Collective Patient Participation

Patient Voice and Civil Society Organizations in Healthcare
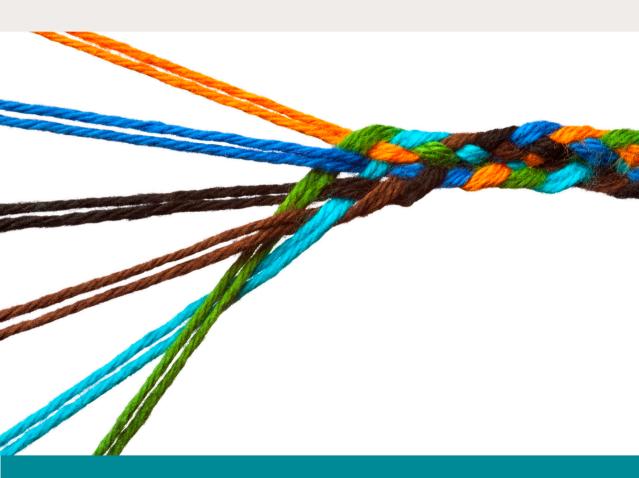
Anna Mankell

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Abstract

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The importance of engaging patients in the development of healthcare services and policy has received increasing attention over the last decades. However, this attention has mainly been directed towards various forms of involvement of individual patients. This dissertation shifts focus to the collective forms of patient participation and the specific values they bring. The overall aim of the dissertation is to explore how collective patient participation is shaped, in an increasingly individualized and marketized society. The articles included in the dissertation analyze aspects such as advocacy work, representation mechanisms and coproduction practices at different levels of healthcare. These aspects are studied from the perspective of civil society organizations navigating current social trends such as individualization and marketization. Taken together, the findings point to the importance of considering the preconditions of the individual patient to engage in patient participation in a collective form. This appears to be an important factor in the shaping of collective patient participation, as well as a potential challenge for both advocacy and representation. The findings also indicate that individual and collective forms of participation should not be seen as two conflicting interests, but could rather be mutually strengthening, something that should be considered both by civil society organizations and healthcare policymakers. Furthermore, this dissertation contributes to a better understanding of the diverse nature of patient participation, and how these variations all play important yet distinct roles in improving democratic and quality aspects of healthcare.

To my mother, Bia,
for leading the way.

List of Papers

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

I.   Mankell, A., & Fredriksson, M. (2020). Two-front individualization: The challenges of local patient organizations. *Journal of Civil Society*, *16*(1), 77-95.

II.   Mankell, A., & Fredriksson, M. (2021). Federative patient organizations in a decentralized health-care system: A challenge for representation? *Health*, 25(6), 722-738.

III.   Mankell, A (2021). Individual, Community and Organizational Coproduction and their relevance for service quality – the case of Japanese health cooperatives. *Manuscript*.

IV.   Mankell, A., & Hvenmark, J. (2020). Variations on a theme: exploring understandings of the marketisation concept in civil society research. *International Review of Sociology*, 30(3), 443-468.

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Contents

Abbreviations

Abbreviation	Term
CSO	Civil society organization
PO	Patient organization
PPI	Patient and public involvement
SACHSA	Swedish Agency for Health and Care Services Analysis
SFS	Swedish Code of Statutes *(svensk författningssamling)*
WHO	World Health Organization

1. Introduction

Although invaluable and indispensable, healthcare services can be truly intrusive for the patient. Because of the intrusive, mystifying and seemingly impenetrable nature of the medical profession and healthcare services, it is especially important for patients' and citizens' voices to be heard, in order to create legitimacy, transparency and trust in the healthcare system and professionals (Coulter, 2011; Hogg, 1999). Furthermore, as the population gets older and medical sciences advance, healthcare is experiencing a never-ending increase in demand along with increasing costs (Blank et al., 2017). It is clear that priorities become more and more important to make, priorities that will have enormous consequences for the users and funders of the healthcare system – the citizens. For legitimacy reasons, it is essential that citizens are included in the process of constructing guidelines concerning priorities, policies and quality (Clark & Weale, 2012). In the WHO's 1978 Alma-Ata declaration, it was declared that people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare (WHO, 1978). Integrating the will, voice and experiences of patients when shaping healthcare practice and healthcare systems has since then increasingly been put in the spotlight, often in terms of patient involvement or patient centeredness (Coulter, 2011; Taylor, 2009). Importantly, the purpose behind patient participation or involvement is often not related to such intrinsic goals as the democratic aspects of healthcare, but is instead related to extrinsic goals of efficiency and service quality and often formed according to a consumerist perspective on healthcare (Haarmann, 2018; Tritter et al., 2010).

1.1. Individual or Collective Patient Participation?

Much like the motives for patient participation, the fashion in which patients can participate varies greatly. Patient participation can be directed towards the planning or implementation phases of healthcare, sometimes described as input and output phases (Hogg, 1999). Participation can be more or less active, for instance the difference between being asked a question and being able to raise a question (Arnstein, 1969). Finally, patient participation can occur at an individual patient level and at a collective, patient group or citizen level (Coulter, 2011). In this dissertation, the focus will be at the collective level. Nevertheless, individual-

level patient participation will be continuously discussed as well, as an important point of reference.

Individual patient participation can occur both in the meeting between care professionals and patients when discussing the care for the individual patient and when patient representatives are consulted before decisions are made in a healthcare organization. Individual-level participation provides a unique knowledge about a person, a direct representation of a patient that can never be as perfectly reflected by a group representative. It is a quick and easy way for decision-makers to ask patients for feedback or to make a choice of provider, compared to asking a group to form a common position for a certain issue. Furthermore, involving individual patients is assumed to have a positive effect on both the healthcare service and the patient, as patients are not reduced to a group or category of patients or diseases (Coulter, 2011; Mol, 2008). This allows the patient to contribute with their unique preconditions, histories and resources, and is assumed to create better compliance with medical treatments and furthermore a sense of empowerment of an individual in an otherwise vulnerable exposed situation (Ekman et al., 2011; Vedung & Dahlberg, 2013). The downside of individual participation methods, such as choosing a provider, filing complaints or giving feedback, is that they require resourceful, informed patients that are able to vocalize their needs. The increased power of the individual may thus lead to an increased responsibility that lands on each individual patient. Several studies indicate that patients may not want to be involved but would prefer professionals to make decisions for them instead (Fotaki et al., 2008; Fredriksson et al., 2018). This has proved to be especially problematic in regard to market-oriented types of influence, such as patient choice systems where sick and fragile patients are required to be informed and make the "right" choice (Glendinning, 2008; Meinow et al., 2011). Furthermore, when individual patient voices represent the voices of patients as a general group (for instance as a patient representative on a user panel or committee), the generalizability of that one voice can be seriously questioned (Hogg & Williamson, 2001; Torjesen et al., 2017). For this reason, the potential of individual participation to contribute to long-term solutions that have transformative potential within healthcare can and has been questioned (Pestoff, 2021).

The value of the *collective* kind of patient participation is that the voiced opinions represent more than one individual, which can facilitate representation for less resourceful patients. Representing a group of patients enables the influencing of policy rather than the specific care context that individual patients can influence. Also, working as a group brings other values like the deliberative benefits of sharing experiences and learning from each other. A deliberative element also exists in individual forms of participation, through dialogue between patient and care provider. Collective participation enables, however, a sharing of experiences between fellow patients, creating a common understanding as well as a support structure. Furthermore, mobilizing professional resources within a collective of individuals increases strategic competences, which enables a more sophisticated advocacy work. In a context of a cooperative, for example, patients can even co-manage an entire service organization, adjusting it to the needs of the users and to specific local conditions (Pestoff, 2021). The disadvantage of the collective side of participation is that while representation could be of great benefit, it can also, if it fails, lead to a serious misrepresentation of patients, where the more resourceful patient groups are heard to the cost of less organized groups (Haarmann, 2018; Halpin, 2014; Hogg, 1999). Furthermore, it is demanding to engage collectively, which may lead to a situation where only people who are healthy, resourceful and educated are involved in collective patient participation, which may create further misrepresentation of the patient group. Due to the more far-reaching impact that collective patient participation can have, such misrepresentation becomes especially problematic in collective forms of participation.

Differences in the perceived value of individual and collective participation are often ideological, where the individual form of participation is often encouraged from a liberal perspective, as the individual freedom is prioritized as well as a belief in market-oriented mechanisms to increase the efficiency, quality and diversity of choice for users. Several of the individual methods of participating are directly linked to a process of marketization of welfare services (Fotaki, 2005; Moberg, 2021). The collective form of participation follows, at least in the Nordic setting, more of a social democratic, traditional perspective on the representation of different citizen groups. These two ideological positions regarding individualism and collectivism have implications both for the purpose and for the

nature of patient participation. These differences between collective and individual influence often circle around the issue of what kind of patient representation is desired and who's voices are being listened to when shaping healthcare services and deciding on treatments for patients.

1.2. Redirecting Attention to Collective Participation

The tension between the individualist and collectivist perspective is often polemically interpreted as one side threatening the other. Either the individual freedom is threatened by the dominant group or the collective group logic is threatened by a plurality of individualist self-interests (Eikenberry & Kluver, 2004; Friedman, 1990; Newman & Tonkens, 2011). This positioning risks creating a gridlock in the debate on participation, hindering a more nuanced and open approach to the two different aspects of patient participation. As we have seen, individual and collective participation bring both values and shortcomings to the shaping of healthcare policy and practices, albeit in different ways.

Larger developments in society, such as individualization and an increased market and consumer logic in all policy fields, have created a tendency to understand patient participation increasingly as an individualist activity (Haarmann, 2018). Today's society is characterized by a strong specialization, enabling individual adjustments to a large extent in many areas of society, including technology, products, services and media. It is not surprising that this also characterizes welfare services such as healthcare. As the institutional settings adapt to a more fragmented, pluralistic and individualist approach, individual patient participation is increasingly integrated in the healthcare system, through patient choice systems, patient surveys and other patient-centered initiatives (Coulter, 2011). The same attention or acknowledgement is not given to actors of collective forms of participation, such as civil society organizations (Swedish Agency of Health Care Services Analysis (SACHSA), 2015). Collective forms of participation, for instance in interest organizations, were mainly formed in another time, constructed to fit another type of society, when joining groups and mobilizing interests was the natural and perhaps only possible way to make oneself heard by decision-makers. Today, there is another kind of specialized knowledge and channels of mass communication to include and listen to individual perspectives

to a higher degree. Leaning against this backdrop of a societal development as well as a scholarly focus that tend to elevate the individual perspective, this dissertation wishes to redirect the spotlight to the collective dimension of participation in healthcare. What can collective participation bring in this individualized world? How does it handle the individualist dominating ideology and possible conflicts with the collective logic? How are the unique values that come with collective engagement maintained, managed and perceived? The dissertation contributes to the literature on patient participation by shedding light on the today often-overlooked collective patient participation, here represented by civil society organizations (CSOs) with an ambition to fill a democratic function in healthcare, at local, regional and national levels. The studies of this dissertation will provide empirical and theoretical examples, illustrative of the conditions for some core elements of collective participation through CSOs.

The disposition of this introduction to the dissertation is as follows. In the following Chapter 2, the overarching aim and research questions of this dissertation are presented, along with an explanation of how the four research articles contribute to this aim. Thereafter, the vast literature on patient participation is described in Chapter 3 through a conceptual summary of how different research fields contribute to the topic and how they connect to each other. The chapter concludes with a short review of the recently published literature on collective patient participation and patient organizations (POs) in particular. In the following Chapter 4, the different theoretical tools used in this dissertation to explore collective participation are presented. Chapter 5 provides a summary of all four articles, followed by a chapter on methods and design (Chapter 6), which discusses both the different methods used in the articles and the ethical considerations made. Lastly, Chapter 7 discusses the overall findings, and both the empirical and theoretical contributions of the dissertation, as well as providing suggestions for future research.

2. Aim and Research Questions

The general aim of this dissertation is to explore how collective patient participation is shaped in today's increasingly individualist and marketized society. The following overarching research questions reflect three different approaches by which the dissertation proposes to meet this aim:

1. What are the barriers and facilitators for patient organizations in contributing to democratic qualities in terms of political influence and representation in healthcare policymaking?
2. How can individual and collective patient participation relate to each other and to service quality?
3. How is marketization discussed in relation to civil society organizations in the academic literature?

An important part of the aim and research questions is to increase the knowledge of different types of values (both intrinsic and extrinsic) and challenges that come with collective forms of participation today, in contrast to the recent focus on individualist forms of participation. The object of the study is civil society organizations both in general and more specifically patient organizations and user cooperatives.

The aim and research questions refer both to individualization and marketization processes, and the connections between these two concepts should be made clear. In general, I view individualization as a broader development than marketization, and often preceding marketization. Marketization is often a consequence of more individualist ideals of free choice, pluralism and personalized services, that is, one of many expressions of individualization. Marketization and individualization can be more or less closely interconnected, and marketization can also be used in order to enable other values, not necessarily tied to individualism at all, such as efficiency. Nevertheless, when marketization is promoted to meet consumerist goals, there is most certainly an overlap between individualization and marketization processes at play (Hvinden & Johansson, 2007). In other words, when marketization is related to consumerism, marketization is also a sign of individualization. These distinctions and overlaps are useful to bear in mind when

the two concepts are used in close relation to each other. Another frequently used term in this dissertation is "civil society organization" (CSO). The term is chosen due to its inclusiveness, suitable for the diverse types of organizations that are studied here. "CSO" is a more general term than, for instance, "voluntary organization," "nonprofit organization" or "interest organization," which imply a somewhat more limited and defined type of organization.

Separate from the overarching research questions, four distinct research questions are posed in the articles included in this dissertation. Articles I and II are based on interviews with local, regional and national representatives from POs in Sweden. The empirical setting is the Swedish corporatist model with membership-based federative associations. Article I explores whether and how these organizations, at a local level, adapt their advocacy strategies to individualist tendencies in healthcare and in civil society. The research question in this study is: *How are patient organizations adjusting to an increasing individualization both in healthcare and within civil society?* Article II delves into the important question of representation at both local and national level within these organizations and aims to identify which aspects of representation are well-functioning and which aspects are more challenging. The research question in this study is: *How are federative patient organizations shaping representation in a multilevel healthcare system?* Both these studies contribute to the knowledge of the representative role of POs as they study important features of collective patient participation such as the conditions of including patient groups in policy dialogue, and the basis of representation among those groups. Consequently, these two studies respond to the first research question, and to some extent the second research question, as the interviews provide us with knowledge about their perception of individual patient participation as well.

Article III is a mainly theory-driven study of patient participation in the form of collective and individual coproduction in healthcare. Leaving patient interest organizations influencing healthcare policy behind, this study turns instead to the service providing role of user cooperatives, and patient participation within this type of organization. Special attention is given to an extrinsic outcome of patient participation, in terms of service quality. The research question in this study is: *How do different forms of coproduction in healthcare relate to each other and to service quality?*

The study explores and compares individual and collective patient participation, thus responding to the second research question.

Article IV uses a different angle than the three previous articles to contribute to the overarching aim. This article illustrates more general tendencies in CSOs than those only related to healthcare participation. Through this shift of perspective, the tendencies found in healthcare-related CSOs are raised to a universal trend of increased consumer and market logic within civil society. Furthermore, the focus of the study is not CSOs per se, but rather the scholarly discourse on CSOs. The empirical focus is peer-reviewed research articles, and the research question is *How is the concept of marketization used and defined in civil society studies?* This study is thus closely related to the third research question.

Together, the articles all contribute, from different theoretical angles, empirical settings and at different levels within the healthcare system, to an increased understanding of the role CSOs can play for patient participation, and the prevalent conditions for them to fulfill this role.

3. Patient Participation: Rationales, Variations and Tendencies

This chapter will provide a broad picture both of what is commonly discussed in the literature on patient participation and what aspects are important to consider in order to better understand the research field of patient participation and more specifically collective forms of patient participation. Besides the important contributions from health services research, public health, social medicine and other disciplines in the medical research area, there are important insights from the social and political sciences to gain, especially when turning the focus to collective aspects of patient participation. Examples of social science research fields included in the following chapter are public administration, democratic theory, comparative welfare politics, civil society research and organizational studies. In order to place this project more clearly in this vast literature, the chapter concludes with a short review of the five most recent years of publications concerning collective patient participation and POs.

3.1. Collective Participation – a General or Particular Interest?

Citizens engaging in and aiming to influence politics in other ways than through general elections have gained a strong focus globally over the last 50 years as different social movements, such as the civil rights movement, the women's movement and the patient rights movement, started to grow (Davis et al., 2005; Luders, 2010; McCarthy & Zald, 1977; Power et al., 2013; Williamson, 2008). This *participatory* democracy was encouraged as a complement to *representative* democracy, and was built on an idea of selflessness, solidarity and sacrificing one's needs for the good of the group. This was expected to prevent elitism within political decision-making (Pateman, 1970). These movements are assumed to act according to a group logic rather than the individual voices characterizing representative democracy, i.e. participation through voting (Jarl, 2003; Pateman, 1970).

A challenge for the idea of participatory democracy is the fact that participants do not reflect the whole population (as is more often the case in representative

democracy with a high voter turnout), but more often rather represent resourceful diasporas (Brady et al., 1995). This imbalance would not be problematic if the resourceful, active citizens were driven by a general interest in working for the good of the society as a whole, rather than a narrow particular interest departing from personal benefits. However, strictly rationally speaking, if people were to engage for a general interest, there would not be such a strong incentive for people to engage, as their interest would be covered already by other people's participation (Teorell, 2003). For this reason, participatory democracy is strongly driven by particular interests. Thus, so-called "between-election participation" has inherent problems in terms of legitimacy and representation. Following this logic, the stronger the impact of the participation efforts, the more problematic this kind of participation becomes.

Within the healthcare policy field, different kinds of between-election participation by citizens and patients play an important role in creating responsiveness in healthcare policymaking, especially since healthcare policy rarely has strong implications for the outcome of general elections, even in a country like Sweden where healthcare is closely governed by elected regional politicians (Erlingsson, 2009; Lidström, 2012; Montin & Olsson, 1994). Nevertheless, as we have seen, such participation may challenge basic democratic values, and a critical perspective is needed when studying all types of participation.

