, study II), in hands-on use of the DST in their clinical practice (study III) or to preconstructed cases in role play during testing/training (study II), the practicability of SDM and value of user participation were often recognized. (These role plays were part of the development process and implementation program.) In many cases, it was noted how initially perceived conflicting issues between the values held by the service users and providers could be resolved through a careful process of deliberation that was centered on the concerns and priorities of the service users and where user knowledge was elicited and considered alongside their professional knowledge. As intended by Elwyn, et al. (2012), who had developed the original model on which we based our approach, this process was characterized by a methodological step-by-step progress as well as by iterativity and recursiveness.

The providers in the studies, who had different occupational roles, described how these roles concerned different tasks in decision-making processes. Some pointed out that their professional tasks did not include formal decision making (this was normally expressed by the staff from the municipal social services). However, some of the providers noted that they were never involved in decision making, but still had used the DST together with service users. They noted how this had provided an opportunity to explore values and

goals and to help service users access and assimilate information and prepare before encounters with professionals that *did* include decision making. This observation showed how components of SDM could be supported and implemented in many ways, even by providers that did not influence formal decisions.

This mode of reflective thinking in diverse roles and forms of knowledge was also apparent in the bulk of the user-generated data. When service users reflected and discussed (in focus groups, study I) and in usability testing sessions (study II), issues of gathering, valuing and sharing knowledge and the influence of different kinds of knowledge in decision making, they too expressed ambivalence to their own competency and roles in decision making processes. Questions were frequently raised as to how trust in their personal knowledge and information-valuing capacities should be balanced against trust in the expertise of professionals. In addition, as noted above and in line with previous findings, service users often primarily focused on the relationship and affective aspects of decision making rather than on knowledge gathering or deliberating on alternatives (Woltmann & Whitley, 2010). It was only when prompted (in interviews/focus group discussions or by the items in the DST) that service users shifted their focus to verbalize specifics on their personal knowledge and needs and preferences in information sharing, deliberation and decision making.

During the project, all these complexities involving attitudes and practice that were reflected in the perspectives of the groups of respondents, offered new insights into the focus of the research project. As will be outlined below, in the findings of each study, increasing knowledge was provided on how support for performing and implementing SDM could be developed in a manner that encourages service users and providers to learn new ways of relating to their own knowledge and to each other's expertise and to take on new roles in deliberation and decision making.

Service users' perspectives on information and decisional needs – Study I

The explorative analysis performed in study I provided an exhaustive understanding of informational and decisional needs in service users of mental health services. In concordance with Elwyn et al.'s (2012) model of SDM for general health care, respondents recounted the importance of considering possible benefits and disadvantages of various treatments or care options regarding personal needs, aspirations, values and activities. The provider skills proposed in the model were found to offer a well-defined structure for providers as to how to convey the importance of respecting individual preferences and transfer information to enable the service user to make informed decisions

with respect to those preferences. Consistent with wishes expressed by the respondents, the deliberative quality of interactions is central to the model of Elwyn et al., who stresses the importance of allowing the person to ponder over these pros and cons both during and in between encounters (Elwyn et al., 2012).

Addendums to the original model of Elwyn et al.

The present results also suggest two additional steps to the model (as previously referred to): a *Preparation* phase entailing preparatory tasks for both provider and service user and a *Follow-up* phase facilitating further contacts with providers for questions or reconsiderations. These proposed additions to the original model might be seen as conceptual extensions in the form of adaptations to the mental health context and to the needs of mental health service users outlined above.

Receiving an agenda and thus being offered the possibility to prepare was described as an indicator of mutuality, which in turn, was depicted as a prerequisite for involvement and agency in decision-making processes. Whereas the Elwyn et al. model starts when the health problem has already been analyzed and defined, the respondents in study I expressed how personal knowledge on various issues of life and of individual recovery needed to be included in the initial analysis of their situation and be considered in conjunction with diagnostic circumstances. For example, increased self-reliance might allow for a decrease in intensity of system services. This argument suggests that DSTs should be introduced early to allow bidirectional communication from the beginning of the SDM process.

As for the *follow-up-step*, respondents' wishes for planned revisits for review were noted. In light of the ongoing and nonlinear nature of illness and care needs noted above, decision processes must be a continuous procedure of adaptation and evaluation. Having the possibility to follow an individual's progress and to review notations of decisions was emphasized, indicating the importance of transparency of documentation and action plans. Respondents also noted how questions often arise after the latest provider encounter and how being offered follow-up contacts by e-mail or telephone would be experienced as stress relieving.

Further adaptations in response to the mental health context

It was also observed that some aspects of the model might need to be emphasized in relation to some of the needs and requirements the respondents expressed that were characteristic to the mental health context. For example, Elwyn's model focuses on communicative skills in the context of accuracy of information transfer and to comprehension, whereas respondents focused on

attitudinal aspects (e.g., how respect and trust are prerequisites for collaboration). Such features of equal-terms communication were, however, expressed as lacking and needed to be concretely manifested in a support structure for SDM.

Another variation concerned the involvement of other people from the service users' wider network. While Elwyn's model suggests that such individuals might support deliberation before and in between encounters, our respondents expressed additional reasons to involve relatives, support workers or peer support workers, and many of these reasons were in connection with support *during* provider encounters. For example, the respondents expressed the importance of bringing someone for memory support, assisting in conveying vital information and counterbalancing power differentials.

In conclusion, a central issue that was acknowledged in this initial analysis and that recurred in studies II - IV was the necessity to offer individualized channels and formats for information transfer that reflect different cognitive challenges and preferences as to channels and formats for communication and receiving information.

Developing decision support designed to strengthen active service user participation - Study II

As described previously, findings from study I provide a service user-based comprehensive understanding of the shared decision-making process and identified what components and functionalities need to be included in a DST designed for this target group. The results of study II show how the involvement of potential end-service users provided an indispensable knowledge perspective in all stages of prototype development and in all aspects of the DST, including language, layout, sequencing and contents.

Service user views and experiences

In the usability testing of the alpha prototype service user' comments on benefits primarily dealt with issues of usefulness and regarded support in preparation, stimulating reflection, identifying concerns, avoiding misconceptions, accessing information and legitimizing their personal knowledge. Negative comments most often concerned issues of understandability. For example, long passages of descriptive text were considered unwieldy and cumbersome to read. Past experiences of dependency on professionals and institutions and of compulsory documentation in contacts with services sometimes led respondents to perceive the items of the support tool as required rather than considering them as a tool for supporting their own agency.

Service provider perceptions

When reviewing and testing the DST prototype for electronic interface, service providers expressed some concerns about contextual issues; in particular, they noted some confusion as to how the DST could be applied in their specific setting and routines, given the time constraints that they experienced and their regular systems for documentation and planning. However, they felt that because the web application could be integrated with these other systems, it might promote continuity by facilitating integration of contacts and documents and provide an overview of plans and channels for communication.

Another concern of the providers regarded items in the DST that focused on service users' wishes and preferences and the risk these might raise service users' expectations by signaling that they have more power over decisions and freedom of choice than they actually do. In reality, service users' freedom to define their needs, choose among interventions and evaluate their benefits varied considerably, depending on the matter at hand and on the individual service user's decision-making capacity.

As for perceived benefits, providers appreciated, in agreement with the service users, how the DST might support service users in eliciting and verbalizing their needs and preferences and in obtaining a better overview and greater control over decision-making processes. They also observed how the DST could serve as a tool for the providers and service users in supporting preparation, communication, deliberation and continuity. A possible barrier to implementation mentioned by the providers concerned limitations to computer access and computer experience among service users.