3.2. Variations of Patient Participation

In the specific context of healthcare, participation can take many different forms depending on the actors involved, the institutional and political context and the motives for participation, to mention only a few. In this section, some of the frameworks for visualizing variations that have been discussed in the literature on participation, specifically in the healthcare setting, are presented and discussed.

3.2.1. Choice, Voice and Coproduction

One way to distinguish between types of participation is by identifying participation in terms of either *choice*, *voice* or *coproduction* (Dent & Pahor, 2015; Greener, 2008; Haarmann et al., 2010; Le Grand, 2009). Another similar division is between consumerist, deliberative and participatory user participation (Fotaki, 2011; Tonkens, 2016), a description that better illustrates the logics and

motivations behind them. Patient *choice*, which is often referred to as *exit* in the more consumer-oriented literature, has increasingly been used as a way of allowing the preferences of patients to guide the shaping of healthcare services (Blomqvist, 2004). This is a low-threshold kind of participation, but it contains limited opportunities for learning in a more long-term way (Dowding & John 2011; Ewert, 2011; Forster & Gabe, 2008; Greener, 2008). Using choice as a method for patient participation is a passive form, which can only result in a binary outcome – a yes or a no. Nonetheless, choice systems serve their purpose of adjusting healthcare to each individual patient. It is important to note, though, the risk of "forced responsibilization" when the choice is not free but forced upon patients, leading to misdirected or uninformed choices (Dent & Pahor, 2015; Fotaki, 2011). Using *voice*, on the other hand, makes it possible for patients to express their needs and preferences in a more sophisticated manner, which enables healthcare organizations to adjust and develop their service according to the aggregated claims of patients voicing their opinions. Expressing your voice, however, can be done in many ways, for different reasons, leading to different outcomes and carried out both individually and collectively. Patients' voices can be heard through patient surveys, suggestion boxes or through participation in patient or user committees (Charles & DeMaio, 1993; Coulter, 2011), with the purpose of improving healthcare organizations and the services provided. Patients' voices can also be directed at a higher policy level, for instance through citizen dialogues (Charles & DeMaio, 1993; Maxwell et al., 2003). Participation in the form of *coproduction* refers to a way of including patients through involvement in the implementation of feedback through voice. This form of patient participation has increasingly gained ground within the patient participation movement. Participation in the form of coproduction allows for patients to become partners and be engaged in delivering their own treatments (Batalden et al., 2016; Coulter & Collins, 2011; Dent & Pahor 2015; Dunston et al., 2009, Palumbo, 2015). According to Dent and Pahor's framework for patient participation, coproduction is distinct from "voice." However, there are blurry lines between these two forms of participation, since patients' opportunities to speak and be heard are a necessary foundation to build coproduction on. Just as with voice, coproduction can also be performed individually by patients and collectively by groups of patients or through organizations. The original understanding of coproduction was evolved within the field of public

administration and was traditionally more related to cooperative forms of governing (Alford, 2014; Ostrom, 1996). Lately, however, coproduction has become increasingly used within the specific field of patient participation, thus focussing largely on an individualist understanding of coproduction as a partnership between patient and medical professionals (Fusco et al., 2020).

Defining participation along a scale of intensity is one way to differentiate between modes of participation building on voice. An established figure in the form of a "ladder of participation," created by Sherry Arnstein (1969), is often used in various adaptations in analyses of inclusion, democratic processes and involvement (Burns et al., 1994; Charles & DeMaio, 1993; Wilcox, 1994). The Arnstein ladder consists of eight steps ranging from manipulation at the bottom (substitute for genuine participation) to information and consultation towards partnership and complete citizen control at the top steps. In terms of Arnstein's ladder, coproduction would be represented by the higher steps of the ladder. Criticism of these kinds of figures centers on their focus on outcome, when rather it can be argued that the deliberative process is the goal of involvement (McKevitt et al., 2018; Tritter & McCallum, 2006). Also, others emphasize the importance of being open to different forms of participation in different contexts. Not all situations are appropriate for the higher steps of the Arnstein ladder, where instead some of the lower steps can fulfill an important and sufficient function (Haarmann, 2018). For instance, patients with chronic diseases may have more to gain from long-term dialogue-oriented participation, while patients with either less severe or short-term conditions are satisfied with more consumer-oriented ways of being involved. Nevertheless, the ladder of participation serves as an important reminder of the differences between various forms of participation, and especially visualizing the issue of "tokenism" in patient involvement (Hahn et al., 2017; Ocloo & Matthews, 2016).

3.2.2. Problematizing the Individual – Collective Dimension of Participation

Separating between individual and collective participation, which is the focus of this dissertation, can seem easy at first. The actor in individual participation is one participating individual, and the actor in collective participation is a group of some kind. When looking beyond the type of actor, and focussing instead on the

purpose of the participation, or the recipient of the benefits coming from the participation, important nuances emerge. The following table is inspired by a typology by Meuwisse and Sunesson (1998) and is an attempt to make these nuances clearer, illustrating the many different motives that individual and collective participation can have.

Table 1

Variations of Collective and Individual Participation. *2nd Person Singular

	Individual participation	Collective participation
Individual change	"Me for me"/"Me for you*"	"We for you*"
System/group-level change	"Me for you"/"Me for us"	"We for us"/"We for you"

The most common understanding and characterization of individual versus collective participation is probably the top left box and the bottom right box, i.e. individuals for individual change, and groups for group-level change. Individuals can however strive for system changes, just as collectives can engage in specific, often distressed, or vulnerable individuals. Another dimension of participation illustrated by this table is the difference between engaging for self-interest versus other groups' particular interests (the latter would fall under philanthropy according to Meuwisse and Sunesson). The "me for us" category can be exemplified by the concept of "expert patients." This mainly concerns chronically ill patients, who through their unique knowledge of their disease and themselves qualify to be key informants for decision-makers, as well as a help in developing the field (Tattersall, 2002).

However, these nuances and classifications of participation also include grey areas, often linked to problematic representativeness. For example, one can problematize "we." It may be a group being consulted before a policy decision ("we for us"). But the members of the group can be composed on the basis that they should represent only themselves, not a group of patients ("me for us"). The same problem occurs when using aggregated feedback from individual patient surveys to improve care. In this type of feedback, patients are encouraged to express what they as individuals want and think they are entitled to, and rarely what patients can imagine sacrificing for others to gain an advantage, or what they

see as their obligations as a patient. Defining aggregated information from a group of individuals as collective engagement is therefore problematic (Coulter, 2011; Hogg, 1999). Similarly, it is worth questioning whether it counts as individual participation when an individual acts to change the system for the benefits of the collective. Of course, many "me for me" opportunities for patient participation will indirectly also provide an advantage at the social level, such as happier and at best even healthier citizens. Examples of such forms of influence are choice in healthcare and complaint notifications. All of these are functions of individual participation, which at an aggregated level are expected to contribute to a more responsive healthcare and to improvements at the group level.

What is missing in many of these one-way, fragmentized initiatives for patient participation is the deliberative element of patient participation. The idea that patients and decision-makers discuss issues in a dialogue, exchange experiences and listen to the other part before potentially reconsidering and re-evaluating arguments is something that creates an added value, on top of the aggregated individual feedback such as patient surveys or patient choice systems. A form of patient participation that acknowledges the value of the deliberative element is shared decision-making and person-centered care approaches (Davies et al., 2006; Safaei, 2015). The deliberative element is naturally included in collective forms of participation, as this more often is done through recurring dialogue with decision-makers, and what is unique for the collective forms is that the positions brought forward by collective interests have likely been developed through internal deliberative processes as well.

3.2.3. Expected Goals and Potentials of Individual and Collective Participation

Although methods of participation vary, many of the main motives of individual and collective participation are common. One of the more instrumental, extrinsic motives is the ambition to improve healthcare (Crawford et al., 2002; SACHSA, 2015). Another, more intrinsically motivated, shared motive is the enabling of self-expression and empowerment of patients (Coulter, 2011; Haarmann, 2018; Söderholm Werkö, 2007; Vedung & Dahlberg, 2013). Some goals, however, are more closely connected to individual or collective participation. More unique for individual participation are arguments of *efficiency*, where the idea is to let patients

voice their opinions and expectations, and then scale away unnecessary parts of the service. This motive is closely related to New Public Management, privatization and patient choice and more common from the perspective of policymakers than that of participating patients (Tritter et al., 2010; Vrangbaek et al., 2012). For collective participation, the motive of holding decision-makers accountable and increasing legitimacy in policymaking is probably more central than it is for individual participation (Haarmann, 2018; Hogg, 1999).

Getting individuals to voice their opinion in healthcare may be easier as individuals have a strong incentive to improve services according to what they see fit for themselves. It is easy for individuals to vocalize a position in specific questions when only taking their own perspective into consideration, and the channels for individual participation are often easily accessible, such as responding to a survey that is presented to you. The relatively low threshold for individual participation makes it more broadly used. However, these individual voices are scattered, making them more difficult to integrate into change in policy or practice compared to mobilized collective patient voices through CSOs. Patient participation at the individual level can perhaps be more helpful from a patient perspective, when participation is used as a way to increase the patient's ability and understanding of their health, in order to enable a more equal relation with health professionals (Coulter, 2011). Nevertheless, collective participation can be helpful in reaching these goals of individual empowerment as well. Patient groups can more easily monitor rights and create channels of influence that individuals can later use to exert their influence. Studies have shown that patients lacking sufficient knowledge of health and disease management risk negative outcomes not only for themselves but also for healthcare services in general, such as poor disease management and rising costs (Edwards et al., 2012). Organizations, through their commitment to the group, can help individual patients interpret and evaluate all the information available to the patient, in order to rightfully be able to practice individual ways of participating such as by making informed choices or having the knowledge needed in order to be a coproducer of healthcare (Batalden et al., 2016; Coulter, 2011; Holland-Hart et al., 2019; Marteau, 2009). Together, individual and collective participation share several goals from a patient perspective and can complement each other in order to achieve them. Individual participation has a lower threshold to get patients

engaged, while collective participation can achieve broader, more transformative change.

Summing up, methods of participation vary greatly, especially between collective and individual participation. This section has tried to nuance this distinction, and problematize the dimensions of who is engaged, by reflecting on the purpose of engagement and the opportunity for deliberation. The following is a closer look at CSOs as actors of collective patient participation.

3.3. Patient Voice and Civil Society Organizations

Civil society organizations can play an important role in healthcare in different ways. CSOs are very diverse, and the nature of participation through CSOs will therefore vary along with the type of group or organization. For instance, CSOs can take the shape of self-help groups or mutual aid groups. In these groups, the purpose is mainly directed at helping the specific individuals in these groups, by being able to share experiences, find support and learn from each other, with the best-known example being Alcoholics Anonymous (Borkman, 1976; Karlsson et al., 2002; Katz, 1993). These groups are often characterized by an informal, nonhierarchical structure and the deliberative role is central to these groups. The purpose here is not necessarily to achieve system-wide change, but to improve the situation for their members (we for us).

A very different kind of CSO active in healthcare is the cooperative, which is controlled and managed by patients or patients and professional medical staff. User cooperatives are mainly characterized by the coproduction approach to participation. Within the field of healthcare, however, these are very rare (MacKay, 2007), but are theoretically interesting as an extreme case in a discussion on the range of patient participation (see Article III). Although rare in healthcare, the cooperative movement is not uncommon within other fields of welfare and has a strong tradition, for instance within childcare, in the form of parents' cooperatives (Vamstad, 2012). Within health and social care, worker cooperatives are more common than user cooperatives, for instance through a group of professionals coming together to manage a health or social care facility (Berry & Bell, 2018; Borzaga & Galera, 2016). Studying patient participation, especially

through collective coproduction, the user cooperative with patients as active members is nevertheless especially interesting as a form of CSO that encourages not only the voice but also actions of patients to be a central part of the organization. An important challenge to these organizations, however, is how to balance the need for professional expertise within healthcare services with the strong presence of patient participation (Bovaird, 2007).

Perhaps the most intuitive form of CSO related to patient participation is the patient organization (PO), or patient association, which is the main study object in Articles I and II in this dissertation. POs are often formally organized, gathered around a condition or a group of conditions, with the mission of helping those affected by this condition, directly or indirectly as next of kin (Rose, 2013; SACHSA, 2015). The literature on POs is relatively small and is not easily compiled. One reason for this is that organizations seem to play different roles in different countries, something that will be further explored below (Baggott & Forster, 2008; Toiviainen et al., 2010). There are, however, similarities and common patterns in this literature. The general lifeline of POs seems, despite possible current differences, quite similar across nations. Many POs started as charity-based organizations and later became politicized. Traumatic experiences such as wars and economic recessions were the trigger to organize around common health challenges in society (Toiviainen et al., 2010). Some organizations were initiated by patients or next of kin, but many of the early associations from the late nineteenth century were often also started by physicians and nurses (Coulter, 2011). Today, POs are often democratically organized associations, with a strong voluntary element, coordinated under umbrella organizations (Coulter, 2011; SACHSA, 2015; van de Bovenkamp & Trappenburg, 2011). The literature bears witness to an increased politicization of these organizations, an increased focus on consumerism as well as a general increase in number (Baggott & Forster, 2008; Mold, 2015; Toiviainen et al., 2010; Tomes, 2006; Winblad & Ringard, 2009; Zimmerman et al., 2005). The fields of interest in the most recent literature on POs are discussed further under Section 3.6.

POs usually serve several purposes simultaneously and can be a key coordinator within a specific patient community (Akrich et al., 2008; Haarmann, 2018, SACHSA, 2015). They can serve the same purpose as self-help groups by creating a social platform for patients sharing a condition and enabling shared experiences,

while also functioning as a support for patients by gathering and disseminating useful information, guiding patients to different clinics or physicians, updating new policies, and regulations or medication that are of interest to the group (Söderholm Werkö, 2007). Some POs are also service providers, for instance by providing proactive health support such as training groups, or simple forms of treatments (SACHSA, 2015). This function is less common, and the general trend of CSOs to move from voice to service (Wijkström, 2000) seems not to have reached POs in Sweden in a substantial way yet, at least not as more formalized, professionalized services.

The role that is of interest to Articles I and II in this dissertation, however, is POs' representative role in trying to influence healthcare policy and practice in the interest of their members. In an ideal situation, POs contribute with a strong connection to the patient's experiences of healthcare and treatments of specific diseases, and fulfill an important monitoring function, by pointing out shortcomings in healthcare services. In addition, by keeping up to date in their field, they can contribute innovative ideas and also quickly signal as new challenges approach (Buse et al., 2012). However, when including these groups, account must be taken of the fact that their own interest may be co-opted by other collaborations such as pharmaceutical interests, which is the main concern of the scarce literature on POs (McCoy et al., 2017; Rose, 2013; SACHSA, 2015).

There are different ways to approach the goal of influencing healthcare policy and practice as formal organizations, and different strategies to use, for instance conflict-oriented (Blease & Geraghty, 2018) or cooperative strategies (van de Bovenkamp et al., 2010). The differences between these two ways of influencing are sometimes referred to as insider and outsider strategies (Binderkrantz, 2005; Buse et al., 2012; Halpin, 2014). Which type of strategies are suitable depends to a large extent on the institutional setting and political culture of the society they are active in, which will be further explored below.

3.4. Political and Institutional Settings Shaping Collective Patient Participation

Variations between healthcare systems, such as if they are tax-based or social-insurance-based, if provision is private or public, and the degree of centralization,

are important factors in how patient participation is best carried out in one specific setting. In a society where the citizen privately enters with a large part of the cost, it makes sense that, according to a consumer logic, the individual also has an apparent right to question and to hold healthcare providers accountable directly. Where healthcare is financed to a large extent with common tax resources, such as in Sweden, it will instead be the responsibility of third parties, the state, to ensure quality and to hold providers accountable (Blank et al., 2017). In these systems, therefore, accountability is demanded by the collective rather than the individual patient. In Sweden, this is done partly through monitoring authorities but also through basic democratic institutions such as general elections, and by engaging interest groups like POs. In this way, the influence of the individual is delegated to a collective interest (Blank et al., 2017).

In the UK's nationally governed healthcare system, the local clinical commissioning groups (CCGs) are professionally governed, and not by elected politicians. The basic channel of influence, regular elections, will therefore not be a very effective channel for influencing healthcare, as the distance between elected national politicians and actual decisions on local healthcare is large. Here, participation is often created through patient representation on advisory boards/councils (NHS England, 2017). Norway, a country that recently centralized its hospital system, also creates involvement by user representatives on boards within hospitals (Lindahl, 2015; Torjesen et al., 2017). The German system, being a corporate, insurance-based healthcare system, functions in a similar way, although the boards are not part of a national healthcare system, but rather healthcare organizations (sickness funds), which are independent from the government. The Japanese healthcare system, which constitutes the context in Article III, is also an insurance-based system, modeled after the German system, where patients' co-payments go up to 30% of the cost (Hwang, 2008). Nevertheless, the Japanese healthcare system has traditionally had a very strong hierarchical, paternalistic character where physicians enjoy strong respect, and patients have had a passive role. According to Salamon and Anheier's social origins theory, civil society in Japan is characterized as having a "statist" civil society pattern, where the state dominates civil society and input from nonelites is not commonly requested (Salamon and Anheier, 1998). Although patient rights have started to gain attention in Japan recently, according to several studies, this

paternalistic tradition may impede patient involvement in treatments as well as opportunities for collective participation in the governance of healthcare (Hamakawa et al., 2021; Kodate, 2018; Sekimoto et al., 2004; Uddin et al., 2020).

There are big differences in the role of the PO in a larger institutional context, where the comparative approach of Baggott and Forster (2008) shows a close connection and strong access to government among the British, Swedish and Finnish POs. These interest organizations have historically been invited to provide input before policy decisions are taken. A similar, corporatist-style system is described by van de Bovenkamp et al. (2010) in their study of Dutch POs' relationship with decision-makers. This access to politics is in strong contrast to, for instance, the pluralistic US model where autonomy from the state is important for CSOs, and their work is completely focused on lobbying from the outside as independent actors. In this setting, interest groups are unorganized and interact with the state independently, and interests represented by these groups will sometimes overlap and sometimes collide with each other (Janoski, 1998).