Revisions made in response to views of respondents and testers

In response to service user comments, efforts were made to revise the prototype to avoid presentation overload and jargon issues, which were experienced as sustaining power imbalances. Formal language was replaced with more ordinary language to emphasize the personal support focus of the tool. In response to cognitive challenges and preferences regarding channels and formats for communication and information transfer, the functionality of printable PDF pages was inserted as well as voice files for descriptive texts. A major modification pertained to redesigning the tool in the form of an interactive web-based application with separate, overlapping interfaces for the service users and providers. This functionality allows the service users and providers to communicate ideas about options and permits responses to each other's questions and suggestions. The purpose of this revision was to strengthen service users' experience of mutuality and active participation and to support a deliberative process in which service users and staff may move forward and backward in the process as their interaction develops and moves towards de-

cisions. The possibility to exchange information via such a shared digital platform may enable service users to assimilate information, ponder and reflect, ask questions and verbalize needs and wishes, all without stress and in a setting of their own choice. In addition, by using this platform, the providers and service users may be better prepared before face-to-face encounters. Regarding the ongoing nature of decision-making processes, a feedback question was inserted in the follow-up section. The question was formulated to allow service users to document, through their own interface, any thoughts and reflections they might want to discuss at the next contact meeting. With such a procedure, the central place of the service user in the process is honored and reinforced.

In addition, concerning the diversity or heterogeneity of the service users' needs and the different services that are available, the need was identified to design the DST so that it might be adaptable to different service contexts and relevant for specific local organizations.

Service providers' perceptions in the implementation of SDM using a decision support tool (DST) - Study III

Study III aimed to describe and analyze an implementation process of a shared decision-making intervention for service users with mental illness in Sweden. In accordance with this aim, the study reports on numerous issues related to implementation.

Although the process evaluation results showed that levels of implementation of the DST were low at all units included in the implementation program, the overall findings from the FGI data and checklists suggest that the participating staff experienced the DST as service user-friendly and helpful in including user perspectives in decision-making processes.

Perceived barriers to implementation

As previously noted, some providers expressed that they were already working according to the principles of SDM, although not in a formalized and systematic way as would be the case when using the DST. Some stated that they were following the general approach of SDM through other methods, such as MI (motivational interviewing) and case management.

Structural factors (e.g., time constraints and workflow issues) were reported as barriers to implementation, and because the DST was not integrated in service providers' regular systems for documentation and care planning, it was perceived as an 'add-on' to their already stressful workload. Moreover,

the lack of an organizational agenda ensuring a robust commitment to increasing service user participation was noted as an additional contextual barrier to implementation.

As regards barriers related to the service users, many of the service providers expressed a lack of confidence in the commitment and ability of their service users to participate in decision-making processes, a perception that made them less willing to embrace the intervention. Some providers raised concerns that cognitive abilities or computer literacy in many cases would be insufficient for using the DST. Some felt that the availability of alternatives offered by the DST might cause stress and time-constrained decisional pressure.

Perceived benefits of the DST

Many of the providers expressed support for SDM and felt that the DST could be helpful in capturing service users' preferences. In turn, this would increase their (the providers') ability to structure their work based on service users' needs, wishes and conditions. Some providers stressed how the DST illustrates the importance of the staff being transparent and non-selective when sharing information with service users. Even if some information might be perceived as stressful or uncomfortable, it is still necessary for the providers to convey an accurate view of options with corresponding pros and cons. These providers noted how SDM challenges traditional practices where the provider is the expert. They also came to understand how SDM can motivate service users to actively participate in their own care, increase their ability to be more active in decisions and support them in validating their own personal knowledge.

A minority of the staff that had used the DST expressed how it had increased their ability to apply SDM and raised their awareness of their attitudes in relation to involving service users in decision making. They described how the DST had made them more aware of their own communication patterns and increased their inclination to pose fewer leading questions, instead offering the service users the chance to reflect and discover things for themselves. Using the DST together with service users contributed to the providers' ability to actively listen and consider the opinions and priorities of the service user rather than moving too quickly toward decisions, something that they noted that they often were inclined to do in their eagerness to help.

Prerequisites for successful implementation

The present results confirmed previous findings showing how managers need to be committed to SDM, provide sustainable structures for implementation and have a clear vision of SDM that constitutes a formal component of the ongoing activities (Ramon et al., 2017).

In addition, the results reveal the need to apply strategies that target attitudinal change. Although generally positive to the idea of SDM, providers continued

to describe user participation in terms of attitudes more related to promoting compliance rather than shared ownership of goals and plans.

Furthermore, providers frequently voiced the desire to *feel safe* with the method before applying it together with service users. This result shows that pedagogical efforts are necessary regarding technical support and hands-on skills training. In response to these identified needs, the involvement of facilitators with *lived experiences* of mental illness and service use might be viewed as particularly suitable for providing various kinds of implementation support because they might contribute with experiential knowledge that could be relevant for the learning process and facilitate attitude change.

Investigating the barriers involved in user knowledge being expressed and legitimized - Study IV

As previously noted, a crosscutting theme throughout the various datasets collected in the process of developing a supporting structure for SDM was the poor degree to which service users' knowledge was expressed, requested and considered in deliberative practice. This recognition inspired a theory-driven analysis to elucidate the complexities related to this phenomenon, which, in the study, were seen as service users' vulnerability to epistemic challenges. Because the analysis was performed on data collected in studies I - III, the findings of study IV relate to the inquiries of studies I - III, by viewing the collated data in a theoretical light.

Analyzing service users' and providers' narratives collectively helped to unravel the epistemic mechanisms at play in interactions between these groups. Both groups perceived how mental health service users constituted a group exposed to epistemic challenges. However, even if the service users and providers, to some extent, described similar issues, the groups often understood these issues differently.

Testimonial injustice – having ones accounts unduly devalued

Service users expressed how being attributed with characteristics that downgraded the credibility of their testimonies constituted a fundamental base of their experience. Respondents referred to various kinds of information that they wanted to bring to the table in decision-making processes. Some service users were active knowledge seekers with the routine to consult different sources of information (e.g., the internet, books and peers). As noted, many service users had lived with illness for a long period. It was noted that while personal knowledge on for example self-help strategies and early signs might often be relevant to consider when choosing among different options, it was often not sufficiently expressed or considered.

While service users stressed that providers need to be conscious of the power differentials embedded in their respective roles if dialogical interactions are to occur, such awareness was noted as largely absent.

Staying silent or editing communication due to imbalances of power was commonly expressed in service users' comments. Some noted how they chose to stay silent from previous negative experiences when it had proved useless to try to contribute with input. Other service users described how they modified their communication in order to increase the likelihood of being listened to, or of fear of not being cast as *a difficult patient* if they seemed too assertive. Applying the framework of epistemic injustice, such strategies can be understood in terms of *testimonial smothering*, where the speaker *edits* communication to be able to deliver their message or to avoid negative consequences.

Among the service providers, there were many comments on service users' incapacity or lack of decisiveness for participating in decision making. Some noted recurring difficulties in getting service users to speak. This silence was understood by some providers as an unwillingness to be an active participant. Other providers however, acknowledged the predicament of service users and noted how service users sometimes tend to hold back from voicing to their concerns and wishes because of feelings of dependency and insecurity in the face of authority. Furthermore, the risk was noted by service users as well as by providers, that doctors might misinterpret this silence as an unwillingness to participate in decision making.

Participant-based injustice - not being invited as a collaborator

Service users' experiences and perceptions of fruitful participation related to collaborative dialogical practices such as being able to i) add issues to the agenda before encounters, ii) of being able to discuss information collected from various sources and iii) review the same notations of what has been discussed and decided. However, for the most part, service users expressed how these equal-term features of full transparency and collaboration were largely lacking in interactions with providers.

As for knowledge gathering practices, many of the service users noted how bringing up ideas and questions on information that they had gathered from peers or online often seemed to be perceived as challenging by the providers. They wanted to feel invited to raise such inquiries and to have them met with openness, reasoning and clarification instead of dismissal.

On their part, service providers referred to the importance of carefully listening to service users' reports. However, some providers explicitly stated that they know best on how to make sense of all available information and come to a resolution on the best course of action. Information sharing with the service users should, according to them, be strategically selective with the intent to motivate the service users to go with the option preferred by the service

providers. Providers motivated such strategies with the concern of safeguarding service users who, according to these respondents, were prone to experience information overload or to make self-destructive choices. Involving service users in deliberative practices was seen as adding responsibility of uncertain outcomes onto already vulnerable individuals. Some providers pointed to the complications when service users consult outside sources (e.g., the internet and peers). Again, such concerns related to the problems it might entail for the service users since the prospect of relating to multiple sources of information was thought to be challenging to individuals who risked becoming confused by misleading or irrelevant accounts.

To conclude, some providers described how assessments of needs and benefits, are often strongly conditioned by regulations. Inviting service users in deliberative practices where they are requested to express their own valuations of their needs and benefits on various options might entail the risk of signaling the notion of *promising more than you can deliver*.

Hermeneutical injustice - not having resources for or control over interpretations

Service users often noted how important aspects of their life stories, their social lives and their strengths and weaknesses remained unexpressed or were lost in communication because time conditions and formats to collect information did not allow such testimonies. The analysis revealed how such barriers were most often related to the frames of interpretation operating in the system. Reports from service users indicated how organizational structures were underpinned by diagnostic, symptom-focused practices that did not seek or allow for holistic perspectives and personal narratives and reflection. Service users frequently expressed how providers are prone to view them through diagnostic frames of interpretation, something that made them feel perceived as *an object*, rather than as a *whole human being*. Some service users noted how the interpretations of providers always had precedence over their own understandings of their situation. Some perceived how their illness was unduly conceptualized as chronic, and how lack of knowledge of recovery caused outdated labels of illness and dysfunction to be stuck on them and follow along in the providers understanding of them. Being misinterpreted and having little or no control over how their problems were conceptualized, categorized and documented was expressed as frustrating and detrimental to joint deliberation.

Service users frequently reported on experiences of lacking the linguistic or conceptual tools to articulate or understand their experiences or to comprehend what service providers tell them about their conditions. Many service users commented on difficulties in understanding the psychiatric terminology used by providers and expressed that they wished that a more ordinary lan-

guage could be used. Some expressed difficulties in understanding and conveying their problems since their psychological problems were too diffuse and multifaceted. Service users noted this lack of vocabulary and lack of concepts to understand and explain aspects of their situation as a source of frustration, stress and disempowerment.

In contrast however, it should be noted that medical definitions and modes of explanation were expressed by some service users as vital for well-grounded decision making, and how having access these concepts *increased* their understanding of their conditions and thereby their manageability. The conceptual and therapeutic scope of medical knowledge thus *added* to their hermeneutical resources in that it provided the tools required for comprehension and explanations to bewildered relatives.

Discussion

The main objective of this thesis was to explore how service user perspectives and user knowledge might be incorporated and supported in SDM processes in the context of mental health services. In alignment with international research, the overall findings from a Swedish context confirm the endorsements of the inclusion of service users as playing a legitimate role as knowledgeable agents in decision-making processes as well as the challenges involved in realizing this goal (Morant et al., 2015; Ramon et al., 2017).

The present findings demonstrate that the prospect of supporting service users and providers to participate in SDM is associated with a number of complexities and barriers, regarding systemic processes and constraints as well as attitudinal, interactional and relational issues. Indeed, the findings make explicit how achieving meaningful dialogue in a *meeting of experts* in practice requires radical changes at every level (attitudinal, interactional, organizational and systemic) in the current mental health practice.

These findings provide insight into the different dynamics at play in the domains of power, role expectations, knowledge production and knowledge transactions. These insights have not only progressively informed the design of the DST described in this thesis, but might also guide future development of methods that may empower service users in their communication with providers and adequately target obstacles for honoring personal knowledge in decision making in a mental health setting.

Notably, it was the process of developing and testing a concrete structure for supporting service users to be active contributors of their knowledge and perspectives in SDM, that led to the identification of an array of specific factors that may hinder or facilitate full participation. Through this process, a more detailed and comprehensive understanding of this matter emerged.

In this way, the findings make a significant contribution to the understanding of how DSTs can be tailored to meet the needs of service users of mental health services and how such a tool may challenge established provider-service user roles and relationships. Moreover, the findings demonstrate the importance of participatory approaches in which the experiences and views of potential end-service users can contribute with knowledge in all stages of formation of a DST in order to consistently build user perspectives into its structure. The findings consistently confirm that service users possessed various forms of knowledge, often including scientific knowledge as well as experi-

ential knowledge involving, for example, detection of early signs and strategies for self-help and coping, and how this knowledge needs to be expressed, legitimized and considered in decision making.

In a similar manner, the findings underline a number of characteristics of mental health care decisions that require special considerations when developing supportive structures for service users to be able to play an active role in decision making. The wishes expressed and prerequisites identified by service user respondents for supporting their participation in decision making corresponded with key values related to being in control over their life, such as personal autonomy and self-determination, that have been outlined as essential for a PCC as well as for a recovery-oriented mental health practice (Onken et al., 2007; Slade et al., 2012). This further substantiates how a holistic view of mental health and illness is required in which symptoms and diagnostic circumstances are considered alongside issues relating to life context, personal strengths, aspirations and levels of self-help competency.

Making explicit multiple mechanisms of covert power

The findings underscore the importance of making explicit the barriers that exist regarding the inherent power imbalances present in the meeting between service users and providers, as well as with the mental health system at large and how these barriers need to be targeted in order for user knowledge to be acknowledged and respected in decision-making processes. In study IV, a theoretical framework of *epistemic injustice* was applied to shed light on the epistemic dimensions of planning and decision making. The findings, however, did not reflect a unidimensional representation of reality in which one group subjects the other to injustices, either consciously or unconsciously. Rather, the findings revealed a complex set of covert mechanisms in the interactions between members of highly heterogeneous groups using or working in a variety of care and support systems in which assessments of needs and benefits of interventions are often circumscribed by different regulatory systems. The analysis made visible the complexities involved for providers in balancing conflicting values and of interpreting and relating to users that prefer (or seem to prefer) to take on passive roles in decision making. A key for providers to understand and be responsive to these mechanisms was to acknowledge the power imbedded in their roles.

Whereas service users were often aware of issues of the power differentials underpinning practice, the provider perceptions seemed more diverse. While some providers indeed noted certain power asymmetries, others described the exposedness of service users more in terms of unwieldy organizational infrastructure and noted how navigating these systems often posed unreasonably high demands on a group of service users with typically lowered cognitive, epistemic competency.