3.4.1. The Democratic Function of Patient Organizations in the Swedish Healthcare System

As in other countries, the institutional setting is central to the way patient participation has been arranged in Swedish healthcare. The Swedish healthcare system is characterized by its universal coverage of all Swedish citizens, who jointly finance healthcare through taxes. It is, furthermore, a decentralized healthcare system, managed by 21 independent regions managing their own budget. Legitimacy and accountability are secured through general regional elections, every fourth year, where regional politicians closely tied to healthcare policymaking are elected every four years. Thus, in the shaping of Swedish healthcare, representative democracy is a stronger tool than in many other countries (Haarmann, 2018). Nevertheless, these regional elections have been criticized for being based on uninformed and uninterested citizens (Erlingsson, 2009; Karlsson, 2003; Montin & Olsson, 1994). As focus has increased on the patient as a consumer, and power increasingly shifts to both private providers and individual patients, the representative element of healthcare democracy is further challenged (Fredriksson, 2013). Given the weak representative function of regional elections along with increased consumer power, collective patient

participation through between-election democracy becomes even more important.

Swedish between-election democracy, or participatory democracy, is shaped, as mentioned previously, according to a corporatist tradition. The tradition of people's movements developed strong interest groups covering workers', tenants', women's and patients' interests (Lundström & Wijkström, 1997). These wide-ranging mobilized interests have shaped several strong interest organizations who have been invited to function as a partner in negotiations and as a legitimizer for policy decisions. A central mechanism for participation at the collective level in Sweden is the remittance system, inviting interest organizations to give feedback to different policy proposals (Lundberg, 2014). Citizen participation is thus represented through interest groups that are organized, stable and more or less mutually exclusive (Janoski, 1998).

Swedish POs must be understood in this context of strong people's movements that have characterized Swedish civil society over the last century, and their close relations to political power and being substantially financed by government grants (Haarmann, 2018; Holmqvist, 2019; Söderholm Werkö, 2007). Swedish POs typically have a federative structure, based on local associations that are coordinated by a national office. As large parts of Swedish welfare are local authorities' responsibility, it has been relevant for organized interests to have branches at different levels of government. Swedish POs thus work in a strong institutional setting that has been shaped to fit a specific type of organization. This strong tie to the government can have a stabilizing effect in terms of a direct link to political power and stable funding but can also be paralyzing for organizational innovation in a time of change in terms of pluralization, fragmentation as a consequence of privatization and an increased focus on the individual rather than collective rights.

3.5. Tendencies of Individual Patient Participation

3.5.1. A Changing Citizenship and Implications for Participation

As we have seen, patient participation is closely shaped along with the construction of the healthcare system but has traditionally also been closely connected to the larger ideas of the role of citizens, and the balance between rights and obligations in different welfare regimes. In a liberal welfare regime, a strong focus is on the rights of the individual towards the state, and obligations towards the state are kept to a minimum. The pluralist, or liberal model, for instance with the United States as an example, is characterized by a fragmented civil society with a clear liberal focus on the individual (Janoski, 1998). In a communitarian regime, traditional values of a hierarchical community entail strong obligations, which in the long run also creates rights for citizens. In the Nordic, social democratic regime, however, departing from an egalitarian view of citizenship, rights and obligations are balanced (Janoski, 1998). Conflicts between the individual and the collective are de-emphasized, along with the focus on rights. According to Karlsson (2003), collectivism means that there is no apparent difference between the individual interests and that of the collective.

Scholars have, nevertheless, identified a shift in citizenship in the Nordic countries from a more traditional corporatist, social democratic perspective on citizens towards a more active, consumer-based perspective, with a stronger autonomy on the part of the state (Hvinden & Johansson, 2007), which thus can be expected to also be reflected in the way people participate in healthcare. For example, traditional long-term volunteering is changing into short-term engagement, as the sense of a group identity is less central. The traditional membership in organizations thus tends to turn into short-term engagements, such as volunteering for a specific event rather than supporting the cause of a group through membership (Hustinx & Lammertyn, 2003; Robertsson, 2021; Tranvik & Selle, 2007). By extension, as POs are losing members in Sweden and having trouble recruiting new ones, influencing healthcare collectively might be challenged by the new focus on empowerment of individual patients (Eriksson, 2018; SACHSA, 2015).

3.5.2. The Individualist Focus in Healthcare

Different developments occurring at the same time, such as an aging population, technical advantages and lifestyle changes, all lead to the need for policy reforms in healthcare systems, adjusting both funding and provision to create a harmony between a good access to healthcare and good quality (Blank et al., 2017; Haarmann, 2018). All these developments are simultaneously influenced by the above-mentioned changes in the perception of citizenship and rights, which increasingly strengthens the individual patient and challenges the traditional hierarchical relationship between physician and patient (Haarmann, 2018). This can be exemplified by a focus on the individual patient's understanding, approving, shaping and to some extent also becoming an active part in treatments, often under the umbrella of person- or patient-centered care, "shared decision-making" or coproduction (Batalden et al., 2016; Coulter & Collins, 2011; Elwyn et al., 2012; Godolphin, 2009; Palumbo, 2015).

From an advocacy perspective, emphasizing individual patient stories is also effective in engaging people in healthcare issues, in terms of media, politicians or other actors wanting to influence healthcare. It is easy to become involved in an individual's fate, access to treatment or medicine regardless of cost, and more difficult to make an overall assessment of how healthcare resources are distributed and prioritized to an entire population (Hogg, 1999). This thus creates an individual focus among an entire population in how one tends to value healthcare, a kind of "we for you" mindset.

As was mentioned in the introduction, individualism in healthcare is also exemplified by the increased consumerist logic applied to patient participation. Examples of these developments are the pluralization of providers and an increased choice for patients (Dowding & John, 2011; Le Grand, 2009). According to Tritter et al. (2010), these developments have been especially true in Swedish healthcare, where patient participation has been more characterized by turning the patient role into a consumer role than, for instance, the UK focus on empowering the patient though involvement. Other examples of how these market elements are gaining ground within traditionally state-controlled systems from a patient perspective are the possibility of private health insurance that creates opportunities to increase access, and to buy extra services (Kullberg et al.,

2019; Lapidus, 2017; Sagan & Thomson, 2016). Market elements can also be expressed through a growing sector of alternative medicine and treatments, which is not included in the publicly financed provision. These products and services can give the impression of greater room for manoeuvre and influence for the individual, but of course come with great risks as this sector is often completely out of regulation and control (Buse et al., 2012).

In a healthcare setting that is so strongly developing in a direction where the individual is becoming empowered, it is natural to also shape channels for patient participation according to this norm. It is thus a logical step to take, when asking for and inviting patients' voices, even at a group level, to interpret this as the voices of individual patients rather than groups of patients (Eriksson, 2018). The collective perspective is perhaps too close to the mindset that today's healthcare is distancing itself from, that is, seeing patients as a group under the umbrella of a specific condition rather than individuals with unique experiences and medical histories. Together with an increased consumerist logic, these tendencies all present examples of a shift towards the individual voice in patient participation. From a democratic perspective, the increased focus on individual rights and heightened expectations of healthcare among citizens in general can become a problem, since the only ones that can set limits on accessibility are politicians, and politicians are elected by citizens (Blank et al., 2017). Patients' and citizens' ability to influence access to care can therefore be problematic if it is governed too strongly by an expression of the individual's rights, rather than the collective needs of a population.

Although it has been pointed out that the collective side of patient participation has to some extent been overlooked as focus increases on individual participation (Coulter, 2011; Haarmann, 2018; Jongsma et al., 2018; SACHSA, 2015), the literature on collective patient participation remains scarce in comparison. In the next section, a limited descriptive review of the recently published literature on the subject is presented with the purpose of providing insight into the research field as it stands today, what scholars seem to focus on and thus what the studies of this dissertation can contribute with.

3.6. Review of Recent Publications in the Field

In an overview of the literature on collective patient participation (or patient involvement) published in the last five years (2016–2021), it becomes clear that collective patient participation is not a broadly studied field today, and studies with a specific focus on collective participation within healthcare are few and far between[1]. This could possibly be explained partly by the fact that the collective perspective has yet to become an established, distinguished part of the literature on patient participation, and therefore the term "collective patient participation" may not yet be fully established. So what are the *collectives* referred to in this limited literature? In recent publications on collective patient participation, the collectives in question seem to be mainly POs or other self-help organizations (Gerhards et al., 2017; Kofahl, 2019; Rojatz & Forster, 2017; Souliotis, Agapidaki et al., 2018; van de Bovenkamp & Vollaard, 2018). In some cases, the collective is constructed by patient representation in panels, as a top-down created channel for involvement in decision-making within healthcare organizations or at the policy level (Abma, 2019; Woelders & Abma, 2019). These patient representatives can be, but are not always, representatives of organized patient interests. Often, collective patient participation also includes studies focussing on the "public" part of the "patient and public involvement" concept (PPI), commonly studied during the last 10–15 years with roots in the UK. In these cases, the collective refers to a more general, public interest rather than particular group interests that studies on POs tend to focus on. An example of this is Alexander Haarmann's book on collective patient involvement in Europe, where the collective is described as "the majority, or at least a larger group of patients" (Haarmann, 2018, p. 7), and often used interchangeably with "citizen." In some rare cases, collective participation is used to refer to family or next-of-kin involvement in decisions on patient treatment (Broom et al., 2017).

The majority of the literature on collective patient participation is directed towards participation in policymaking processes. This is especially common in the

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[1] A literature search was conducted at the Uppsala University library in June 2021, using the search words "Collective patient participation" and "Collective patient involvement," limited to the time period 2016–2021, including only peer-reviewed literature in English. Looking through the first 40 hits, sorted by relevance to the search words, it became obvious that the studies' relevance increasingly declined, leading me to conclude that going through more than the first 40 hits would not lead to more relevant literature for this purpose.

part of the literature departing from the PPI discourse. Some of these studies also discuss specifically the difference between the individual and the collective perspective (Eriksson, 2018; Fredriksson et al., 2018; Fredriksson & Tritter, 2017) in influencing or participating in policymaking, while others focus more on how to develop functioning channels for citizens to become involved, through mapping and evaluating different methods (Abma, 2019; Thomsen & Hølge-Hazelton, 2020). It is obvious that collective patient participation is more directed to participation at the policy level, rather than at the treatment level, although collective patient participation in the form of POs could have an important role for individual patients in understanding, making choices and dealing with their treatment.

Another common topic in the literature on collective participation is the complexity of representation that comes with the collective perspective (Gerhards et al., 2017; Luce, 2018). The literature emphasizes, for instance, the challenges of representing the very heterogeneous landscape of patient interests (Schicktanz et al., 2018; van de Bovenkamp & Vollaard, 2018). Others apply a more critical perspective on the credibility and autonomy of representatives (Luce, 2018; Rojatz & Forster, 2017). The majority of the studies on representation aspects of collective patient participation during this time period specifically study POs, and rarely other forms of collective involvement. Exceptions can be found, of course, for instance in O'Shea and colleagues' study of patient perceptions of representation in clinical commissioning, using the British context of a more institutionalized patient and public involvement. O'Shea and colleagues lift the confusion that arises when it comes to representation of an individual or of a larger community interest, and participants' own hesitation as to whether their own experience-based knowledge would suffice for being representative (O'Shea et al., 2017).

In the literature, it is not very common to study these organizations from a civil society perspective, i.e. looking specifically at the conditions and traditions of civil society as a factor in the realization of collective patient participation. A few exceptions can be found. Gerhards et al. discuss civil society issues in their study of PO trust models (Gerhards et al., 2017). Hester van der Bovenkamp also tends to use a civil society perspective in her studies on Dutch POs, in 2018, together with Vollaard, using representation theory (van de Bovenkamp & Vollaard, 2018),

but also in earlier publications, for instance using a political opportunity structures perspective (van de Bovenkamp et al., 2010). Another example is Eriksson's study from 2018 on the proposed co-optation and individualization of a user/patient organization (Eriksson, 2018). Eriksson discusses the organization as part of a social movement and proposes a clash of logics when organizations from this social movement are invited to take part in user involvement initiatives in welfare services, as this would lead away resources from other, grass-roots-initiated tasks that their constituency sees as more important, thus losing autonomy.

Looking more specifically at recent literature on POs in general, not necessarily related to patient participation, the studied topics are widened[2]. It appears that the focus is not necessarily their ambition to be included and participate in healthcare services in different ways. Rather, the most common topic in literature published on POs during the period 2016–2021 is critical research concerning their funding and subsequent problems of credibility and conflicts of interest. Especially common are their financial ties to large pharmaceutical companies (Bruno & Rose, 2019; Fabbri et al., 2020; Singer & Mostaghimi, 2019). The central theme for this group of publications is the need to make these relationships more transparent, as they appear today to be underreported (Kato et al., 2019; Mandeville et al., 2019; Rose et al., 2017; Taylor & Denegri, 2017). For some studies the main purpose is to disclose the large extent of these financial ties (Mandeville et al., 2019; Mulinari et al., 2020). Although the main purpose is to shed light on these ties, many studies go further and express concerns regarding the POs' independence. The studies on connections to the pharmaceutical industry are all quantitative survey or register analyses, or literature reviews. It appears that the field would benefit from more qualitative approaches to the topic, revealing the positions and attitudes among the organizations and their members toward the issue, and also trying to evaluate the actual bias created by such funding ties.

Other than that, recent publications on POs are often instrumental, studied from the point of view of healthcare. For instance, questions asked include how POs

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[2] A literature search for recent literature on patient organizations was conducted at Uppsala University library in June 2021, using the search words "patient organizations" and "patient associations" and limited to the time period of 2016–2021. The first 35 hits were considered relevant to include in the review and form the basis for this brief review.

can contribute to better results in treatments, what function POs can serve in regard to healthcare, and what can and should the relationship between hospitals and POs look like. Several articles have identified POs' role in identifying problems of access to treatments, and helping overcome these (Folkers et al., 2019; Hughes et al., 2019; Koutsogianni, 2018; Mikami & Sturdy, 2017). Another common role for POs, according to this recent literature, is conveying information and knowledge from medical professionals to patient groups (Matos et al., 2020; Vandenplas et al., 2021). It is somewhat less common with studies departing from the role of POs for the actual patients. Topics studied in this smaller group of publications concern whether and how the individual patient benefits from being part of a PO. The benefits raised in these studies are improvements in health, health literacy, compliance and risk assessments (Langenbruch et al., 2018; Matos et al., 2020). This literature focussing on the function of POs is typically very positive about the potentials and function of POs. Furthermore, this research is mainly provided by medical researchers, specializing in the specific disease connected to the POs in the studies. Therefore, more literature on collective patient involvement and the role of POs in healthcare in general, from a social science perspective, would be valuable.

Consequently, studies on how POs can contribute to a more democratic healthcare are less common. Those who perform such studies are also those who tend to connect POs with collective patient participation more clearly as mentioned previously in this section (see Gerhards et al., 2017; van de Bovenkamp & Vollaard, 2018). An example of a research that explicitly connects POs with democratic values is the construction of the Health Democracy Index (HDI) by Souliotis and colleagues (Souliotis, Agapidaki et al., 2018; Souliotis, Peppou et al., 2018), which aims to measure the degree of participation of POs in policymaking. The HDI is an interesting attempt to create an evaluation tool for collective patient participation, something that is more common for individual patient participation.

Presented above are only studies published after 2016, and if the review had included a longer time period, other themes could possibly have emerged as more common, and more examples could have been found of topics that, in this review, seem scarcely researched. Nevertheless, this section illustrates what has, and what has not, been in the eyes of researchers lately, constituting the research front from

which future research will depart. For instance, given the many recent studies on coproduction within healthcare in the larger field of patient involvement, surprisingly few studies have studied coproduction from a collective perspective in recent years, and the term has only been mentioned in passing in the literature on collective patient participation and POs of the past five years. A large part of the literature on collective patient participation discusses participation at the policy level, but looking at literature on POs in general, it rarely covers POs as interest groups trying to influence healthcare policymaking. The civil society perspective on collective patient participation is an important but also seemingly understudied perspective that contributes with knowledge from the CSOs as representative organizations rather than with their potential benefits for healthcare organizations. This dissertation thus contributes to the research field with a civil society perspective, lifting the potential democratic function of collective patient participation, and, furthermore, develops this by adding a local and regional perspective on PO literature – an important part of these organizations that has been greatly overlooked in the literature

4. Theoretical Approaches for Understanding Collective Patient Participation

In the section below, the theoretical perspectives used in this dissertation to analyze collective patient participation will be presented. In the first part, the tension between individualism and collectivism will be briefly presented, mainly with the purpose of setting the context for the following, more instrumental theories. This should be viewed as the general frame within which the dissertation is situated as a whole, each study in a different way. In the second part, a multilevel framework is presented, providing a systematic structure to distinguish between patient participation at a micro, meso and macro level. This framework is used mainly in Chapter 7, in order to discuss the findings depending on where in the healthcare system patient participation is occurring, as this has implications for the conditions for, and the purpose of, patient participation. As the macro level is of particular interest to the dissertation, it is discussed at greater length by including aspects of democratic theory. In the third section of this chapter, the three theoretical frameworks used in Articles I–III are presented, through which collective patient participation can be understood and analyzed. These three theories are chosen in regard to the specific research question of each article, but they all relate to the overall framework of individualism-collectivism, and are applicable to the micro, meso and macro levels of healthcare services in different ways.

4.1. Collectivism in an Individualist Era

The tension between collective and individualist logic that constitutes the frame of this dissertation is a classic polemic that has been discussed probably since the birth of social science. Nevertheless, recent decades have been particularly characterized by individualist values and logics, which have also been widely acknowledged by scholars, for instance sociologists such as Ulrich Beck and Zygmund Bauman, as "liquid modernity" or "second modernity," a time when society is rearranging and structuring itself from the perspective of self-interest

and individuals rather than collectives (Bauman, 2005; Beck & Grande, 2010; Inglehart, 1997).

Ronald Inglehart illustrates this development among Western countries towards individualization through the increased post-materialist values of autonomy and self-expression (Inglehart, 1997). However, individualization entails, according to Beck, the process of letting go of some traditional bonds (family and social class) just to create new dependence towards trends and market, in a new role as consumer. Individualization, entrenched by the institutions of society, constitutes a new frame of life choices. Through norms of individualization, it is thus possible to institutionalize and politically shape the life patterns of people (Beck, 1998). According to Beck, as individualization progresses, people lose their social connections and increasingly stand alone. This diminishes the areas of life where collective organized action can have an influence on one's life situation, and we are instead left to individually take charge of our own circumstances (Beck, 1998; Beck & Beck-Gernsheim, 2002). Similarly, Bauman also claims the individualization of our society through the fragmentation of social structures and adds the implication this trend may have for our well-being as we become increasingly isolated. Furthermore, Bauman emphasizes that not everyone is capable and resourceful enough to enjoy the benefits of the freedom and emancipation that individualization brings, and that the individualized society thus increases inequality (Bauman, 2005).

In their recent book, Robert Putnam and Shaylyn Romney Garrett (2020) illustrate through vast empirical data how this shift from collectivist to individualist logics developed over the last century in American society. They establish how society shifted from an individualist logic at the turn of the twentieth century to increasingly value the community and collectivist values up until the 1960s, which is described both as the peak of collectivist values and the time period when suddenly the development changed direction towards increasingly prioritizing individualist values, and the state of today is presented as the highest point of individualist values so far. This is, of course, a description of the specific American political, social, cultural and economic developments but is likely applicable to other similar countries as well, with variations depending on historical events, but still following the same trend. The point to be made, however, is that in our near history, our society was characterized by a collective

logic, which has formed our institutions, organizations and perceptions of society deeply.

The limitations of this brief introduction to individualization will not allow a satisfactory recapturing of this debate, but rather aims to emphasize the importance of this individualist shift for how to understand collective patient participation today. The turn towards an individualist society is perhaps well acknowledged, debated and studied, but due to social inertia, many organizations, and the structures and settings they operate in today, are formed along more collectivist values. The individualist-collectivist shift should be understood as a background in which these studies, with their respective theoretical frameworks, are placed.

4.2. Patient Participation at the Micro, Meso and Macro Levels

As was described in Chapter 3, patient participation entails a collective and an individualist dimension, both concerning who participates and who is the beneficiary of the participation. From the perspective of healthcare, participation can be directed either to the individual's treatment (micro level), the healthcare services (meso level) or the policy level (macro level). At all three levels, participation can be carried out by either individuals or by a collective, as shown in Table 2 below. The micro, meso and macro division has proven to be a useful tool for approaching the multidimensional phenomenon of patient participation (Carman et al., 2013; Charles & DeMaio, 1993; Goss & Renzi, 2007; Tambuyzer et al., 2014). Through this structure, it becomes clear how differently patient participation can be understood, even when specified as collective patient participation.

Table 2

Examples of Patient Participation at Micro, Meso and Macro Level

	Micro level	Meso level	Macro level
Individual participation	Shared decision-making Individual coproduction Patient choice	Patient surveys Patient choice Complaints	Voting in general elections Contacting politicians
Collective participation	Fundraising Self-help groups	Patient councils POs (local branches) Collective co-production	Advocacy work by POs

As shown in Table 2 above, all three levels serve different purposes in the ambition to improve healthcare services in terms of quality, responsivity, legitimacy and democracy. While the focus lately has been on the first row of individual activities, this dissertation will mainly illustrate examples from the collective row, with the individual row discussed mainly as a point of reference. The macro level will be more elaborated on below through a discussion departing from democratic theory. The often-used reference to a ladder, when discussing patient participation, is sometimes added to this table as another dimension where variations in patient participation take place (Charles & DeMaio, 1993). I will not discuss this dimension further here, but it is relevant to bear in mind that each of these fields holds the dimension of more or less active engagement methods as well, in the spirit of the Arnstein ladder of participation (Arnstein, 1969).

At the *micro* level, patient participation will mainly be directed at the specific treatment of the individual patient. The engagement of the patient concerns the individual's values, previous experiences and other health concerns, when managing and developing the patient's health plan. This level can also include the possibility of choosing healthcare provider or treatment (Goss & Renzi, 2007; Tambuyzer et al., 2014). From an individual perspective, patient participation at the micro level could be patient choice, or even just sharing information regarding

health and treatments. Much of what is included in so-called *patient-centered care*, *shared decision-making* or individual-level *coproduction* will also fall into this category (Goss & Renzi, 2007). Even though the individual perspective at the micro level of patient involvement may be more common, there is also a collective aspect to this. One such example can be support groups such as self-help groups, where patients act as a collective in order to improve the situations for the individual. Carman et al. (2013) emphasize that patient involvement at this level does not even have to include healthcare providers but can just as well be the patient looking for support, information from other sources, which could be a PO or support group, or just searching for information online.

At the *meso* level, patient participation mainly takes place within the healthcare service organization, also referred to as the "service level" (Charles & DeMaio, 1993). Measures of patient participation at the meso level serve to improve the responsivity of hospitals or clinics. At this level, representation becomes important, whether it be realized through individuals or delegates from patient groups (Tambuyzer et al., 2014). At this level, an important goal for healthcare professionals and managers is to interact with patients in order to receive feedback, evaluate their care services and to better understand what the optimal treatments are for their patients (Carman et al., 2013; Goss & Renzi, 2007). From an individual perspective, patient involvement at the meso level could consist of individual patients engaging either passively by responding to patient surveys or using suggestion boxes at the healthcare facility. Patient councils, on the other hand, are an example of a collective activity most common at the meso level (although patient councils can serve different purposes, and sometimes be directed to a policy level as well). Representing different groups through advocacy efforts directed towards specific healthcare service facilities is an important task for local patient associations, and the collective dimension at the meso level is thus substantial for these organizations. It is, of course, not only advocacy work that is included here, but also more collaborative projects, where patient associations may work together with staff at organizations in order to organize events, seminars etcetera, perhaps to some extent also some self-care treatments, or rehabs organized by these associations, instructed by healthcare staff.

At the *macro* level, patient participation activities are mainly directed towards policymaking and the potential of influencing the development of such policies.

Depending on the healthcare system, such policymaking can be performed at a national level or more locally (or both). The common denominator, however, is that this level is shaping healthcare for a larger jurisdiction – for instance a state or a region (Charles & DeMaio, 1993), through legislation or resource allocation. Although perhaps intuitively more common among representatives of collectives of patients, individuals may be involved at the macro level as well and mainly in their role as citizens. This is done, for instance, through general elections, as citizens have the opportunity to influence politics in the way they wish to improve and develop healthcare policies and, importantly, hold decision-makers accountable for past performance. Another possible way is to use the opportunity to leave citizens' proposals to politicians, or in other ways direct attention to certain problems experienced in healthcare services. From a collective perspective, patient participation at the macro level is often in the form of representatives of POs, either invited into a collaboration with politicians and decision-makers or working from the outside trying to influence policymakers. A more passive form of collective patient participation could be POs organizing educational events, in order to enlighten citizens and the public about specific challenges experienced by some groups of citizens or patients.

4.2.1. Democratic Theory and Macro-Level Patient Participation

At the macro level, in particular, patient participation is closely connected to democratic processes, as it becomes an issue of citizens, individually or as representatives of specific groups, being included in the making of decisions that are affecting them as a people. This democratic aspect is especially relevant in the Swedish case, due to the previously discussed close relationship between, on the one hand, regional elections and the healthcare policymaking, and, on the other hand, between politicians and interest groups, in line with the Swedish corporatist tradition. Therefore, both from an individual perspective (as in voting) and from a collective perspective (through POs), democratic ideals are closely related to the mechanisms of patient participation at the macro level.

Commonly, three types of democracy are discussed: representative, participatory and deliberative democracy (Axberg, 1997; Cunningham, 2002; Gilljam & Hermansson, 2003). *Representative* democracy is mainly carried out from the

individual perspective, as it is based on individuals' independent choices in electing representatives to make decisions for them. As mentioned previously, in the Swedish tax-based healthcare system where healthcare is shaped regionally, regional elections become a relevant tool for patient participation at the macro level. Due to the previously mentioned challenges of transparency and uninformed voters in these elections, it becomes even more important to study the two other forms of democracy, participatory and deliberative democracy, as a complement to representative democracy. In these democratic ideals, the role of collectives of different kinds becomes especially central. These are discussed here as distinct theoretical types, but in practice, deliberative elements occur in participatory democracy and vice versa.

The main idea of *participatory* democracy is that several separate interests are included in the decision-making, usually via delegates of these citizen groups. Through this inclusion, a better and more direct representation of the variety of interests in a population would be achieved, compared to when only elected politicians make decisions. The process of decision-making is then based on aggregation of these separate perspectives. Through committees or written feedback by remittances, different groups, such as POs, may voice their perspective and concerns in different policy issues. Reaching a decision that will be equally good for all the separate interests included in the process is often impossible, and negotiations need to take place instead (Axberg, 1997). Within healthcare, forming committees where patients are invited is a common method for getting these different interests together (see Kelly et al., 2017; Nathan et al., 2011). Although such committees vary somewhat in purpose, methods of working and actual influence, an interesting connection can be made to the work of Sartori (1975) on the role of committees in participatory democracy. According to Sartori (1975), committees enable the same people to meet continuously, which allows representatives and decision-makers to understand different positions of the same issue better, but also to enable compromises and negotiations, as one may lose something in one issue but knows that this loss will be remembered and substituted for in another issue in the future. Decisions based on participatory democracy are thus not necessarily made based on what is perceived as the best solution, but rather on negotiations and compromises between these diverse interests (Amnå, 2003; Axberg, 1997). The value of this democratic ideal is mainly

that a plurality of interests have been included in the process. Thus participatory democracy is legitimized by procedural arguments (Hermansson, 2003).

The *deliberative* democratic ideal is based instead on the assumption that argumentation will lead to better decisions. By critically assessing arguments for a specific policy decision, it is assumed that the decision made is more qualitative and grounded, and thus objectively better. The deliberative ideal is thus motivated by a consequential argument, emphasizing the importance of a qualitative outcome of the democratic decision-making (Hermansson, 2003). To achieve a deliberative context, there must be interaction between the different stakeholders. Arguments need to be taken in, critically assessed and re-evaluated. The Swedish remittance system is thus not designed for an ideal deliberative decision-making process as different interests are only sharing their position, and not taking in other interests' arguments before making their own. Although often described as a deliberative element in the Swedish democracy, only when remittance processes allow for reassessments and repositioning from all parties would they meet the criteria of the deliberative democratic ideal. Fishkin (1991) argues that a better instrument for a deliberative democratic decision-making is to create advisory panels before decision-making. In contrast to the committees mentioned above for the participatory ideal, such panels are only advisory (Fishkin, 1991). The lack of decision-making power in these panels creates a conversation without pressure of negotiations and forceful inclusion of less valid arguments in the decision-making. Arguments are instead tested and assessed, and if valid, they are considered when making decisions.

The type of patient participation at the macro level studied in this dissertation can both be conceptualized as deliberative and participatory, and it is not always easy to distinguish between the two. The POs are active in a system organized along the logic of a participatory democratic ideal, but there can still be deliberative qualities in the specific activities these organizations take part in. Coproduction is perhaps the method that is more closely related to deliberative ideals, where the collaboration between patient and provider organization is not mainly a negotiation between different stakeholders but has the purpose of working together to reach the best possible healthcare, thus motivated by consequential arguments. Importantly, though, coproduction is rare at the macro level, and more common at the micro level. Taken together, it is suitable to apply democratic

theory to the macro-level kind of patient participation, and it contributes to a deeper understanding of the arguments for different kinds of macro-level participation.

In the next section, the theories used in Articles I–III are presented. First, a theory of participation aimed either towards the input or output of policymaking and service production is presented, as the two other theories are used to understand participation specifically on the input side. This framework is used in Article III. The theory of representation is then presented as a way of characterizing the legitimacy of the participating organization, which is used in Article II. The third perspective, mainly used in Article I, is considering different strategies these organizations can choose to use, and how individualist trends can play into which strategies are chosen.

4.3. Theoretical Frameworks Used in the Articles

4.3.1. Participation in the Input or Output Phase

In order to understand the nature of patient participation, it is relevant to analyze participation in regard to how far the influence can go, and the scope of policy and people affected by the policy that has been subject to citizen participation. One such distinction, which has strong implications for the impact range of influence, is whether participation is carried out in the input or output phase of policymaking within an organization or social service. This distinction was made early on by Easton (1965) in his widely used model of policymaking as a black box, taking in input and delivering output, but with little insight into how the decision was actually made (thus, a black box). It has since been further developed, for instance by Scharpf (1997, 1999), and more directly discussed in relation to democracy and specifically democratic legitimacy. Either influence can be exercised as giving input before a policy decision, expressed by Schmidt (2013) as participation *by* the people, which would lead to an influence in all areas regulated by the policy, or it can be exercised in the implementation phase of a policy, i.e. the output phase (Hogg, 1999; Scharpf, 1997; Schmidt, 2013). The latter reflects a more local type of participation, where change occurs mainly to those who are involved and participating – i.e. participation *for* the people

(Schmidt, 2013). The overall effect may not be as large as in the input phase, but the ones involved will be those affected, which could be seen as a value of a more direct and qualitative participation. According to Jarl (2003), participation within public services, such as healthcare, constitutes a problem when users, involved for particular interests rather than general interests, claim influence over policy input, which impacts all citizens – not only the ones who were invited to contribute to the decision. However, citizens and users driven by a particular interest can very well be helpful when directed towards policy output in the local context where the user is active. For these reasons, Jarl claims that participation focus should be on the output side of policy (Jarl, 2003).

It is important to clarify, though, that depending on the policy level studied, the input phase can refer both to input to politicians before a decision (the macro level) and to input to managers before deciding on an internal policy for an organization (the meso level). In this dissertation, both levels are studied. The POs studied in Articles I and II, for instance, often carry out advocacy work towards politicians and other decision-makers, oriented towards policy input, but are simultaneously working together with local clinics in order for them to be responsive to the local needs of the specific patient group. Coproduction in patient cooperatives, studied in Article III, on the other hand, mainly occurs at the meso and micro level.

Coproduction is a form of participation that can be understood as influence on the output of policy, that is, the actual service production, as an implementation of a policy (Pestoff et al., 2006). The input/output framework can also be used when applied to a service production process, rather than policymaking process, where the input phase of coproduction is often referred to as "co-design" or "co-commissioning," and the output phase is referred to as "co-creation" or "co-delivery" (Brandsen & Honingh, 2016; Nabatchi et al., 2017). Coproduction taking place in the input phase, for instance by being involved in policymaking or designing the service, is mainly characterized by more collective forms of coproduction (in Article III referred to as "community" or "organizational" coproduction). Furthermore, coproduction taking place in the output of the service production process, for instance by taking an active part in one's own healthcare plan and treatment, is more often characterized by individual forms of coproduction. This distinction, although not specifically formulated as input and

output in the coproduction literature, is important to illuminate, and is productive to use in Article III in order to understand which types of coproduction is useful for what reasons.

Studying participation as directed to input or output is strongly oriented towards the outcome of participation, and Article III also applies these different kinds of coproduction to an outcome measure, self-perceived service quality. Ostrom et al. (1978) suggest that by coproducing services, involving citizens in the input phase and service activities, the output of the service can be understood as two different kinds of *outcome*. There is the objective outcome, which in a healthcare setting can be objective measures of healthcare quality. Through participation and coproduction, though, Ostrom suggests another form of outcome is produced, the subjective outcome, which is characterized by other subjective values such as increased patient satisfaction, or increased trust in healthcare staff and services (Ostrom et al., 1978). This way of looking at outcome includes both intrinsic and extrinsic values and is a useful approach to discussions on both the purpose and the expected outcome of coproduction and patient participation in general.

4.3.2. Representation Theory

CSOs, including POs, are often organized according to a democratic logic of representation, as members elect representatives to boards to represent their common interests when communicating with macro-level decision-makers. Allowing these organizations to participate requires such representatives to have legitimacy from the group they represent. This is one of the main qualities of collective, rather than individual, patient participation, and the basis for representation therefore becomes important when studying the potential democratic contributions of collective patient participation. The theory of political representation (Mansbridge, 2003; Pitkin, 1967; Rehfeld, 2017; Urbinati & Warren, 2008) can be a useful tool for evaluating these internal structures. When speaking of representation of interest groups, it is important to separate the internal democracy at work within the organization, electing representatives for its leaders, and the external democracy within which these leaders play an important role as representative actors at the macro level of a participatory democracy. That said, the internal process of shaping representation is of course

a precondition for the legitimacy of these representatives in the larger democratic context.

Hannah Pitkin published a seminal work on political representation in 1967 where she presented a new conceptualization of representation, with the argument that previous research, which basically emanated from Mill and Burke, had focused too much on whether the representatives should be seen as a *delegate*, with instructions from the represented, or a more autonomous *trustee* (Pitkin, 1967). Her four categories, or rather "perspectives," of representation allow for more nuances of representation, which inspired a range of scholars to follow and develop her typology (Andeweg & Thomassen, 2005; Mansbridge, 2003; Rehfeld, 2006). Pitkin's first perspective is *formal* representation, which includes aspects such as accountability and authorization. For instance, accountability requires responsiveness from the representative towards the represented, and ability to adjust positions to a changing constituency. Another important aspect for accountability is transparent decision-making towards the represented. In regard to authorization, an example is a well-functioning election when choosing the representative, with legitimate selection criteria. Another perspective brought in by Pitkin is the *symbolic* representation, which points to the symbolic role a representative may play to the represented, whether they want it or not. If the symbolic representation is good, it means the represented are accepting the representative's mandate as an agent for the group (Pitkin, 1967). This could be related to traditional ceremonial aspects, such as the symbolic value that comes with the appearance of a monarch at important national events, or perhaps the role that a widely acknowledged activist such as Greta Thunberg can fill for the climate movement. Pitkin also introduces the *descriptive* representation, which emphasizes the resemblance to the represented – be it physical, interests or life experiences. This aspect has been increasingly emphasized in the debate on the (under)representation of disadvantaged groups in the public sphere (Haider-Markel, 2007; Mansbridge, 1999; Williams, 1998). The fourth aspect Pitkin raises is the *substantive* representation, by which she means the actual change and activity performed by the representatives (Pitkin, 1967). This aspect introduces an interesting aspect that there is a representative value in the action itself, regardless of who the representative is and how they are selected. No matter how free and fair electoral processes are, and how representatives' characteristics can be

perfectly descriptive of the constituency, the actual representing may be inadequate. Actions must, according to Pitkin, be a part of the requirements for representation.