It is indeed emphasized in previous literature how acknowledging power differentials is essential, in that the veil of ignorance thereof may mask vital aspects of experiences. For example, Skau & Jonsson (2007) identified how providers might be inclined to misinterpret behaviors of service users if they are unaware of the aspects of power asymmetry. Being reserved or quiet might then be interpreted as unwillingness or complacency when in truth it is a manifestation of feeling exposed and powerless. Correspondingly, several studies highlight how service users' passivity is often understood in terms of *learned helplessness* or lowered self-efficacy, whereas others argue that it might be better understood as *false compliance* (Kaminskiy, 2015) or "realistic defensiveness born of past experience with mental health services" (Holmes-Rovner et al., 2010, p. 77).

Indeed, in the current study, providers interpreted silent service users as expressing an unwillingness to participate, whereas service users reported how they frequently edited or curtailed their accounts in interactions with providers from fear of being disliked for being too assertive or from earlier experiences of not being ascribed credibility. This observation might entail that providers lack the awareness that relevant information is unexpressed by service users or circumscribed because of earlier experiences of epistemic injustice. In terms of the epistemic injustice framework, these mechanisms are described as *testimonial silencing* or *testimonial smothering* (Blease, Carel, & Geraghty, 2017).

The present findings, in which service users describe experiences of having to struggle to be considered a worthy interlocutor, of providers deferring information, of feeling inferior and dependent and of being regarded as incapable to make decisions are in line with previous studies examining service users' conditions for uttering their knowledge and perspectives in SDM (Dahlqvist-Jönsson, Schön, Rosenberg, Sandlund, & Svedberg, 2015; Fossey et al., 2012).

In agreement with previous research the present findings point to the necessity of establishing a trustful relationship and of communicating to service users that they may express any views, accounts or questions in deliberation processes, without risking being labeled as untrustworthy or difficult (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). As reported by Davidson and Chan (2014, p. 676), recovery-oriented providers "will have to earn the trust of a distressed and possibly skeptical person who may have become accustomed to being misunderstood by people", of being stigmatized and discriminated.

False consensus due to conceptual unclarity

Although the providers included in the implementation study (study III) experienced the DST as relevant, levels of actual implementation of the DST were low at all participating units. Provider-generated data from all phases of research, together with previous research findings on barriers to SDM, led us to

assume that the mechanisms causing this low embrace of SDM and the DST needed to be explored and better understood as a prerequisite for tailoring structures for service user participation that will be accepted and applied by services and providers.

A key barrier to the use of the DST was identified to be providers' perception that they already worked according to the principles of SDM, a notion that is frequently expressed in the literature (Elwyn et al., 2012; Ramon et al., 2017). At the same time, a sense of being excluded from decision making was frequently expressed by service users, another finding that corresponds with the bulk of previous findings on service user experiences in relation to participating in SDM (Dahlqvist-Jönsson et al., 2015; Goscha & Rapp, 2015; Morant et al., 2015).

This discrepancy of perceptions might be due to some confusion about the meaning of user participation and SDM. As suggested in the discussion of the *polyvalent* nature of SDM, conceptual unclarity regarding SDM is evident in the present findings. Although there is a general agreement among different stakeholders on the value of SDM, the term seems, as noted by Slade (2017), open for differing interpretations and may conceal conflicting beliefs and expectations, thus obscuring complexities that need to be targeted and scrutinized.

In response to this conceptual confusion, Arnsteins' ladder of participation, which presents service user involvement as a continuum (Arnstein, 1969), may be applied for clarification. The findings of this study are congruent with previous empirically underpinned discussions showing that service providers are often prone to perceive their habits of creating a trustful atmosphere, valuing user perspectives and honoring transparency as guarantors of service user involvement. (Carel & Kidd, 2014). However, although such activities are vital prerequisites for service user participation, Arnsteins' model suggests that they belong on the lower rungs of the ladder and do not reach above the *consultative* level of involvement, implying little service user influence over decisions. Simply 'making the service user feel involved' should not be confused with actual sharing of decision making.

The collaborative features of SDM, in which providers and service users are conceptualized as equally valuable sources of knowledge and where desired outcomes are centered on service user preferences, are located in the upper rungs of Arnstein's ladder, i.e. on the level of *partnership* and *delegated power*. From the perspective of providers who perceive themselves as pedagogical information sharers and attentive listeners of service user accounts, the commitment to these activities may obscure prevalent power differentials and a failure to invite service users to be full partners in shared inquiry and deliberation.

Besides the obvious obstructions for person-centeredness implied by not acknowledging service users as valid partners, the consequences of such disqualification might be understood in terms of *participant-based injustice*,

shedding light on the effects of being thus excluded. According to Fricker, not being regarded as a full epistemic subject might be experienced as a distinct form of epistemic objectification, something that might cause harm, both to a person's psychology and to his or her practical life. Such harm might naturally have a silencing effect on these subjects (Fricker, 2007; Kwong, 2015).

Together the application of these theoretical constructs serve to highlight the importance of not regarding service users only as a valuable informants but how they need to be invited as partners in analyzing, interpreting and acting upon the information that is shared.

A logic of care as a barrier to partnership

Consistent with previous findings on providers' views on SDM, provider-generated data in the present study revealed how the prospect of actually ceding professional power, as required in order to achieve SDM in a real sense, was a matter of concern. The current findings resonate with previous analyses demonstrating the complexities and sometimes conflicting ideas involved in the movement towards person centeredness (McCormack & McCance, 2010; K. Smith, 2016). As Smith points out:

[PCC] overtly requires that health practitioners put aside their own judgements, beliefs and attitudes in order to develop care that takes seriously the idea that the person being cared for has the greatest expertise about their own experience, and that this expertise is an essential component of the healing process (p. 2).

The narratives within the current thesis reflect the complexity involved in balancing between the values of autonomy on the one hand, and safety and professional accountability, on the other. Reports from service providers frequently implied how a protective stance took precedence over honoring self-reliance and autonomy by for example, shielding service users from the confusion, uncertainty and anxiety that can be caused by too much information and multiple options. These attitudes correspond with previous studies and elucidate how the reluctance of providers to engage service users in SDM is typically related to their faith in their own ability to assess what is best for the user, to concerns about the users' condition becoming less controlled (Morant et al., 2015; Younas et al., 2016) and to concerns about burdening vulnerable individuals with responsibility (Patel, Bakken, & Ruland, 2008).

The typically low expectations among service providers on service users' capacity and the attitude of leaning towards protection and safety have been described in research on recovery as following a *logic of care* and is assumed to stem from a lack of knowledge as to possibilities for rehabilitation and re-

covery (Lindqvist, Markström, & Rosenberg, 2014). Considering the experiential, process-oriented understanding of recovery, the importance of focusing on the strengths and resources of the person is emphasized, as is the value of supporting *positive risk-taking*, i.e. respecting the choices of the person, even if some activities or tasks they want to perform might involve some risk. (Barnicot et al., 2017; Lindqvist et al., 2014; Morant et al., 2015)

Contrary to these recovery-oriented notions however, being selective in information sharing, and limiting the options from which to make decisions, was described by providers as a necessary means to steer users towards the best decision (as unilaterally defined by themselves as professionals). As noted, theorists such as Bachrach and Baratz (1963) who draw attention to the *area of non-decision making* note how such a practice is an exercise of power although not always consciously intended as such. Furthermore, a prerequisite for participating in SDM frequently voiced by the service user participants was to have the possibility to influence the agenda before meetings, a request that similarly might be understood according to the analysis of Bacharach and Baratz on decisions and non-decisions in which they highlight the power involved in having control over the agenda. (Bachrach & Baratz, 1963).