What has been added in several studies more recently, though, is a more complex, reflexive view on representation, with aspects such as deliberation, responsiveness and an increased focus on discursive representation (Dryzek & Niemeyer, 2008; Urbinati & Warren, 2008). Where previously focus has been on elected politician representatives, perceptions of representation would increasingly include the voices of interest organizations in the analysis of political representation (Dovi, 2017). The increased focus on the deliberative perspective on representation opens the door for advocacy groups in a natural way, as participants in the deliberative process of political decision-making. Urbinati (2000) emphasizes how advocacy as deliberation leads us away from the traditional study areas of formal procedures and allows us to discuss other important aspects such as inequalities, disagreement and argument formation in civil society (Urbinati, 2000). Dryzek and Niemeyer (2008), for instance, suggest that what they call "discursive representation" reflects and represents *discourses* rooted in the represented, rather than actual people (Dryzek & Niemeyer, 2008). This aspect becomes important as true participatory democracy is rarely feasible in any democracy, and there will always be a distance between the represented and the representatives (Dovi, 2017). By speaking of representation of discourses rather than a more direct representation of people, this gap may be bridged.

Although her conceptualization of representation has been discussed, evaluated and adjusted to adapt to current discourses, Pitkin's categories remain a stable point of departure when discussing the different qualities required in political representation. Pitkin's theory of representation can help us understand important contemporary issues of collective participation, when developments such as marketization, professionalization and individualization are suggested to challenge basic democratic structures and values in CSOs.

4.3.3. Insider or Outsider Advocacy Strategies

A widely used distinction when studying interest groups and their influence on policymaking is the distinction between insiders and outsiders depending on the proximity of the organizations to the decision-makers. The term *Insiders* usually

refers to groups that have some kind of established relation with decision-makers, being a part of a closer network of interest groups to politicians. These preconditions shape the kind of strategies used in advocacy, which focus on direct communication with decision-makers, through consultation, negotiation and compromises. *Outsiders* are those who do not have these established contacts and thus stand on the outside of the close network surrounding politicians. These groups need to focus their strategies on making noise and mobilizing masses in order to get the attention of decision-makers, in competition with other outsiders.

Through history, this distinction has had a hierarchical nature, with insiders as the prioritized group, and insider strategies have been considered the desired strategy for advocacy groups. Schattschneider (1935) described insiders as those who knew very much and outsiders as those who knew very little regarding the way to succeed in a mission (cited in Maloney et al., 1994). The distinction was later developed by Wyn Grant (1978) relating it rather to strategies used by a group to influence, rather than knowledge. The division remained hierarchical as Grant discussed it as outsider and insider "status," with the insider as the preferred status. This hierarchical perspective is a government perspective, as it is assumed that the category of strategies is dependent on the conditions provided by government for interest groups to be part of consultation in policy decision-making. By speaking of the insider/outsider division in terms of a deliberate choice of strategies, the agency is instead shifted towards the interest organizations, although institutional context of course continues to be very relevant for which strategy has the best condition to be successful.

Although Grant acknowledged that it is possible to combine insider and outsider strategies, according to Grant this can only be temporary, and the organization will have to choose direction. The reasoning is that the valuable insider network will be damaged with the simultaneous use of more confrontational strategies such as media or demonstrations. However, Binderkrantz (2008) opposes some of the earlier literature on insider and outsider groups, arguing that outsider strategies are not necessarily inferior to insider strategies. Furthermore, contrary to Grant, Binderkrantz's studies show that an organization will very likely operate through both insider and outsider strategies. Although insider strategies contain close contacts with power holders, there can be other values using outsider strategies. For instance, visibility increases when using outsider strategies.

Strategies such as using media and/or public mobilization such as demonstrations are more common when organizations are trying to attract more members, in order to appear active and efficient (Beyers et al., 2008). Furthermore, Opedal et al. (2012) suggest that outsider strategies may be chosen because of their more direct, ideologically true methods. Insider strategies can lead to far-reaching compromises and thereby suffer in terms of legitimacy in the eyes of the members. The choice (to the degree it can be expressed as a choice) between insider and outsider strategies can thus have implications for the democratic logic in member-based organizations, and the balance between mobilizing members and actually achieving change (Beyers et al., 2008). Schmitter and Streeck (1999) differentiate between a "logic of membership" where organizational behavior relates to the characteristics of the members and "logic of influence" where strategies rather relate to the behavior of the state (Schmitter & Streeck, 1999).

The framework of insider and outsider strategies is especially fruitful when studying the changes potentially driven by individualism and their implications for participation, as the use of insider or outsider strategies often reflects the political institutional setting in which organizations are active. The state of the Scandinavian corporatist institutional setting has been discussed as potentially changing into a more pluralistic setting (Munk Christiansen & Rommetvedt, 1999; Öberg et al., 2011). As a pluralistic political context would not have the established channels for participation that insider strategies require, this theory is useful in identifying a shift from insider to outsider strategies, and furthermore, potentially larger changes in the state of collective participation.

4.4. Application of the Theoretical Approaches

Presented above are several different theoretical dimensions, starting with a broad framework and contextualization through individualization theory, and ending in more concrete theoretical frameworks used in three of the articles. In this section, these different theories will be discussed in relation to each other and to the overall purpose of the dissertation.

Figure 1

The Theoretical Layers of the Dissertation

Individualism/Collectivism
(Articles I–IV)

Patient participation at the micro, meso
and macro level
(Articles I–III)

Democratic perspectives on healthcare
(Articles I and II)

The four articles constituting this dissertation relate to the above-presented theories to different degrees. The theories operate at different levels of concretization, but they all fill important functions in order to meet the overall purpose and to answer the questions of this dissertation, and, consequently, the specific research questions of the articles.

As illustrated in the figure above, the framing of the broader discussion of a collectivist-individualist shift relates to and provides a theoretical setting for all four articles, including Article IV, a review article that does not use a specific theory. As this framing perspective relates to all articles and encompasses the theoretical perspectives of all theories presented above, it provides a theoretical base for the purpose of the whole dissertation – to better understand the shaping of collective patient participation given the increasingly individualist setting. Furthermore, it provides the frame for the research field investigated in the review article (Article IV).

At a more concrete level, the theory of patient participation occurring at either the micro, meso or macro levels within healthcare offers another perspective of this more general collectivism-individualism polemic, as this categorization includes both individual and collective patient participation. Furthermore, it

visualizes the different purposes of different kinds of patient participation. Articles I–III all relate to the micro, meso and macro framework of participation as both the POs and the user cooperatives studied direct their activities to all three of these levels, and understanding these levels becomes important for comprehending the role and function of these organizations. The specific theoretical approach used in Article III, which focusses on coproduction on either the input or output side of healthcare services, speaks directly of micro, meso and macro levels. Both individual patient participation and coproduction can be said to focus on the micro level, that is, the output side of healthcare policymaking, while the collective forms at the meso and macro levels, as well as community and organizational coproduction, to a further extent focus on the input side.

Looking more closely at collective patient participation at the macro level, a democratic theory perspective is helpful for grasping the democratic role of the POs, specifically in the Swedish healthcare system. By analyzing the role of these organizations from the perspective of different democratic ideals, the findings in the two studies on POs (Articles I and II) are furthered and the dissertation is provided with useful analytical tools for responding to Research Question I. The specific theories used in these two articles, representation theory and insider/outsider perspectives, are closely related to core functions of democratic theory, specifically the participatory democratic ideal. Representation theory is an important tool for understanding the grounds for qualifications for the delegates representing citizen groups. The participatory democratic ideal is motivated, at least partly, by procedural arguments such as fair and equal participation (Hermansson, 2003). For the procedural argument for participatory democracy to work, there must be a legitimate process in the selection of delegates of the different citizen groups included. Although Article I mainly turns to groups that are traditionally considered insiders, using the insider/outsider characterization emphasizes the diversity of groups that aspire to contribute to a healthcare system inspired by participatory democracy.

5. Presenting the Articles: Aims, Methods and Findings

5.1. Article I: Two-Front Individualization: The Challenges of Local Patient Organizations

5.1.1. Aim

An increasing presence of individualization in many parts of society has placed CSOs with an ambition of influencing welfare policy in a challenging position, where they have to adapt to individualization-related changes both in the civil sector and within the welfare service they wish to influence. These change processes include diverse trends such as a decrease in long-term membership and engagement in CSOs, professionalization, rationalization and pragmatism (Hustinx & Lammertyn, 2003; Papakostas, 2011), marketization of welfare services and the introduction of user choice systems (Le Grand, 2009). This study aims to examine how local and regional branches of well-established patient organizations, organized according to the traditional Nordic corporatist model, respond to these two types of individualization processes in the voluntary sector and in the healthcare system. Assuming that the organizations would adapt their advocacy strategies, as the power structures around them were changing, the study set out to establish which paths were chosen.

5.1.2. Method

Semi-structured interviews with representatives from regional and local branches of three well-established POs, in three large and population-dense Swedish regions, were conducted with questions regarding routines, organizational structure and advocacy strategies. The selection criteria were based on a typical case logic, so the experiences of the organization are likely to be valid for other organizations. Furthermore, the study was limited to well-established organizations that have been active for a long period of time, and have experienced change and adaptations over time. Respondents were furthermore chosen to represent both local and regional levels in each region. The interviews were mainly analyzed deductively and categorized according to a framework built

on a mapping of an interest organization's activities (Binderkrantz, 2005) departing from theories of advocacy strategies in terms of insider and outsider groups (Grant, 1978).

5.1.3. Findings and Conclusion

The analysis shows that the marketization of healthcare, in terms of privatization, choice systems and fragmentation of health services counterparts, had not been reflected on within the POs, and there was no perceived need to change routines or their advocacy strategies as a response to individualization in terms of market reforms in healthcare. Individualization within the civil sector, however, was affecting the local branches deeply. Most importantly, there was a strong lack of voluntary engagement in the organizations. This prevented boards from engaging in advocacy efforts at all, as focus was on survival and recruitment rather than influencing politics. We expected to see a movement from the traditional corporatist insider characteristics in these organizations toward outsider characteristics as traditional structures developed towards diversification. Outsider activities, such as organizing demonstrations or contacting media, were however seen as too resource-demanding, so the organizations continued with the insider strategies that they were used to, for example writing to politicians or participating in different councils. These results show that individualization changes occurring in healthcare are not taken much notice of, as organizations are busy dealing with challenges connected to individualization processes within civil society. Such challenges are difficult to adapt to, as energy and engagement is low and organizations are trapped in organizational inertia (Ahrne & Papakostas, 2002; Stinchcombe, 1965).

5.2. Article II: Federative Patient Organizations in a Decentralized Healthcare System – A Challenge for Representation?

5.2.1. Aim

Increasingly, healthcare as a policy field has called for more deliberative elements in including patients in policy dialogue. In Sweden, the traditional, corporatist way to do this has been to invite POs to committees, dialogue meetings or other

consultations. The federative structure of these organizations reflects the Swedish decentralized healthcare system, with representatives both on local/regional levels and the national level. As healthcare policy in a decentralized healthcare system is expected to reflect local conditions, it becomes important that representatives of interest organizations reflect such local conditions. Nevertheless, centralization and professionalization tendencies within POs could cause an imbalance in terms of representation, as more focus is put on national-level representation than regional level. This article studies the democratic legitimacy of these POs, and how representation is shaped in a time of centralization and professionalization within CSOs. Using Hannah Pitkin's theoretical framework of political representation (Pitkin, 1967), the study sets out to map PO representation with a focus on institutional arrangements and characteristics of the representatives.

5.2.2. Method

The interviews used for Article I were used in this study as well, with the addition of six interviews with national representatives, two from each organization – one from the national board, typically the chair of the board, and one representing the national office, usually a manager or someone responsible for interest politics. The local respondents' responses to questions regarding the organizational structure, their relation to the national board and office and general questions on their role as actors in healthcare politics were specifically analyzed for this study. The national respondents were asked similar questions, but with a focus on routines for transparency and election procedures, their experiences of representation and their relationship to the local branches. The 22 interviews were analyzed deductively according to the Pitkin framework of formal, descriptive and substantive representation.

5.2.3. Findings and Conclusion

The analysis shows in the organizations, at all levels, a strong respect for, and awareness of, the formal representation mechanisms and descriptive representation in terms of geographical representation on the national board and the electorate of the national board. In general, the national level is better equipped for the mechanisms for formal and descriptive representation, such as accountability and authorization measures and mechanisms for ensuring that representatives reflect the members. Challenges among local branches can be

explained by a low engagement. As regards the substantive representation, the study identified a potential problem concerning democratic legitimacy since those who contribute most actively to interest politics activities in the organization as a whole are the nonelected employed staff. Those are, furthermore, often Stockholm based, directing interest politics activities toward national-level public actors that do not, in fact, shape regional healthcare politics. The combination of the challenges of representation of all three kinds at a local and regional level, and strong activity by nonelected staff, constitutes a problem of representation. The staff, though professionals, often lack the patient experience themselves, and they are not getting continuous feedback from members. Furthermore, as the main activities of the organization direct their interest politics towards national actors that only by recommendations can influence regional healthcare, the representation of the federative organization aiming to influence a decentralized healthcare is challenged.

5.3. Article III: Individual, Community and Organizational Coproduction and their Relevance for Service Quality – the Case of Japanese Health Cooperatives

5.3.1. Aim

The concept of coproduction has increasingly been adopted by health services research, practice and policy. The focus of this type of coproduction is at the individual level. However, a large literature has for decades explored the values and logics that come with coproduction at a collective level, be it in groups or a more general active citizenship (Brandsen & Honingh, 2016; Pestoff, 2021). Values that come with coproduction between users and producers of public services are discussed in this vast literature in terms of quality, efficiency and democracy (Filipe et al., 2017). This study combines the different theories of coproduction by studying two Japanese healthcare cooperative organizations, where the individual-level, healthcare-related type of coproduction exists along with more collective forms such as community coproduction, where activities and services are realized through collaboration between different local actors, and organizational coproduction, which enables members to participate in the

governing of an organization. The study aims to establish this three-part typology of coproduction, and how the different types of coproduction relate to the important outcome measure of self-estimated service quality. This analysis covers data from both staff and patients, allowing for a comparison between stakeholders in the analysis.

5.3.2. Method

The study uses survey data from the period 2016–2017 collected at four cooperative hospitals in Japan, covering both staff and patients. The staff data set, which includes both administrative staff and medical professionals, covers 3,356 respondents, and the patient data set covers 631 respondents. The three types of coproduction were operationalized through the construction of indices based on survey questions that together were expected to measure the ideas of individual, community and organizational coproduction, respectively. Furthermore, an index that measures self-estimated service quality was constructed in each data set, which served as the dependent variable. The coproduction and service quality indices were then correlated to each other through a Pearson's R correlation analysis. Furthermore, a stepwise regression model was created where one coproduction index was added as an independent variable in each step and regressed with the service quality index as dependent variable. This type of analysis made it possible to see the effect that each coproduction index had on service quality and compare them to each other. This analysis was conducted on data from both patients and staff separately, enabling a comparison between stakeholders.

5.3.3. Findings and Conclusion

In the correlation analysis with quality and coproduction indices, it was clear that all three types of coproduction had strong and positive correlations with self-perceived quality. It was furthermore clear from the data analysis that individual coproduction is most strongly correlated with service quality and explained a large part of the variation of the quality index in all regression models. The collective forms of coproduction had strong correlations with each other, but in the regression analysis it became evident that these types of coproduction were experienced differently by patients and staff. For staff, the inclusion of the community coproduction index in a model with individual and organizational

coproduction did not have a significant effect on quality. For patients, the organizational coproduction index did not have a significant effect on service quality when added to a model with individual and community coproduction. The lack of effect on service quality is discussed in relation to the assumption that community coproduction is more demanding for staff, while organizational coproduction is more demanding for patients. These results lead to a discussion on the barriers of collective coproduction and suggest that more demanding participation may not necessarily lead to better outcomes in terms of service quality.

5.4. Article IV: Variations on a Theme: Exploring Understandings of the Marketization Concept in Civil Society Research

5.4.1. Aim

As developments such as individualization, professionalization, commodification and marketization are increasingly used in social, political and business-related research, the need to understand these concepts better also increases. This study focuses on the concept of marketization, and how it has been used in research conducted on civil society and CSOs. By reviewing the literature, the study aims to expand the understanding of the concept of marketization in civil society studies. This is done by identifying and explaining some of the mechanisms, contexts and perspectives that are important factors in how the concept's meaning is created among researchers. This increased understanding will bring clarity to readers and writers interested in this field regarding the different ways marketization as a concept tends to be used, what meaning it brings in specific contexts and what misunderstandings may occur.

5.4.2. Method

The texts constituting the empirical data were identified from a literature search in a number of databases, searching for literature that combined marketization and different notions of civil society and CSOs. Analyzing the sample found after excluding irrelevant articles, it was clear that the majority of the articles were published within the last decade, despite no time limits in the search, which

further motivated the ambition to clarify the use of this common concept. The main analysis included 90 articles out of a total search result of 210 relevant articles (which in turn were selected from the 888 articles that came from our literature search). The close reading of these 90 articles was guided by the ambition to find *definitions* of marketization, *where* marketization was expressed as occurring, *why* it was occurring and also *what implications* of marketization were emphasized in the literature. From this reading, three dimensions emerged that were considered important for how the concept's meaning was created, and how this meaning varied among authors.

5.4.3. Findings and Conclusion

The three themes identified in the literature were related to normativity, political and cultural context, and lastly whether marketization was perceived as occurring outside or inside the CSOs. With regard to normativity, it became obvious that this aspect strongly affects the meaning given to marketization, as it is often connoted with negative implications for civil society organizations. The political and cultural context appears to be important as countries and regions with a more recently developed market economy, or CSOs with traditionally strong ties to the government, appear to have a more positive approach to market influences in civil society. By contrast, in countries where civil society has been free from oppressive governments, focus can be on how this freedom could be threatened instead by intruding market elements in an organization that is not organized in accordance with a market logic. Lastly, a variation was found in whether marketization was seen as something coming from the outside world, and something that had to be adjusted to, or whether it was seen as a productive method of developing and improving CSOs. The study shows that the meaning attached to the concept largely varies along these three themes, and it is furthermore rare to find a developed definition or discussion regarding the meaning of marketization in the articles, which makes it even more difficult to fully understand what the author intended when using the concept, and how readers should interpret the concept. The intention of this study was not to identify a correct definition of marketization but to enlighten authors and readers about specificities of these variations and encourage scholars to be more transparent in their own use of the concept.