Low trust in ability, agency and insight

In agreement with previous results on provider perspectives, assumptions were repeatedly expressed by service providers that some service users did not have the ability to participate in SDM (Simmons et al., 2011), and that some decisions were entirely outside the sphere of SDM activity (Deegan, 2014; Ramon et al., 2017). As noted by Ramon et al. (2017, p. 266), such assessments of sufficient decisional capacity for participating in SDM risks leading to a “circular argument (e.g., SDM being seen as a virtue until there [is] disagreement and then it reverting to an issue of insight and SDM then becoming a risk)”. Decisions that are weighted towards risk or safety concerns may consequently place limitations on SDM.

Lack of computer access and poor computer literacy were described as user-related barriers. This might however be more fittingly understood as a structural-organizational problem, highlighting the obligation to provide users with the structures and skills required for them to be able to participate as stipulated as a service user right in policy and legislative frameworks.

Consistent with previous research (Andrews, Drake, Haslett, & Munusamy, 2010), the current findings showed how users had a variety of cognitive difficulties associated with their mental health conditions which posed challenges for information assimilation, communication and decision making. However, in concordance with prior development and implementation efforts related to electronic DSTs, it was evident that a DST that is designed to meet the heterogeneous support-needs of mental health service users may enable even people with considerable cognitive challenges to assimilate

information, deliberate on alternatives and make decisions, thereby increasing their possibility to influence decisions (Andrews et al., 2010; Ben-Zeev, Davis, Kaiser, Krzsos, & Drake, 2013; Bonfils et al., 2016; Deegan, 2010; Scholl & Barr, 2017).

Equally consistent with other researchers (Torrey & Drake, 2010), our findings show that service user ability and preferences as regards participation in decisions are not static qualities. Aligning levels of user participation with levels of insight, capacity and determination is consistent with the principles of PCC (Chong et al., 2013) (Chan & Mak, 2012; Hamann & Heres, 2014) and was mentioned as crucial in the current study by service providers as well as service users. However, as illustrated by Arnstein's ladder and the findings of this as well as previous investigations, activities that belong on the lower rungs do not in themselves involve SDM in any real sense.

In relation to assessments of user epistemic capacity, (and equally congruent with previous research findings, (Shepherd et al., 2014; Younas et al., 2016). S), a key observation of the current study was that service providers often tend to be pessimistic towards both service user capacity and motivation for participating in decision-making processes. Service users for their part, noted the tendency of providers to devalue their accounts due to conceptions about lowered epistemic capacities that were associated with their mental conditions. Such a dismissive stance was expressed as obscuring important information in cases where their accounts warranted credibility and attention and discouraged service users from active participation in discussions.

These provider perceptions regarding insight, decisiveness and decision making competency might be viewed in light of previous literature highlighting how while these capacities might certainly be impaired during periods of acute illness, these temporary lowered capacities may lead to prejudiced beliefs of mental illness being generally associated with irrationality and untrustworthiness (Sanati & Kyratsous, 2015).

As noted by Morant et al. (2015), such underestimations serve to devalue legitimacy of user perspectives and risk amplifying inequalities between mental health service users' personal knowledge and the providers' scientific knowledge base. Such judgements are seldom made "in other domains of health care, in which patients views are generally considered valid even if they disagree with providers" (Morant et al., 2015, p. 1007).

Along the same lines, Kaminskiy (2015) makes the following remark in her analysis of power and SDM (which in terms of the current analysis can be described as a palpable expression of epistemic injustice):

[W]hile in other areas of health, decision-making capacity may be limited by service users' knowledge of medical conditions and treatments, their ability to reason is not in dispute. In mental health, the capacity to reason and make effective decisions resides with others rather than with the service users themselves (p. 25).

These insights highlight the importance of providers' shift in attitude in support of the key assumption of PCC, namely that people have capacity and determination with respect to decision making that directly affects their lives. As phrased by Buchman & Goldberg (2017) in their recommendations for achieving greater levels of epistemic justice, providers need to adopt a *default* attitude of trust in service users being capable epistemic agents.

Some of the providers recognized and highlighted how traditional mental health care throughout the years has contributed to role expectations on service users that favored passivity and compliancy, and how this current switch to expecting self-reliance and participation requires fundamental changes in attitudes and habits of both providers and service users, as well as access to concrete support structures for all concerned.

The present results demonstrate the hermeneutical disadvantage of not having control over problem definitions and access to the linguistic tools of the professionals. It was discernable how the frames of interpretations that operating within the systems regulated the conditions for knowledge transactions and the value scale against which accounts and narratives are weighed. Such findings provide evidence for the hermeneutical injustice experienced by users as a structural problem.

In accord with previous findings, the present findings show how service users sometimes downgrade the expertise they themselves could bring to the decision process, which likely stems from the prevailing view *that the professionals know best* (Korsbek & Tønder, 2016). This lack of self-efficacy, which is noted to be particularly salient among mental health service users, challenges key tenets of SDM such as partnership and open information exchange (Delman et al., 2015; Eliacin et al., 2015a). Low self-esteem and self-stigma among mental health service users affect their interactions with providers (Alguera-Lara, Dowsey, Ride, Kinder, & Castle, 2017; Hamann et al., 2017). Thus it is noted that providers need to empower service users by creating and encouraging a "participatory atmosphere" (Hamann & Heres, 2014).

The present findings might be viewed in relation to the ideas of Foucault and Freire who describe repressive cultures and self-stigma, and argue that the legitimacy of expert knowledge and expert language becomes internalized. As emphasized by Wiggins and Schwartz (2005), these phenomenon underscore the importance of providing cultural legitimacy for the individual's own voice. The results suggest that this may be achieved by actively and systematically requesting and validating service users' experiential knowledge as well as the language in which it is expressed.

The value of exploring assumptions underpinning practice

The current analysis reveals service users' powerlessness in face of what was documented (e.g., how journal notes biased providers' perceptions of the service users' predicaments). As detailed in the theory section, some theorists suggest that professionals might not be aware of the power embedded in their authority to classify and categorize (Holstein, 1992; D. E. Smith, 1978). Based on the current results, it is visible how knowledge might more fruitfully be both accessed and created where the perspective of service users affects how aspects of their problems may be perceived, categorized and remedied (Svensson et al., 2008) and how this may be achieved by actively and systematically including service users' descriptions of what's going on. As these findings suggest, concrete documentation of service user preferences and input into decisions may influence staff behavior and promote reassessing attitudes towards service user involvement.

The findings also show how interpretive frameworks and basic assumptions on what it means to be a mental health service user underpin practice and how symptom-focused and deficit-based perspectives on mental health problems need to be challenged by a recovery-oriented and asset-based perspective (Kretzmann & McNight, 1993). In view of the current findings, becoming aware of the conceptions and values that legitimize the logics of organization, the routines and the goals in the current practice, might reveal to providers that they actually can promote culture change and that they have a greater degree of freedom than originally assumed, when considering inviting service users in as epistemic agents. This idea is represented in Johansson's exploration of determinants for implementation, in which he points to the value of scrutinizing the environment or policy context since it affects "norms and values as well as the way we perceive the world" (Johansson, 2010, p. 116).