6. Research Design – Methodological and Research Ethical Considerations

In order to find answers to the research questions of this dissertation, the four articles have used various methods, types of data and, as was discussed above, a variety of interrelated theories. In this chapter, the different methods used will be presented and assessed, followed by a discussion on the multimethod approach. The chapter concludes with the ethical considerations that have been made throughout the work with the four different studies.

6.1. Semi-structured Interviews

In order to get a deeper understanding of the experiences of POs concerning their efforts to influence healthcare politics and internal organizational processes and routines, semi-structured interviews were conducted at different levels of the organization – local, regional and national levels. In total, 23 semi-structured interviews were carried out with representatives from three different POs. The interviews were about 40–90 minutes long, and the majority were carried out through physical meetings at the organizations' offices. The benefit of semi-structured interviews is the opportunity to follow up answers, allowing the conversation to lead to topics that may be important for the issue, but unknown to the interviewer beforehand (Brinkmann, 2014). This was the case in the interviews at a local level, where focus shifted from marketization and individualization processes within healthcare towards the apparent problem of recruiting members. This issue overshadowed all other topics, including the one that was anticipated concerning marketization and individualization.

6.1.1. Sample

For the local and regional interviews, three densely populated regions were selected in order for the local and regional branches to represent as many patients as possible. Of course, had more rural areas been selected other issues may have arisen, such as problems of access to healthcare etcetera. However, these densely populated areas have, to a larger extent than rural regions, experienced marketization reforms, which was an important part of the study's area of interest. The selection of the three POs was carefully made, in accordance with the typical

case selection criteria (Gerring & Cojocaru, 2016). Since the focus of the two studies is the specific form of interest organizations historically common in Sweden, it was important that the organizations had been around for a long time and were organized in accordance with the traditional Scandinavian model. Furthermore, it is relevant to take into account the specific group of patients that these organizations represent, since different diagnoses and illnesses come with different needs and interests. The organizations were chosen to represent patients with chronic illness, since a continuity in the organizations and people engaged in them was important. Furthermore, since the study specifically concerned advocacy work towards healthcare policymaking, and not, for instance, making the community accessible for these groups in general, I turned to organizations where I assumed that their interests were more directed towards healthcare (for this reason, large and important associations for rheumatics or allergy and asthma were not included). Nevertheless, this selection implies a limitation as it does not represent all kinds of POs, including those working for better access to society, which is a significant part of the work of patient and user organizations. Furthermore, it excludes organizations that are not arranged in line with the traditional structures of the neo-corporatist settings, thereby not reflecting potential new trends or developments in the organization of the patient movement.

6.1.2. Interviews

Two respondents from each organization at the local branches were selected, where one of them would also have a formal position on the regional board, usually the head of the local board. Another respondent would be an ordinary member of the board, but someone who had been active and experienced in the organization. At the national level, one elected representative from the national board was interviewed, along with one representative from the professionally recruited staff. The choice to conduct elite interviews, rather than interviews with members, was based on the assumption that those with formal power within the organizations had the best knowledge of the issues concerning internal organizational routines and strategies (Hochschild, 2009; Natow, 2020). Interviewing members, nevertheless, could have had the benefit of revealing the actual representativity of the organizations, how well the members feel represented and furthermore enhancing the understanding of what keeps

members from engaging more actively in the organizations, which appeared to be a big problem when speaking to the formal representatives. It would have been a useful complement to the elite interviews, but it would also require other ethical considerations as it would reveal sensitive information about individuals' health status (SFS 2003: 460).

Two separate interview guides were constructed, one for local respondents and one for national-level respondents. Questions for the local respondents were mainly developed based on literature describing different roles, strategies, activities and internal structures of POs and CSOs in general. These interviews were conducted in the period 2016–2017. The interview guide for national respondents was more strictly based on Pitkin's representation theory, but also questions regarding the internal structures of the POs that had been included in the interviews with local respondents. These interviews were conducted in 2018. Both interview guides were first tested on one or two interviews, and then reassessed for smaller adjustments, before continuing with the remaining interviews.

6.1.3. Analytical Strategy

The transcribed interviews were analyzed using the method of a qualitative deductive content analysis, sometimes referred to as "directed content analysis," which is suitable for testing concepts and theoretical models (Hsieh & Shannon, 2005). In Article I, an *unconstrained* deductive analytical strategy was used, which is characterized by a more open approach, basing the analysis on the table covering the different activities of the POs, but allowing for other possible themes as well (Elo & Kyngäs, 2008). Meaning units were therefore identified, and sorted into nine categories, which all related to the table and, furthermore, three categories that were inductively identified. From the 12 categories, a smaller number of themes were identified and then analyzed, which provided a basis for the findings of Article I. In Article II, a *structured* deductive analysis was performed, which means that data are only included in the analysis if they fit the categorization matrix (in this case, the different types of representation) (Elo & Kyngäs, 2008). Thus, the transcripts of the local and regional interviews, already used in Article I, were sorted along other themes, and new meaning units, relevant for the representation theory, were identified.

6.2. Statistical Analysis of Survey Data

With the purpose of providing detailed knowledge on the relationship between individual and collective forms of patient participation, more specifically as *coproduction*, a statistical analysis was carried out on data collected through a survey directed at patients and staff at cooperative hospitals in Japan. These data analyses allow for a measurement and comparison of both individual and collective forms of coproduction, thus responding to Research Question 2. Furthermore, in regard to the overall aim of the dissertation, the quantitative analysis complements the findings of the qualitative interview studies, which reflects the perspective of individuals with a specific interest in collective patient participation, with measurable information from people who do not specifically work with, or are not engaged in, promoting patient participation. This generates an important balance in terms of whose voices are represented in this dissertation.

6.2.1. The Data

The surveys were conducted in 2016 and 2017, as part of a larger research project on cooperative healthcare facilities. The project was designed and conducted by Professor Yayoi Saito and her research group at Osaka University, in collaboration with Professor Victor Pestoff and Associate Professor Johan Vamstad at Ersta Bräcke Sköndal University College. The survey was conducted by a professional survey company (Tokai Kyodo Printing Company Ltd in Aichi Prefecture) and was directed at hospital staff, patients and volunteers at a number of public, nonprofit and cooperative healthcare facilities. The survey questions covered themes like work environment, service quality, participation, and social and political values. More information on the research project as a whole can be found in the book *Coproduction and Japanese Healthcare: Work Environment, Governance, Service Quality and Social Value* by Victor Pestoff (2021). For Article III in this dissertation, mainly questions concerning participation in the shape of coproduction were analyzed, and only staff and patient data from cooperative healthcare organizations were used. The staff data consisted of 3,356 respondents with a response rate of 67%, and the smaller patient data consisted of 631 respondents. Unfortunately, for these data, there is no information on the total number of distributed surveys, so the response rate cannot be calculated (Pestoff, 2021). The respondents of the patient surveys were only outpatients, and surveys

were distributed both in waiting rooms and at patient meetings, with a prepaid return envelope (Pestoff, 2021). Three different types of coproduction were identified in the literature and then operationalized through the construction of indices. *Formative* indicators in the data surveys were chosen to measure different aspects of these complex constructs and combined into three different indices (concepts by postulation) (Diamantopoulos & Siguaw, 2006; Saris & Gallhofer, 2014). Formative indicators, as opposed to *reflective* indicators, are assumed to cause, rather than be caused by, the construct measured (Diamantopoulos & Winklhofer, 2001). This is suitable in cases where the constructs measured are complex concepts that are assumed to be a result of various measurable indicators (Diamantopoulos & Siguaw, 2006). A fourth index was created, this time through reflective indicators of the construct *service quality*. Using reflective indicators for this index was relevant since service quality is easier for the respondents to relate to and they can be expected to be able to answer a direct question regarding service quality (Saris & Gallhofer, 2014). All indices were validated through Cronbach's alpha.

6.2.2. Generalizability and Theoretical Relevance

The survey data from the Japanese healthcare cooperatives are a unique opportunity to study healthcare coproduction both in its individual form and its collective forms, and furthermore from two different stakeholders – both patients and representatives of the organization (staff). From a theoretical point of view, this makes it an interesting case for scholars of patient participation. For the sake of the development of the research field of collective coproduction, I wish to emphasize the theoretically relevant aspects of studying both individual and collective forms within the same data set, rather than elaborating on contextual factors. For this reason, and due to the limitations that come with the article format, the Japanese context has not been developed in detail in the text, as this would overshadow the theoretical importance of the case. It could, however, be questioned whether applying theories of coproduction, which mainly has been developed in America and Western Europe, to the Japanese context is justified. It should be noted, however, that focus is on the Japanese cooperatives, rather than, for instance, the Japanese healthcare context in general. This is an important distinction since the studied cooperative organizations are more comparable to cooperatives in other parts of the world than Japanese healthcare is in general

(Kurimoto, 2010; Kurimoto & Kumakura, 2016). Since the cooperative organizational form is what justifies the use of coproduction theory in this study, it can be argued that coproduction theory is a suitable theoretical perspective to use when studying these organizations (Pestoff, 2021). Nevertheless, there are indeed limitations in terms of generalizability when choosing such a specific context to study. The Japanese social and cultural context is likely relevant for the outcome in these data to some extent, such as the Japanese healthcare system, and the specific development of the two studied cooperative organizations. For instance, some of the response options were developed to fit the services of these organizations specifically, which makes it difficult to apply the results directly to other organizations (although they are examples of more general phenomena). However, important aspects of these data should be relevant for other contexts as well, as many of the issues covered by the survey are widespread in healthcare services and other welfare organizations throughout the world: for instance, patient involvement and coproduction, the interplay between medical staff and patients, and the ambition of community outreach in healthcare organizations. To illustrate and support the theoretical value and general relevance of the study, previous international literature on different types of coproduction plays an important role in the research design.

6.3. Systematic Literature Review

So far, the focus has been on methods aimed at studying patient participation, qualitatively and quantitatively. In order to place this topic in a more general research field, a broader approach is taken through a systematic literature review in order to study the existing academic literature on civil society handling and relating to marketization. This methodology strengthens the connection between this dissertation and previous literature on similar topics, thus placing the research in a broader setting.

6.3.1. Configurative Systematic Review

The systematic review method has been the subject of debate for a long time (Levinsson & Prøitz, 2017). Criteria of what is required for reviews to be systematic have been disputed, along with the different purposes of what their contributions are. Part of the debate on reviews has been between scholars of quantitative and qualitative traditions, as reviews of qualitative literature have been

difficult to place in the traditional systematic review template (Barnett-Page & Thomas, 2009). A way to understand the inherent differences between the synthesizing of quantitative and qualitative studies is by discussing them through the different approaches of aggregative and configurative reviews (Gough et al., 2012). The aggregative review focusses on synthesizing the findings of studies to obtain an increased knowledge of a limited topic. In this approach, evaluating the rigor of methods used is important, and the synthesizing of the review follows a summarizing, deductive logic to aggregate the knowledge provided by the included studies (Gough et al., 2012). The configurative review, on the other hand, is more suitable for topics that tend to be more complex, multifaceted and understood in different ways. The analytic strategy is inductive and interpretative, with the purpose of relating the included studies to each other in order to gain new insights into how a phenomenon can be understood (Levinsson & Prøitz, 2017). The systematic review conducted in Article IV is driven by configurative logic, as this is most suitable for the topic studied. Nevertheless, the study also includes aggregative elements. The first part of the analysis is a mapping of the literature, which through a deductive, aggregative strategy provides a description of how many articles there are, from where and in what disciplines. This aggregation provides a useful basis for the following, more inductive thematic analysis, in line with the configurative review strategy. The combination of the aggregative and configurative ideals is common, which is indicative of the benefits of combining quantitative and qualitative approaches for a fuller picture (Levinsson & Prøitz, 2017).

6.3.2. Selection Criteria

In identifying relevant articles for the review, several necessary choices of selection and exclusion were made that potentially had implications for the findings in the study. One central initial choice was to not include any synonyms of marketization in our literature searches. Had we chosen to include related concepts, it would have likely enabled more nuances and perhaps other patterns of the conceptual usage could have been identified. Nonetheless, it would have broadened an already disparate research focus. The focus on one concept limited the review to a conceptual analysis of the concept of marketization, not the phenomenon of marketization, which was also a valuable approach that had not, to the best of our knowledge, been taken before. Another important demarcation

was that we wanted to focus our analysis on civil society-related literature. As there is no obvious distinction between research fields, this was a judgement that had to be made in each case. There is a risk that articles were included that were more characteristic of other disciplines than specifically civil society studies, which could have an impact on how the author defined and used the concept of marketization. Another choice was to focus only on peer-reviewed articles, thus excluding all publications that were published in other ways, including full-length books, dissertations and anthology chapters. This was a practically justified choice, but it likely excluded a substantial amount of relevant literature.

6.3.3. Analytical Strategy

The categorization of articles and the following thematic analysis was a joint effort between the two co-authors (Nowell et al., 2017). Due to the inductive method of analysis, a continuous dialogue with several reconciliations throughout the analytical phase was required in order to ensure that both authors had the same understanding of the analytical process and made the same judgements. Our initial ambition was to identify themes of common conceptualizations of marketization in civil society literature (where marketization was a central concept). The very multifaceted nature of the concept made it difficult to identify such common themes, and instead we shifted our analysis towards identifying common dimensions within which the literature provided large variations. This development further illustrates and motivates the need for clarifications on the various uses of the concept.

The method of the systematic review provides an understanding of the complexity of the research field in which this dissertation is placed as it enables the synthesizing of a large quantity of research covering many different traditional disciplines within social science. The configurative review approach is suitable when attempting to account for a topic that can be understood in so many various ways when the texts and analyses as a whole are more important than the actual findings of the study. The inclusive approach enabled by the systematic review method also visualizes the challenges of a cross-disciplinary research field, where larger societal change processes such as marketization and/or individualization can mean one thing in, for instance, civil society research and something else in, for instance, health services research.

6.4. A Multimethod Approach

The design of this dissertation includes, as illustrated above, multiple types of data, multiple theories, multiple analytical strategies and multiple research questions. A central argument for such a *multimethod* approach is that by combining different methods, for instance qualitative and quantitative methods or a combination of different qualitative methods, they will compensate for each other's weaknesses (Anguera et al., 2018; Brewer & Hunter, 1989). A multimethod subcategory that has become more widely used in recent years is *mixed methods*, which are often used specifically to describe the combination of both qualitative and quantitative methods (Sandelowski, 2000) but have increasingly been used to cover multiple research in more general terms, making the concept and literature somewhat fuzzy (Anguera et al., 2018).

Multimethods, as opposed to mixed methods, allow for more variation in methods and the studies can be more or less integrated. An example of integration of methods is that one method is more suitable for the first step of the research, and another method is suitable for following up findings of the first study, i.e. a sequential approach (Cameron, 2009). This dissertation follows instead a parallel design, where the studies are conducted independently, and methods are not necessarily adjusted to the results of previous studies (Tashakkori & Creswell, 2007). A sequential element exists, however, in the development of the interviews of Article II, which partly builds on the knowledge of the POs already developed in Article I. This sequentiality should, however, be regarded as a pragmatic use of such knowledge rather than a strategic guiding principle for the development of Article II as a whole. As the dissertation consists of four independent studies, the degree to which the different findings can be integrated is limited. Pat Bezeley defines multimethod design as parallel or sequential methods, and integration is not made until inferences are made (as cited in Anguera et al., 2018). Following this definition, the integration of this design is limited to Chapter 7, where the separate findings of each article are discussed in relation to each other and to the overall research aim.

The degree to which the different studies include different perspectives of the studied topic has been important for the design. For instance, the studies on POs include both national and local levels (empirical breadth), and different core

aspects of interest groups such as both advocacy strategies and representation (theoretical breadth). Articles I–III covers all three levels of participation (micro, meso and macro) in both voice and service organizations. It has also been important for the design to study different types of populations – both formal representatives (Articles I and II) and individual patients (Article III) complemented by the general literature in the field (Article IV). The combination of qualitative and quantitative methods also serves a purpose, where the detailed knowledge from the qualitative interviews can be related to, and broadened, in the quantitative survey data of Article III. Although the specific questions asked vary between the two empirical settings, common understandings of the larger theme of collective patient participation can hopefully be identified, illustrating commonalities between the different empirical settings that can bring novel understanding to the field.

Using a multimethod design can serve different purposes. Greene and colleagues identify several different purposes in their paper from 1989: triangulation, complementarity, development, initiation and expansion (Greene et al., 1989). Although explicitly using the concept of mixed method, they build their reasoning on "multiple research" (Mark & Shotland, 1987), and their typology includes studies that are less integrated multimethod studies as well. This dissertation strives both for triangulation and complementarity. The ambition with triangulation is that studying knowledge from collective patient participation in one setting can be reflected and validated by another study as several different stakeholders are studied. Some scholars argue that triangulation would demand a more coherent design, with a population that is more similar, but studied in various ways (Moran-Ellis et al., 2006). Nevertheless, I believe that by having a more generally defined population, such as "patients," rather than PO representatives (thus including both empirical settings of Articles I, II and III), there is some benefit of using a triangulation approach here. Nevertheless, complementarity is an important goal as well, as the different settings may serve to broaden the understanding of collective patient participation and identify unexpected common experiences.

While there are several benefits of a multimethod approach, there are of course limitations that come with a less coherent research design as well. One such limitation is that the potential to reach a depth and precision in the overall findings

of the dissertation is challenged by the different populations studied and various theoretical perspectives used to analyze them. Nevertheless, as the four articles included in this dissertation all are independent studies, this depth can be found in each of these articles and integrating them in a common discussion creates an added value to their distinct findings. The four studies of this dissertation illustrate, independently, different important aspects of collective patient participation. They can all stand alone with methodological integrity, but together they contribute to a fuller picture, enabling a better and broader understanding of the aim of the dissertation, that is, to explore how collective patient participation is shaped.

6.5. Research Ethical Considerations

All social science research requires a careful consideration of the potential ethical problems the research may cause, both in the process of collecting data from individuals and the effect the publication of research findings may have on informants. Information concerning health, political or religious views or engagements and also research that may in any way harm the informants are considered sensitive, requires a formal approval according to the Act on the Ethical Review of Research Involving Humans (SFS 2003:460). None of the four studies included in this dissertation were considered to require such an approval. Article IV consists of already published research, and the data files used in Article III are anonymized and respondents of the surveys cannot be identified. The research project from which the data originate has also already obtained a formal research ethical approval. Although my empirical data in the interview studies to a large extent are provided by people selected through their engagement in a patient organization, thus likely suffering from diverse health issues, the respondents of the interviews are formal representatives, thereby choosing to be public representatives of these organizations. More importantly, the interview questions only concern matters of the organization and the representatives' experiences of the organization, and not information about the individual respondent. Although formal permission was not needed, ethical considerations still need to be made throughout the research process. All respondents were sent a letter along with the invitation to participate in the study, which included information on the purpose of the study, and the nature of the questions of the interview. All respondents were furthermore informed that their participation was

voluntary, and that they were free to end their participation in the study at any time. The interviews were informal and relaxed conversations, and the respondents could move into more personal reflections of their own experiences of healthcare or their disease. If parts of the interviews crossed this line from reflections of an organization representative to those of a patient, this was not transcribed or in any way included in the analysis. Furthermore, the geographical belonging of the respondents is not revealed in the articles, and they can therefore not be identified. The interviews were recorded and transcribed by me. The transcriptions are stored digitally at a protected server at Ersta Sköndal Bräcke University College.

Another ethical issue is that of transparency concerning the work put in by each author in co-authored articles, for instance for the sake of accountability but also to avoid awarding wrongful merit to researchers (Vetenskapsrådet, 2011). In a set of principles formulated in the Vancouver Convention (ICMJE) the following guidelines for co-authorship can be found:

> Authorship credit should be based on 1) substantial contributions to
> conception and design, acquisition of data, or analysis and interpretation
> of data; 2) drafting the article or revising it critically for important
> intellectual content; and 3) final approval of the version to be published.
> Authors should meet conditions 1, 2, and 3.

All authors of the co-authored articles in this dissertation (Articles I, II and IV) meet these requirements, myself included. I, as first author, have been central to the work process, driving the project and text production forward. In Articles I and II, both authors were involved in designing the studies, and analyzing the results. I was responsible for literature overviews, conducting the interviews, initial analysis and text production. In Article IV, I was responsible for going through the majority of the literature included to make an initial assessment and categorization, after which the literature was divided among both authors for further assessment. Although both authors have been involved in text production, the writing process has mainly been my responsibility. Being the sole author of Article III, all analytical work, from selecting variables and constructing indices to conducting statistical analyses, is my independent work, albeit based on survey data that had been collected by others.

7. Discussion on Findings

This chapter will attempt to integrate the four independent studies in a discussion that departs from the general aim and research questions of this dissertation. The main findings of the separate articles are discussed in relation to each research question, concluding with a broader discussion related to the dissertation's overarching aim of exploring how collective patient participation is shaped, along with suggestions for future research. To illustrate how the findings from the different settings studied in this dissertation all connect to collective patient participation, the findings are discussed in relation to the micro, meso and macro framework presented in Chapter 4.

7.1. Struggling Patient Organizations at the Macro Level

The first research question posed in this dissertation is *What are the barriers and facilitators for patient organizations in contributing to democratic qualities in terms of political influence and representation in healthcare policymaking?* Starting with the barriers, one such is the POs struggle to engage people collectively. This is identified as a key barrier to POs being able to influence policy or healthcare services to the point they wish. This challenge of engaging people in their organizations also risks undermining another important underpinning of their democratic legitimacy and credibility at both local and national levels, namely representation. The barrier to engaging people in POs is supported by a number of observations made in the two articles on POs. Article I illustrates the difficulty local associations experience in recruiting new members, keeping old members active and getting new people to volunteer for the board. These challenges have been observed in previous literature on CSOs and have been connected to an increased individualization of volunteer work and civil society in general (Hustinx & Lammertyn, 2003; Skocpol, 2003). In Article II, similar challenges are visualized when discussing how POs shape representation, and we see a big difference in the degree of engagement when comparing national- and local-level POs. The struggles of local branches in engaging people create obstacles for the influx of members from local branches engaging in and giving feedback to national-level activity, leading to a discrepancy

in both advocacy activity and representation mechanisms at the national level compared to the local branches. An important reason for this difficulty in engaging patients in POs is a lack of resources at an individual level since those engaged in POs are often weak and elderly citizens in poor health. This inherent weakness in patient participation has been widely discussed in relation to individual forms of patient participation, such as the ability to make informed choices. It has frequently been pointed out that users of health and social care services often do not have the resources to engage, make choices and make their voices heard (Baxter et al., 2008; Meinow et al., 2011). Of course, the same argument can be made regarding collective forms of engagement for the same group of people. The difference in collective forms of engagement is that not everyone needs to be engaged to be represented, as long as there are resourceful participants that can represent them. The question is what happens when these representatives are not as resourceful as they might need to be, or too few to represent larger groups of patients.

The main facilitator for these organizations is identified as the strong and traditional institutional setting of Swedish interest organizations, which has fostered a common knowledge and unspoken agreement between members of the organization and policymakers of how POs can influence politics and how to formally secure representation within the POs. This creates a stability for the organizations that struggle with low engagement. Findings in Articles I and II illustrate a widespread knowledge, respect and loyalty to the traditional way of working in a Swedish interest organization. In Article I, interviews show that local PO representatives rely heavily on traditional insider strategies for influence, such as contacting local politicians by letters or telephone, responding to remittance requests and participating in different councils. In Article II, it becomes clear that there are very clear and formal routines when creating representation. There are also high ambitions in the POs when creating representation that reflects members, for instance in terms of type of disease and geographical origin. The traditional and somewhat rigid institutional setting of this type of CSO provides a useful guide and frame of references for the representatives to relate to. It is possible that if this organizational know-how did not exist and was not carried forward from old to new generations of representatives, these weak organizations would struggle even more to find their way in their ambition to influence

healthcare policy and contribute with legitimate representation when doing so. However, what is described here as a facilitator could also be interpreted as another barrier, in terms of path dependency. Since their advocacy work is seen as insufficient by POs themselves, adjustments in their current way of working would be required but is difficult for them to make. Both studies show that it appears difficult for the POs to adjust to current social developments that are changing the preconditions under which this kind of organization was formed. Organizational inertia in these organizations creates a bad spiral where a rigid institutional setting, created for a certain type of organization, creates barriers to making the needed adjustments to develop participation forms that are desired by citizens and patients. The few indications of a desire for innovation and adjustments expressed in the interviews were hindered by formal requirements for government grants or other institutional restrictions.

Articles I and II have mainly studied the participation of POs at the macro level, i.e. at a policymaking level where patient participation is directed toward the input phase of political decision-making. The interviews with the local branches present a rather pessimistic outlook for the traditional democratic function of local POs. Formally, these organizations do the right thing – they follow statutes, they hold annual meetings, they arrange nominating committees to prepare elections. Yet, the low level of engagement is a problem for these formal structures to function adequately. Adding the more professionalized, national level of these organizations in Article II, the low local activity is somewhat compensated by the activity of the staff and national board. Professionalization can, however, be fuelled by a lack of grass-root activity, a development that disconnects from the democratic structures common in CSOs. Thus, it could be seen as a democratic weakness that the staff are not elected, and not necessarily representative of the member base or the patient group in general.

However, it is difficult to evaluate the democratic contributions of POs without discussing them in relation to different democratic ideals (see Chapter 4) and different potential purposes of patient participation. For the participatory democratic ideal, representation and inclusion of as many voices as possible is central. The goal is to aggregate as many different perspectives as possible, and to enable negotiations between these interests (Axberg, 1997; Cunningham, 2002). The deliberative democratic ideal, however, is not as focussed on including as

many different voices as possible, but rather on creating an open dialogue between stakeholders, where opinions are meant to be challenged, and developed towards an objectively better solution or decision (Axberg, 1997; Cunningham, 2002; Gilljam, 2003). Both decision-makers and patient representatives should in this case be open to developing their original position, as different arguments are presented. Knowing the purpose of the patient participation activity is important in order to understand the democratic ideal at stake (Bombard et al., 2018; Ocloo et al., 2021). A participatory ideal is likely present if the purpose is mainly intrinsic, to create a sense of being included, and for patient participation to be empowering, legitimizing and creating trust towards healthcare decision-makers. The presence of the participants is more relevant than what is actually discussed in these forums. If the purpose of participation is more instrumental, that is, to develop and communicate knowledge to decision-makers, in order for them to make as informed decisions as possible, the intended participation is closer to the deliberative ideal.

Given that the conditions for POs differ greatly at the local and national level, it is possible that the democratic ideals could and should look different at the local and national level. Article II visualizes a lack in the descriptive representation among those that are most active in the organization. The participatory democratic goal of including as many voices as possible is therefore challenged at the national level. From a deliberative perspective, on the other hand, the descriptive representation may not be as important as the actual conversation between PO and decision-makers, something that the national-level staff and board appear to be more capable of. The findings of Article I proposes that at the local level, the benefits of a deliberative communication with local policymakers are harder to reach due to their low activity in advocacy work. Although the participatory ideal may be more achievable at the local level, and the deliberative ideal more achievable at the national level, it is mainly according to the participatory ideal that the POs, at all levels, are working, and from which the structure of involving interest organizations is built in the Swedish context. This example illustrates how something that is problematic according to one democratic ideal may not be as problematic for another democratic ideal. Furthermore, the democratic ideals may differ between the actors involved. Intrinsic purposes may be more important to patients, whereas extrinsic purposes

may be more relevant to policymakers. The purpose of patient participation must therefore be clearly formulated in order for participation to be correctly evaluated in terms of barriers and facilitators.

It is important to acknowledge that the empirical findings of Articles I and II could very well have been different if we had had other selection criteria for our choice of organizations. For instance, more recently formed POs may not be as loyal to the traditional forms of interest group mobilization and may have more innovative approaches to the challenges posed by the individualization of volunteering. Had we chosen to only study the national level, as large parts of the previous PO literature have done, we would probably have perceived the POs as more active and energized. The choice to include the local level has, however, proven to be essential in order to fully understand the whole organization and the conditions that shape PO activities today.

7.2. A Self-Reinforcing Relationship between Collective and Individual Patient Participation?

The second research question is *How can individual and collective patient participation relate to each other and to service quality?* Importantly, the studies in this dissertation can respond only to some degree to this rather general research question, given the specific conditions in which the studies are operationalized. For Article III, this means providing knowledge from the perspective of coproduction when comparing its individual and collective forms by studying them both in relation to a common output variable, in this case self-estimated service quality. In this operationalization, individual coproduction has a stronger positive correlation with service quality than the two forms of collective coproduction (organizational and community coproduction) as perceived by staff and patients. Furthermore, looking specifically at these two collective forms of coproduction, the findings indicate that the more demanding forms of collective participation (organizational coproduction for patients, and community coproduction for staff) have a weaker correlation to service quality. From these findings, it is difficult to draw too far-reaching conclusions on the outcome of patient participation, as increased service quality is not always the main goal of patient participation, but it is safe to say that the more demanding forms of collective patient participation are not necessarily those that have the best effect on service quality.

With regard to the relationship between individual and collective forms of patient participation, findings from Articles I–III indicate that individual and collective patient participation do not need to crowd out one another. Partly, they serve different purposes, but to the extent to which they serve the same purpose (i.e. strengthening the position of patients), the collective type of patient participation may rather improve the conditions for individual patients and, subsequently, for individual participation. The two studies on POs do also contribute with important aspects of how collective and individual participation are related, from the perspectives of POs. From the interviews in these studies, we see that despite what perhaps is expected among these organizations that are concerned with collective patient participation, the increasingly common manifestations of individual patient participation are not considered a threat or something unwanted. From a patient and patient representatives' perspective, it seems that increased individual patient participation is desired, welcomed and considered beneficial. The possibility of choice in healthcare, for instance, was only discussed in positive terms in interviews with patient representatives in the organizations. Adding the findings of Article III that clearly show how important individual coproduction is for the perception of service quality, the importance of individual participation in healthcare is strongly evident both among individual patients, not represented by or active in a patient group, and also among those who actively work to influence healthcare through collective action.

Article III combines different types of patient participation taking place within the same service organization. The individual coproduction type serves as a measure of micro-level participation, and the organizational coproduction type represents a meso-level participation, that is, participation aimed at improving the healthcare facility. Community coproduction, however, is difficult to place into one specific level of participation. Instead, the community coproduction activities are directed towards all three levels, serving the individual patient, for instance, in the ambition of increasing patients' and citizens' health literacy, through activities organized at the organizational, meso level. Community coproduction activities thus invite patients to be involved in healthcare at the individual level. This important empowering role of community coproduction has been discussed previously (Palumbo & Manna, 2018). Finally, since part of the purpose of community coproduction is to communicate with local policymakers, it can also

be seen as participation at the macro, policy level of healthcare. As a response to how individual and collective patient participation relate to each other, community coproduction can be identified as a potential bridge between individual and collective forms of patient participation, bringing together inputs from the micro, meso and macro levels of healthcare.

A productive way of looking at the relationship between individual and collective participation is that the collective work can be seen as an instrument for reaching individual autonomy and empowerment. Perhaps this is the way to understand how collective participation can be used in an increasingly individualist environment. Earlier research has drawn similar conclusions. Feltenius and Wide (2015) suggest a role for collective participation in a marketized environment to be involved in the shaping of more individualist traits such as being consulted in the implementation of marketization reforms and the contracting of private providers. Moreover, van de Bovenkamp and colleagues discuss the potential of POs to help individual patients with their healthcare choices – what they call "delegation of choice" (van de Bovenkamp et al., 2013). So, collective participation has the ability to strengthen and support individual participation, and many of the top-down-initiated projects for increased patient involvement are also directed towards individual participation. Are collective forms of patient participation then left behind, without the support they seem to need to be able to function properly? Theoretically, the strengthening of individual patients, through efforts that collective actors engage in, for instance through POs or through community coproduction, will result in providing individual patients and citizens with the same empowerment, knowledge and resources that are needed for collective engagement. In that way, a self-reinforcing cycle of patient empowerment is created by the strengthening of the individual patient. The relation between individual and collective participation can, of course, be studied in many ways, and it is impossible to cover all aspects. But the findings in Article III, and to some extent Articles I and II, can give us some knowledge about this relationship that can help to further the understanding of this important and current topic. For instance, the approach used in Article III, to combine literature and empirical data on both collective coproduction and the increasingly common individual coproduction within healthcare, highlights the diverse functions and

roles of collective and individual coproduction and their relation to outcome values – intrinsic or extrinsic.

All three articles studying collective participation in healthcare through CSOs (Articles I–III) seem to circle around the issue of collective participation being more demanding than individual forms. When discussing these findings together, as examples of a larger pattern or trend, such as the barriers to becoming engaged collectively for patients, it becomes important to emphasize the very different contexts that the observed organizations operate in. Cultural and social factors are likely to affect the attitudes towards, and preconditions for, engaging collectively, and such factors could preferably have been explored further in this dissertation. It is, nevertheless, important to note that the organizations studied in the Japanese context are not typical for Japanese healthcare and should therefore not be perceived as representative of collective patient participation in the Japanese context. As organizations, though, what the Swedish POs and the Japanese user cooperatives do have in common is that they are organized according to a collective logic. Despite operating in very different contexts, they should both be considered suitable study objects for collective patient participation, and their differences can be seen as a sign of the universality of the interest in, and need for, collective forms of participation in healthcare.

Summing up, individualist traits when studying collective participation cannot be discarded as something that needs to be defeated, worked around or overcome. Individualist ideals should instead be integrated into how collective patient participation is organized and could be part of the goals that collective patient participation strives for. The CSOs may benefit from this later, as empowered individuals might be more prone to engage collectively.

7.3. Marketization in Civil Society Research – Contextualizing the Preconditions for CSOs

Taking a step away from participation within healthcare specifically, the third research question of this dissertation is *How is marketization discussed in relation to civil society organizations in the academic literature?* From the systematic review made in Article IV, a direct answer to this question is difficult to provide, given that there are great and important variations in the large amount of material studied.

Nevertheless, there seems to be a tendency within a large part of the literature to discuss marketization as a process that strikes CSOs from the outside, forcing them to change their activities and behaviors in ways that they or the researchers behind the study perceive as negative and unwanted. Another important finding of the review is the mere mapping of the literature and the exceptionally strong increase in literature on the topic over the course of only six years (2010–2015). Marketization in relation to CSOs is thus discussed *extensively* in the academic literature.

This article does not follow the same theme as the first three articles but contributes instead to placing the theme of this dissertation in a larger academic discourse that is carried out in research on civil society as a whole. Since applying a civil society perspective on patient participation is an important contribution of this dissertation to the patient participation research field, this review provides a better understanding of civil society research and the debate on individualization, and specifically, marketization developments in relation to CSOs. It provides important knowledge regarding the overall purpose, which is to explore the shaping of collective patient participation, and indirectly, the prevalent conditions for this process, in an individualized and marketized environment. In this article, it is the authors of the articles and their analyses that are the research subject, not the CSOs they are studying. This not only contributes to an insight into the empirical conditions of CSOs as agents of collective patient participation, but also adds an analytical layer illustrating, for instance, the main implications of marketization in civil society, according to the scholars of the field.

Some of the findings of the review article support the findings and theoretical departures of Articles I–III. For instance, the review, just as in Article I, identifies an important distinction between the change process of individualization or marketization as external or internal to the CSOs. Nevertheless, for the POs studied in Article I, the external marketization did not impact the organizations to the extent that many of the articles in the systematic review suggest, as these organizations, especially at the local level, seem to avoid adjusting to such external changes.

The review also describes a very normative debate, where a large part of the discussion expresses a critical stance towards marketization in regard to civil

society and its organizations. Interestingly, as we have seen in the previous section, the critique that is so often expressed by scholars and exemplified through their studies, is not as evident among the empirical insights from representatives and patients in these CSOs. The analysis of the concept of marketization illustrates, for instance, the effect on the meaning and perception of a strongly ideologically tainted concept, and the importance of being transparent with the context in which the concept is used. Both Article III and Article IV remind us scholars of cross-disciplinary fields of research to be aware of the various meanings of commonly used concepts (such as coproduction in Article III and marketization in Article IV), and the different meanings that can be attached to it depending on where you stand as a writer and a reader.

Importantly, the review focuses on what I view as one part of individualization, that is, marketization. Other parts of the dissertation discuss individualization rather than marketization, which entails wider developments than only marketization does. Nevertheless, I believe many of the findings in the review are relevant when discussing individualization in regard to CSOs too, as a broader, yet equally well-debated and ideological process (which can, but does not have to, include marketization), and that often is described as contradictory to the logic of CSOs.