The DST as a tool for discovery

The results showed how reflecting upon, testing and practicing with a DST, revealed new ways of working and acting for service users as well as providers. When encouraged, service users increasingly noted the different forms of knowledge they themselves possessed, what information priorities they had and what preferences they had in relation to deliberation processes. Thus, they increasingly recognized themselves as agents and actors in the situation.

On their part, providers noted how the increased influence of users' perspectives in deliberation processes that were allowed to be recursive and iterative, in the way proposed by Elwyn et al (2012), could actually assist in resolving situations they initially perceived as conflictual. As noted, this initial assumption of conflict was sometimes due to the providers' perception that applying SDM implied unfoundedly signaling to service users that they had

full freedom of choice. This assumption seemed to reflect an idea among providers that service users typically perceived participation to imply full decisional-power. Notably however, the current findings indicate that service users' perceptions of participation did not imply either having or having the desire for such decisional freedom. Thus, practicing SDM in a formalized manner might refute prevalent obstructive assumptions amongst providers, both regarding beliefs of service users not wanting to participate and service users wanting complete decisional power.

Together, the current findings correspond with those reported in earlier studies showing how providers who initially point at organizational regulations and responsibilities as barriers for SDM tend to discover, through the practice of SDM, that there is room for in-depth deliberation on how the problems of the individual should be described and how possible interventions should be assessed, thereby increasing service users' influence on decisions (Morant et al., 2015; Munthe, Nykänen, & Sandman, 2015).

Similarly, the present findings correspond with previous studies showing how occasions when service users put forward ideas which might initially lead to disagreements often involves discussions with greater sharing of information and preferences which in turn often lead to more instances of the users preference being reflected in the final decision (Matthias et al., 2012).

Reflecting on the items within the DST, relative to their own practice thus inspired honest assessments amongst providers of their own habitual roles and practices. Thus, the DST became a tool for reflection "that facilitated transformative learning and critical self-awareness" (K. Smith, 2016, p. 1).

In addition, even when consensus was unachievable, (as for example when legislative frameworks placed limitations on the service users' influence on the decisions), the DST aided in maintaining partnership in that some core principles of SDM, such as transparent information sharing and open, mutually respectful dialogue could indeed be experienced. Consequently, it was noted how opportunities existed to support the implementation of components of SDM, (such as exploring values and goals), also by providers who had no part in actual decision making. While maintaining that the core purpose of SDM is users' actual influence over decisions, this benefit of the DST should not be ignored. As noted by Matthias et al. (2012) and as reflected in the current findings, person-centered communication that incorporates some elements of SDM, by for example moving beyond the specific issue of focus for decision making and being allowed to reflect on other areas critical to recovery, has the potential to direct communication toward a recovery-orientation and enhance the relationship between service users and providers (Matthias et al., 2012).

Supporting the legitimization and inclusion of user knowledge in decision-making processes

The overall findings emphasize the value of supporting a bidirectional information flow and deliberative discussion initiated at the very start of decision-making processes and continuing to phases including reviews and reevaluations. This might be supported by using a DST designed to allow for such a process of probing deliberation and dialogue, one that transcends the boundaries of time-limited and infrequent meetings, and which would provide a supportive structure for SDM within the systemic, structural constraints and limitations. Such a supportive structure might be considered in light of the notions of Clegg, Giddens and Archer who stress the dynamic and recursive relation between structure and agency, noting how promoting agency on the level of the individual may influence structural conditions that regulatory constraints create (Archer, 2012; Börjesson & Rehn, 2009; Giddens, 1979).

Such a tool might help service users to think carefully about their circumstances (which might often be multilayered, obscure and imbued with conflicting values) and together with the providers consider which options are available and which are most congruent with their sense of what is worthwhile.

The development of the DST was based on a model for SDM practice in general health care created by Elwyn et al. (2012). The model was later developed with respect to special characteristics prevalent within a mental health context. The original SDM model featured the following three steps: i) introducing choice, ii) describing options and iii) helping patients explore preferences and make decisions. This model was extended with a preceding *preparation phase* and a concluding *follow up phase*. These additions can be viewed as conceptual extensions to the model, promoting mutuality and person-centeredness throughout the decisions process, from problem analysis and development of a shared agenda, through full deliberative partnership in exploration of alternatives towards shared decisions and finally to common reviews and follow-up of decisions.

Throughout, the core notion of *relational autonomy* highlighted by Elwyn et al. (2012), has been reflected in the findings of this thesis. Their affirmation that supporting self-determination does not imply abandoning people was confirmed by these findings, illuminating how individual competence might be respected alongside the interdependence of others.

As noted as an essential assumption of PCC and as reflected in the current findings, what works and what are desirable outcomes are highly individual matters (Deegan, 2007). Personal knowledge on what activities might decrease symptoms and give meaning and purpose to life, (Deegan, 2005), should be allowed to affect choices of interventions. For instance, increased self-reliance might naturally allow for a decrease in intensity of system services provided.

Together these findings, which reflect a strength-based, holistic approach to mental illness and recovery, led us to acknowledge the importance of designing a support tool that helps service users elicit, verbalize and communicate their own understanding of their needs as well as of their personal preferences, values and goals, all in accordance with a wider perspective than the purely medical and symptom-focused model. Guided by input from end-service users as informants and testers, the subsequent prototypes were refined to be increasingly service user-friendly and flexible with respect to individual preferences as well as to various cognitive conditions. The developmental process thus resulted in a DST that may have the potential to transform the traditional ‘script’ of provider-service user interactions into genuine SDM and that hopefully may contribute to a person-centered and a recovery-oriented system.

Methodological considerations

Throughout this study, knowledge has been sought with regards to subjective perceptions of various groups of participants in relation to their experiences and needs, as well as to their views on prerequisites, facilitators and barriers to service user participation in decision-making. Such knowledge is considered a prerequisite for intervention development and implementation in order to tailor working methods that are considered acceptable, valuable and usable by its target groups (Statens beredning för medicinsk utvärdering, 2014) [Swedish Agency for Health Technology Assessment and Assessment of Social Services]. Qualitative methodologies have been applied to acquire a full and rich understandings of the phenomena of interest and of how processes interrelate with each other and with specific contexts and cultures (Graneheim et al., 2017).

Strengths and limitations in relation to trustworthiness of findings

Throughout the research process, selections of contexts, participants and methods for data collection have been utilized to explore the research questions from different perspectives (Patton, 2002). Respondents and testers with diverse experiences and backgrounds have contributed in providing rich and subtle descriptions of the phenomena under study. The complexity of these phenomena, however, posed a challenge when deciding upon the amount of data needed to answer the research questions. Although service user respondents with diverse diagnoses, ages and experiences have been included, there still remains a risk that they are not representative of the broader, multifaceted service user cohort within mental health services.

Concerning the sampling methods for the initial focus groups (study I), the presumption was that service users with experience of being representatives of groups of service users, and those with no such experience might contribute by sharing their perspectives in different, complementing modes of expression. Members of the two service user panel groups were thought to be less likely to place emphasis on their own, personal experiences and contribute with perspectives in a more representative mode, representing groups of people that share experience from the same or similar phenomena as themselves. In contrast, the service users in the third group might contribute with more personal narratives from first-hand experiences. Although less representative, this ‘untrained’ group was assumed to have the potential for bringing to light phenomena that might not appear in more developed descriptions of the wider service user experience (Strøm & Fagermoen, 2014). Accordingly, the aim of this purposive sampling approach was to access a wide scope of perspectives and experiences, as well as modes of sharing experiences, in order to identify a broad range of views and needs.

For the issue of representativeness, the fact that participants in usability interviews and tests in study II were only women might be a limitation to the credibility of the findings (Graneheim & Lundman, 2004). Still, there is no reason to believe that experiences of the study participants differ in any dramatic sense from other people of both sexes in similar situations.

Although time-consuming, the value of using an iterative, participatory design to access experiential knowledge perspectives was confirmed, in that such input proved to be essential in each step of developing support for strengthening service user participation.

The aim of the concluding analysis (study IV) was to cast theoretical light on the findings from study I - III concerning problematic issues on knowledge production and knowledge sharing in decision-making processes. When extracting text excerpts from the total body of data generated in this project, most of the selected data derived from comments of the service users. Consequently, in the analysis, a disproportionately large part of the categories are made up of service user perspectives, which might be a limitation as to the quality of the study.

For studies I-IV, representative citations from text data have been given in order to justify the findings and make it possible for the reader to determine that the interpretations are grounded in participants experiences (Graneheim & Lundman, 2004). Each participant is specified with a number corresponding to the citations, making it possible to recognize that data are reported from a range of participants.

Another aspect of the credibility of the findings of qualitative content analysis concerns how categories are created and how well categories cover data so that relevant data have not been inadvertently excluded. As reported, analytical processes have been continually addressed by an open dialogue within

the research team. Tentative categories have been discussed and revised (Graneheim & Lundman, 2004).

In each paper, clear and distinct descriptions have been provided of contexts, selection and characteristics of the participants, as well as of data collection and data analysis processes. This, together with representative citations, contributes to the possibility for readers to assess the transferability of the findings to other settings or groups.

Reflexivity when studying the familiar – an account of self-monitoring in the role as an ‘insider’

Having shared experiences with the study participants (the mental health service users) has provided a variety of advantages as well as challenges during the course of the project.

Insights of being a service user will, to some extent, be “mediated and diluted” by a persons’ lack of insight into other areas of service provision than those they have experienced, and of “individual nuances within the service user experiences under investigation” (McLaughlin, 2009, p. 1594). When listening to and analyzing respondents’ narratives of various challenges a mental health service user face, I have recalled my own struggles with similar issues. This has required a constant deliberate effort to avoid the risk of blurring boundaries but to maintain the separation between “mine and theirs” (Berger, 2015, p. 224).

When interviewing service users, I believe that my ‘insider’ position provided me some additional access to the field in that the respondents might have been more disposed to share their experiences with someone whom they could identify with as being sympathetic to their situation (Berger, 2015). I also believe that my shared experience helped me to more easily grasp and understand the finer nuances in responses, which in turn enabled me to probe more effectively and recognize clues that others might miss (Berger, 2015). Although my reflective attentiveness certainly has been enhanced since conducting interviews and tests with service users during the first years of the project, I believe I took sufficient care to let respondents tell their stories without pushing them in any specific direction on the basis of my own experiences (Berger, 2015). In addition, I recall being particularly reflective as to how much personal information to disclose before and during the interviews. My objective was to make brief references to aspects of my own experiences, in such a manner and with such timing that it would prompt the respondents to address certain aspects of their own experiences (Berger, 2015).

As a strategy for maintaining reflectivity, it is suggested that one should systematically make notations for self-supervision (Berger, 2015). In my case, I have conducted such journaling in conjunction with making field notes during, and after data collection. Because of my ‘insider’ position, I have taken

extra care to note my own reactions, emotions and my conceptions of their triggers when recording immediate impressions.

During data analysis my 'insider' position required the ability to shift to a meta-position in order to create adequate distance from the study setting in as to avoid that my self-involvement would not unduly steer my interpretations (Berger, 2015). For me, such strategies during the course of the project have primarily been developed in discussions with the research team. The explorative, mode of dialogue and shared inquiry within the research team has served to support and enhance my reflexivity throughout project. As a PhD researcher who shares experiences with a socially sensitive target group, I sometimes noted a risk of emotional and ideological bias in my analysis (Berger, 2015). In no way does the research performed within this project claim to be value free or objectively distant from its subject matters, but is, to a large extent, driven by a social empowerment ethos. However, the discussions within the team have supported me in monitoring the tension between involvement and detachment between myself and what is being studied so as to not let my own sensitivities interfere with seeing and hearing certain perspectives that might be present in the data. The interactivity within the team promoted the development of insights regarding different types of knowledge and of how this varied knowledge can be integrated. Consistently, input from the other team members helped to balance potential bias in my analysis of the material (Graneheim & Lundman, 2004). My user perspective might also have served to balance possible bias in the perspective of the other members of the team. For instance, I might have noted some implications and nuances in respondents' reporting that the others might have overlooked (Veseth, Binder, Borg, & Davidson, 2017).

Having lived experiences of the ambiguous predicament of simultaneously being the subject of care and control, that are commonly shared by mental health service users, offers an important vantage point in exploring the social conditions of this target group (Phillips, 2006). Undoubtedly, this perspective allowed me to discover in the data the various mechanisms of epistemic injustice that were explored in (study IV).

Conclusions and implications

Mental healthcare systems are increasingly required to apply a person-centered practice, a practice in which SDM is frequently highlighted as a key component (Duncan et al., 2008; Eliacin et al., 2015b). In this thesis, an array of challenges have been described, focusing mainly on issues related to honoring service users as capable knowledgeable agents. The findings show how new ways of working are required, in which practice builds on new conceptions of knowledge, in order for user knowledge and perspectives to become central ingredients in decision making.

The findings of this thesis highlight the challenges that SDM presents to predominant practices in that it requires that the traditionally vertical relationship between providers and service users, in which the providers have possessed ownership over competency and knowledge, is transformed in favor of a more horizontal relationship.

In agreement with what is emphasized in research on implementation, the current findings demonstrate how providers need to recognize the clear benefits for service users in order to embrace this new way of working (Nilsen, 2014). When adopting new approaches that may imply conflicts of values, the risk of creating greater harm than good may incline staff to adhere to or revert to their traditional practice. It is therefore suggested that, in relation to person-centeredness and SDM, the indispensable value of autonomy and epistemic justice be clarified to the providers.

The current analysis has illuminated how the extent of agency granted to a speaker is regulated by the ways in which his or her accounts and perspectives are heard, taken into consideration and acted upon by the recipient (Carver, Morley, & Taylor, 2017). The present analysis has served to pinpoint some specifics of what it actually means to service users to have a role as an epistemic agent, and, in contrast, what it implies to be regarded as less than a worthy interlocutor and collaborator.

Consistent with findings from other studies demonstrating how practicing SDM increases decision-making capacity (Larkin & Hutton, 2017), the current findings indicate that willingness and ability to participate are largely matters of receiving adequate opportunity, encouragement and support. Taken together, the present findings suggest that service providers should adopt a default attitude of legitimizing service users' accounts, and of being optimistic about their willingness to be active participants.

In addition, the results draw attention to the biases that might be linked to the interpretive prerogative of professionals. Increased awareness of this phenomenon and insight into the powerlessness service users might experience in the face of it, might make practitioners more inclined to embrace the use of a DST that actively involves service users in epistemic practices such as problem definition, analysis and documentation.

The analysis has shown how inviting user perspectives in all epistemic practices is important given that knowledge per se, as well as its applications, involves aspects of power that have consequences for the persons the knowledge aims to support. For instance, the ways in which service users are categorized in various client groups is a manifestation of the power of defining the problem that is to be managed (Blom et al., 2013).

Using a DST that systematically invites service users as co-writers, editors and reviewers of various forms of notations, might serve to reduce biases related to prevalent deficit-focused frames of interpretation and thereby promote decision making founded on more holistic and person-centered bases of knowledge.

Systematically, the findings emerging from the studies informed the development of a DST that might empower service users in their interactions with service providers by validating their own knowledge and strengths and by putting their individual circumstances and values at the heart of the process. By methodically addressing various concerns and challenges identified throughout the research process that typically prevented service users from formulating and expressing their views and perspectives, a DST was designed that consistently acknowledged service users as carriers of knowledge by inviting them to become full deliberative partners at each step of the decision-making process.

For the providers, who might be unsure as how to ascertain sufficient levels of service user participation in their practice, such a tool might function as a guiding structure for concretely and systematically validating service users as knowledgeable agents at every step of decision making and thus making SDM a practical reality in mental health services. Hence, embracing and using such a DST might not only support service users to be active participants but might thereby also help service providers become aware of new horizons to support recovery.

Suggestions for future research

Research within this area is at a relatively early stage and there are many issues to be resolved. The present study have been an endeavor to explore the barriers and prerequisites involved in developing and implementing a supportive structure for service users to have a valid, meaningful role in SDM. The present studies have referred to several issues that might be important to consider in

future research. First, the findings and conclusions provide guidance for the tailoring of future development, testing, implementation and evaluation of DSTs. The current findings additionally identify special challenges and indicate possible suggestions to address them that would need further inquiry. For example, future research might explore how structures can be redesigned to incorporate DSTs within the framework SDM, and how reflexive learning might be used as a tool for service users as well as providers to take on new roles that promote partnership, sharing of power and sharing of knowledge.

Sammanfattning (in Swedish)

Syfte

Det övergripande syftet med denna avhandling var att undersöka hur brukarkunskap och brukarperspektiv kan inkluderas och stödjas i delat beslutsfattande (DBF) inom psykiatrisk vård och stöd.

Avhandlingen består av fyra separata men sammanhängande studier. Studie I utforskade vilka behov brukare identifierar som viktiga för att aktivt kunna delta i deliberativa processer och beslutsfattande kring sin vård och sitt stöd. Studie II undersökte hur ett beslutsstödsverktyg för DBF kan utformas för att öka brukarnas möjligheter att ha aktiva och meningsfulla roller i beslutsprocesser. Studie III undersökte hinder och förutsättningar i samband med implementeringen av ett webbaserat beslutsstöd utformat för att fungera som en gemensam digital plattform och en konkret struktur för DBF i syfte att stödja kommunikation och gemensamt övervägande. I studie IV genomfördes en teoretisk analys för att belysa de svårigheter som kan finnas när det gäller tillvaratagande och legitimering av brukarkunskap i beslutsprocesser.

Metod

En viktig del av projektet handlade om att undersöka olika aspekter av brukardelaktighet och DBF i utvecklingen av ett webbaserat DST beslutsstöd avsett att stödja brukare i att ta en mer aktiv roll i beslutsprocesser i tillsammans med vård- och stödgivare. Detta utvecklingsprojekt bestod av en process där beslutsfattande och informationsbehov utforskades i ett iterativt utvecklande, testande och utvärderande av beslutsstödet, där determinanter för implementering utvärderades och där implementeringsprocessen utvärderades. I denna process har en rad olika metodologiska tillvägagångssätt tillämpats. Kvalitativa data samlats in genom fokusgruppsintervjuer med grupper av brukare (studie I) och personal (studie III), individuella intervjuer med brukare och personal (studie II), användbarhetstestning ”usability testing” med brukare med ”tänka-högt-protokoll” (studie II) och förkonstruerade checklistor (studie III). Material som samlats in från intervjuer och fokusgruppintervjuer i studie I-III användes senare i en teoretisk analys som genomfördes i studie IV.

Resultat

Resultaten lyfter fram ett antal särdrag som är specifika för den psykiatriska kontexten och som kräver särskild beaktan när man utvecklar stöd för DBF-processer där brukare ska kunna delta som kompetenta samarbetspartners och betraktas som bärare av viktig och legitim kunskap.

Utifrån de förutsättningar för DBF som identifierades inom detta specifika sammanhang utvecklades en DBF-modell för psykiatrisk vård och stöd som inorporerades i ett webbaserat beslutsstöd. Denna modell baserades på en befintlig modell utvecklad för DBF i allmän hälso- och sjukvård (Elwyn et al., 2012), och anpassades och utvidgades för att passa de speciella behov som finns inom den psykiatriska vård- och stödkontexten. Beslut kring psykiatriska tillstånd och behov fanns ofta vara komplexa och omfattade ofta ett antal livsdomäner. Frågor, problem och erfarenhetsbaserad kunskap som rörde sociala sammanhang och individuell återhämtning var viktiga att inkludera och beakta i hela beslutsprocessen. Särskilt identifierades behovet av att förstärka brukarens aktiva medverkan och tillvarata brukarens kunskap i två faser som inte fanns med i den ursprungliga modellen: en *fas för förberedelse* som fokuserar på att upprätta samarbete och ömsesidig förståelse och en *uppföljningsfas* som möjliggör återkoppling och anpassningar kring det som beslutats.

Resultaten tyder på att stödjande strukturer krävs för att brukarna ska uttrycka sina kunskapsperspektiv och för att personal ska inkludera dessa perspektiv i beslutsprocesser. Resultaten visar också hur användningen av ett beslutsstöd kan möjliggöra ett interaktivt partnerskap, öka brukares deltagande och tillvaratagandet av brukarkunskap i beslutsfattande. Ett ytterligare viktigt fynd handlar om hur fördjupad kunskap om hinder och förutsättningar kan genereras genom en utvecklingsprocess av en sådan stödjande struktur som detta beslutsstöd, där potentiella slutanvändare (både brukare och personal) är involverade i idégenerering och testning.

Resultaten belyser vikten av att identifiera och bemöta rådande hinder och utmaningar för att få till stånd dialog och samarbetsprocess. Inte minst identifierades problem som var förknippade med den maktobalans som råder i mötet mellan brukare och personal. Genom att bemöta dessa hinder kan man möjliggöra att olika former av kunskap i högre grad legitimeras i beslutsprocessen.

Slutsatser

De övergripande resultaten visar att villighet och förmåga till deltagande i stor utsträckning är en fråga om att få tillräcklig med möjlighet, uppmuntran och stöd.

Sammantaget tyder resultaten på behovet av attitydförändringar hos personalen så att de blir mer benägna att legitimera brukarnas kunskap och blir mer optimistiskt inställda till brukarnas kompetens och vilja att vara aktiva deltagare i sin egen vård och stöd. Dessutom visar avhandlingen hur ett beslutsstöd som är specifikt utformat för den psykiatriska kontexten och som metodiskt inbjuder brukare till aktivt deltagande i varje fas i beslutsprocessen kan fungera som en vägledande struktur för att validera brukare som kunskapsagenter. På det viset kan DBF stärka brukares möjlighet att vara välinformerade och att erbjudas vård- och stödinsatser som överensstämmer med deras värderingar och preferenser.

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