7.4. The Shaping of Collective Patient Participation – What We Know and What Is Left to Discover

The overarching aim of this dissertation was to explore how collective patient participation is shaped, given the increasingly individualized and marketized environment in which it operates today. The dissertation explores various forms of collective participation, and for the purpose of clarity, the findings have been discussed along the multilevel framework, where collective patient participation has been identified at the micro, meso and macro level. The findings discussed above in relation to the three research questions illustrate how collective patient participation is shaped by a variety of factors and circumstances, ranging from the resources and will of individual patients and members, to challenges and possibilities in the organizational structures of CSOs, as well as more general, societal factors related to changing norms, values and political priorities.

Several of the findings indicate that collective patient participation is to a large extent shaped by the preconditions of the individual patients, such as a lack of time, will and other resources among individuals. These findings emphasize the need for a discussion on what the desired levels of participation are. For a sustainable and reliable collective patient participation, it is essential to depart from what patients are willing to do, and what they wish to be involved in, whether it is at the meso level (Article III) or at the macro level (Articles I and II). Some studies have tried to identify what patients actually wish to contribute with, and at what level (Fredriksson & Tritter, 2020; Tambuyzer et al., 2014). These have mainly studied individual patients, not in the context of a PO specifically. Although civil society research has studied the issue of changing and weakened civic engagement (Hustinx & Lammertyn, 2003; Macduff, 2005; Robertsson, 2021), there is a lack of studies specifically on POs. This would be welcome due to the inherent weakness of the patient group. If the traditional forms of engagement are too demanding for their current as well as potential members, perhaps it is better to accept that and build a better adjusted structure for POs. As Article III illustrated, it is not necessarily the most demanding forms of participation that have the most positive effect. Perhaps it is okay to be a passive, listening representative on a user panel or committee, instead of organizing campaigns and writing debate articles in media, if that is enough for the members of the organization. Simply being included and the sense of value that it brings to the patient, and trust created towards professionals and policymakers, should not be crowded out by high and complex criteria of representation, and long-term obligations to an organization. Individual factors, such as the desired level of participation, represent an important topic to explore further, in order for us to understand what kind of collective patient participation is possible, and for CSOs such as POs and user cooperatives to learn more about what requirements they can have of their members. In order to learn more about these individual factors, there needs to be more qualitative research that studies the perspective of the members, but also the perspective of all the patients that do not become members in POs or do not participate in other collective ways, something that this dissertation has not done. The suggested reciprocity between collective and individual participation, described above as a self-reinforcing cycle of patient empowerment, is an example of how individual and organizational factors can work together to facilitate collective patient participation. Whether that is actually

the case is beyond the scope of this dissertation and provides an interesting opportunity for future research on the relation between collective and individual patient participation.

There are several examples from all four articles in the dissertation of how different organizational factors play a role in the shaping of collective participation as well. The civil society perspective used in this dissertation has enabled useful insights in how organizational structure, both in service- and voice organizations, has implications for their mission, which in this dissertation is mainly to enable patient participation. The organization of collective coproduction through cooperatives is one organizational factor that is visualized in Article III, where the different roles of the two stakeholders of coproduction, staff and patients, clearly need be taken into account in order to fully understand the conditions for collective coproduction in healthcare. As the literature review above made clear (Section 3.6), there is very little research on collective forms of coproduction in healthcare, even from recent years when coproduction has become a strong focus in the field. Hopefully, Article III can broaden the research field of coproduction in healthcare and serve as a reminder to scholars of healthcare coproduction not to disregard the organizational roots of the coproduction discourse, and the values it may bring to both communities and healthcare organizations.

Further organizational aspects of the shaping of collective patient participation are illustrated by Articles I and II, by the very different preconditions of the local levels compared to the central, professionalized level and how they relate to each other. The local perspective is rarely studied, but it is extremely important to understand the variations of the purposes, nature and conditions of collective patient participation between local and national levels. The local level of POs can react to, and be involved in, decisions taken closer to the patients, with a better knowledge of the situation for their patient group in their local context. In this dissertation, the focus has been on the shaping of representation at these different levels, but there are many other aspects that should be studied from this multilevel perspective. For instance, the advocacy work by the POs may need to be different at the local level compared to the national level, depending on the specific governance model of the healthcare system of each setting. In the Swedish system, POs' advocacy work towards the macro level through the local branches is central

due to the publicly financed yet decentralized healthcare. Yet, for instance in insurance-based systems, the meso level would be more suitable for local organizations, and the macro level more suitable for the national level. I therefore encourage more research on the "fit" of the work of POs to the healthcare system they direct their advocacy towards.

Finally, part of the aim of this dissertation was to understand the shaping of collective patient participation in relation to the increasingly individualized and marketized society. Individualization and the related development of marketization, which constitutes the frame of this dissertation, are both examples of societal factors that shape both norms and priorities among individuals, but also policy, both of which CSOs need to adapt to. The apparent impact that marketization has had on CSOs in general is extensively described in the literature reviewed in Article IV, and a combination of changes in norms and policy due to these societal change processes together shapes the conditions for CSOs. The previously mentioned challenges of engaging individuals in collective patient participation can furthermore be symptomatic of larger societal factors such as an increasing individualization and how this leads to changing norms and priorities at the individual level.

Another factor that seems important for the shaping of collective patient participation is its perceived purpose and outcome. The dissertation has discussed this in relation to different democratic ideals. Previous research has emphasized public involvement as drawing on democratic theory, as opposed to patient involvement (micro level), which draws on experiential knowledge (Dent & Pahor, 2015; Fredriksson & Tritter, 2017). In this literature, the deliberative ideal is mainly discussed. Hester van de Bovenkamp and colleagues have discussed the challenges of participatory democracy in terms of equal participation and representation, through the case of Dutch POs (van de Bovenkamp et al., 2013; van de Bovenkamp and Vollaard, 2019). What seems to be missing still is further analysis of different democratic ideals, in regard to collective patient participation at the macro level. The suggestion made here that different democratic ideals could be at play at different levels of governance would be interesting to follow up in thorough empirical research.

Taken together, an important shaping factor for collective patient participation today seems to be at the individual level. Even though organizational factors in the empirical setting of Swedish POs and Japanese cooperatives are assumed to be facilitating for collective participation to function, it is still individual factors that seem to be essential for how well collective patient participation fulfills both intrinsic goals, such as democratic qualities, and extrinsic goals, such as service quality. Societal factors are nevertheless important to identify, in order to understand the context of why individual members behave the way they do, or why organizations make the decisions they do. All in all, these findings illustrate the complexity of collective patient participation, and the many different aspects that need to be taken into consideration when planning for and encouraging collective patient participation. This dissertation contributes to an increased understanding of the shaping of collective patient participation, a knowledge that can be of use for CSOs such as POs and user cooperatives in their development toward understanding their role. This may help them to increase their impact and to adjust their methods to involve people in a way that is desirable for the individual patients, sustainable for the organization and valuable for the development of a democratic healthcare.

As a general contribution, this dissertation serves to broaden the understanding of patient participation as both an individual and collective activity. As such, the phenomenon of patient participation is enriched by more and diverse contributions and qualities, serving to add value to the individual patient, the citizen, the professional, and healthcare policy and organization. Only when the different values brought by different forms of patient participation are acknowledged and fully understood can we succeed in finding the right type of participation for the right people, in the right situation.

Sammanfattning

Patientens delaktighet i sjukvården har fått allt större betydelse på senare tid. I Sverige sker detta både genom utvecklingen mot en mer personcentrerad vård, men också genom olika politiska reformer såsom vårdval i primär- och specialistvård. Samma utveckling kan ses i många andra länder. Uppmärksamheten kring patientens delaktighet har emellertid främst riktats mot former av delaktighet som riktar sig mot den enskilda individen. Denna avhandling vill i stället bidra med kunskap om de kollektiva formerna av patientdeltagande och de specifika värden ett kollektivt engagemang bidrar med. Det övergripande syftet med avhandlingen är att utforska hur kollektivt patientdeltagande formas, givet den samhälleliga utvecklingen mot ett alltmer individualistiskt och marknadiserat samhälle. Detta görs genom fyra separata studier som alla undersöker olika aspekter av kollektivt engagemang genom civilsamhällesorganisationer. Två studier behandlar den representativa rollen och det intressepolitiska arbetet hos patientföreningar i Sverige. En tredje studie studerar hur individuella och kollektiva former av samskapande förhåller sig till varandra och till servicekvalitet. En fjärde studie tar ett bredare grepp och analyserar den vetenskapliga litteraturen kring civilsamhällets organisationer i förhållande till begreppet marknadisering. Resultaten från de fyra artiklarna pekar på den enskilda patientens förutsättningar att engagera sig kollektivt, som en viktig faktor för utformningen av kollektivt patientdeltagande. För att kunna beakta vad den enskilde patienten vill och kan bidra med i dessa kollektiva engagemangsformer, behövs också ofta syftet med engagemanget klargöras. Resultaten indikerar därutöver att individuella och kollektiva former av deltagande kan stärka varandra, snarare än tränga ut varandra. Detta bör tas i beaktan vid utformandet av olika former för patientdelaktighet, både från civilsamhällets och från sjukvårdens sida. Sammantaget bidrar denna avhandling med en bättre förståelse för olika typer av patientdeltagande, vilka olika värden dessa variationer bidrar med och hur de fyller olika funktioner i arbetet med att förbättra sjukvården.

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Appendices

Appendix 1. Interview Guides for Article I and II.

1a. Interview Guide to Local Respondents.

Tema 1. Beskrivning av organisationen

4. Hur länge har du varit aktiv? Vad fick dig att bli aktiv? (till ordförande: Hur länge har du varit ordförande?)
5. Hur ser styrelsearbetet ut, hur ofta träffas ni? Hur ser arbetsfördelningen ut? Har ni anställda?
6. Hur förhåller sig er förening till länsförbundet och riksförbundet? Ex, prioriterar ni andra frågor?
7. Hur stor rotation är det på styrelsen?
8. Är det viktigt för er att rekrytera nya medlemmar? Är det svårt för er? Varför? Gör ni något särskilt för att locka nya medlemmar?
9. Vilken är er förenings viktigaste roll? (Stödjande, företrädande, utförande) Varför? Exempel!
10. Jämfört med andra delar av landet, hur aktiva är ni intressepolitiskt?

Tema 2. Organisationens påverkansstrategier

11. Hur arbetar ni med påverkansarbete? Vilka metoder använder ni främst?
12. Varför dessa metoder? (Beror det på tradition, viss individuell kompetens i föreningen, särskilda upparbetade kontakter?)
13. Vilka aktörer arbetar ni mot för att främja medlemmarnas intressen? Hur arbetar ni med: - media och sociala medier,- mot politiker och tjänstemän, mot allmänhet?
14. Kontakter in i politiken – vilken typ av kontakter – tjänstemän eller politiker?
15. Vilka metoder tycker ni är mest effektiva?
16. Vilka hinder finns? Vad är aktörernas inställning till er?

17. Hur är möjligheterna för att påverka sjukvården direkt? Har ni kontakter med kliniker? Deras inställning till er? Exempel!
18. Finns det påverkansmetoder som ni skulle vilja jobba med och i så fall, vad hindrar er?
19. Finns det påverkansmetoder som ni helt valt bort, och varför i så fall?
20. Tror du att organisationens arbete och metoder skiljer sig på något sätt från andra större patientföreningar i regionen? I så fall varför?
21. Kan du berätta om en kampanj eller liknande som ni är nöjda med (vilka metoder, vilken effekt, varför är ni nöjda med den?
22. Kan du berätta om en kampanj som inte gått lika bra, och vad du tror är anledningen till att de inte gick lika bra?
23. Vad är viktigast – att vara synlig inför allmänheten eller påverka direkt mot personer med makt att förändra?

Tema 3. Marknadsreformer (endast i regioner med vårdval)

24. Påverkar den politiska majoriteten hur ni väljer att arbeta i föreningen?
25. Vad är er inställning till valfrihet inom vården – särskilt den vård som berör era medlemmar? Är det positivt eller negativt?
26. Har vårdvalet inom X (hudvård, ögonbehandling, fotvård osv) påverkat ert arbete på något sätt? Arbetar ni annorlunda? Har det blivit lättare eller svårare att påverka sjukvården?
27. Deltog ni på något sätt i arbetet inför att införa vårdval? Blev ni tillfrågade att ge input?
28. Har ni någon relation med de privata vårdgivarna inom dessa vårdval? Hur ser den i så fall ut? Hur är möjligheterna att påverka privata vårdgivare? Deras inställning? Exempel!

Tema 4. Förutsättningar för patientorganisationerna, nu och framåt

29. Har inställningen till ert arbete förändrats över tid eller är det konstant? Inställningen från beslutsfattare, allmänheten, patientgruppen.
30. Upplever ni att ni kan möta det som omgivningen efterfrågar av er, i termer av resurser och kompetens? Om ej, hur försöker ni tillgodose detta? Är det viktigt för er?
31. Upplever du en förändring i patientens ställning i hälso- och sjukvården? På vilket sätt? Får det några konsekvenser för ert arbete?

32. Har ert arbete förändrats över tiden? Nya strategier? Nya projekt? Andra som blir oviktiga? Hur ser framtidens strategier ut tror du?

33. Någon annan i styrelsen som skulle kunna lägga till något?

1b. Interview Guide to National Respondents.

Intervjuguide förtroendevalda

Del 1: Strukturen – korporativ eller federativ, relation till lokal/regional, relation till landsting, verksamhet i allmänhet?

Tema 1: Intro

1. Hur länge har du varit aktiv?
2. Hur ser styrelsearbetet ut, hur ofta träffas ni? Hur ser arbetsfördelningen ut?
3. Vad är er huvudsakliga uppgift på nationell nivå?

Tema 2. Relationen nationell/lokal

4. Hur förhåller sig riksförbundet till regionförbunden? Hur förhåller man sig till lokalföreningarna?
5. Hur nära kontakt har ni med regionförbund/lokalföreningar?
6. (om bidrag till regioner/lokalföreningar): hur ser beslutsprocesser ut bakom bidragen? Vilka arbetar med detta? Utifrån vilka riktlinjer?
7. Hur skiljer sig arbetet mellan lokalföreningarna, regionförbunden och riksförbunden åt? Driver regionerna andra typer av frågor än riksförbundet exempelvis? Exempel!? (Har regioner mer vårdnära frågor (därmed mer lämpligt på landstingsnivå) medan riks mer tillgänglighets, rättighetsfrågor (dvs högre politisk nivå)?)
8. Hur skulle du beskriva er motpart i det intressepolitiska arbetet? Vem riktar ni er till? (Politiker? Vårdgivare? Anhöriga? Tjänstemän? Allmänheten?)
9. I vilken utsträckning arbetar ni mot landsting/regioner? SKL? Hur ser den dialogen i så fall ut?

Tema 3. Organisationens intressepolitiska arbete

10. Hur formuleras era ståndpunkter? Var uppkommer idéerna om vilka frågor som ska drivas? Vem bestämmer om hur de ska drivas?
11. Hur formaliserat utformas detta arbete? Kan man följa arbetet i dokumentation (mötesanteckningar etc?) eller spånas det fram i mer informella sammanhang?
12. Exempel på kampanj: Hur såg processen bakom kampanj X ut? Var uppkom idén? Vem? Hur kommer ni fram till vad som ska göras – vilka är delaktiga i dessa processer? Var detta en typisk process vid arbetet med en sådan kampanj?
13. Vilka metoder använder ni främst? Varför? Vilka metoder tycker ni är mest effektiva?
14. Vad är viktigast – att vara synlig inför allmänheten eller påverka direkt mot personer med makt att förändra?

Del 2) Representativitet; formella processer och karaktäristik av representanter

Tema 4: Formella processer för utnämnande av representanter och ansvarsutkrävande av representanter

15. Vem skulle du säga att ni representerar i riksförbundet? Organisationens medlemmar? Patienter med diagnosen? Lokala föreningar?
16. Berätta om hur valen till styrelsen går till! Hur arbetar valberedning? Vad tänker man på när man nominerar personer? Hur många nomineras? Hur stor är konkurrensen om platserna?
17. Får ni feedback från medlemmar på ert arbete? Hur sker det i så fall? Exempel? Finns etablerade kanaler för det?
18. Har det hänt att medlemmar har reagerat negativt på ert arbete på riksförbundet och kommit med kritik? Hur reagerar ni om medlemmar kommer med kritik?
19. Hur försäkrar ni er om att ni och ert arbete på riksnivå representerar era medlemmars intressen?

20. Hur sker tillsättningen av kansliets tjänstemän? Har alla erfarenhet av sjukdomen? Är sådan koppling viktig vid rekrytering?
21. Ser man kanslister som representanter?

Tema 5: Vem är representanten? Vad ligger bakom engagemanget?

22. Vad får dig att engagera dig? Vad är drivet?
23. Vad är vanligaste orsaken bland engagemanget i styrelsen/kansliet?
24. Vad krävs för att vara en god representant för diabetiker/psoriatiker/hjärt-lungsjuka?
25. Hur stor erfarenhet av styrelsearbete har ledamöterna i allmänhet?
26. Vad skiljer dem som engagerar sig i styrelsen från vanliga medlemmar? Vad skiljer de nationellt engagerade från de på lokal nivå?
27. Varför tror du att du är en god representant för medlemmarna?

Intervjuguide tjänstemän

Del 1: Strukturen – korporativ eller federativ, relation till lokal/regional, relation till landsting, verksamhet i allmänhet?

Tema 1: Intro

1. Hur ser din bakgrund ut? Hur länge har du varit anställd i förbundet? Är du medlem också? Yrkesbakgrund?
2. Vad ser du är förbundets huvudsakliga uppgift på nationell nivå?
3. Hur ser kansliets relation till förbundsstyrelsen ut? Hur ser arbetsfördelningen ut? Vilken självständighet har ni i kansliet?

Tema 2. Relationen nationell/lokal

4. Hur ser den vardagliga ansvarsfördelningen ut mellan riksförbundet och länsförbund/lokalföreningar? Hur nära kontakt har ni med länsförbund/lokalföreningar?
5. Hur skiljer sig arbetet mellan lokalföreningarna, regionförbunden och riksförbunden åt? Driver regionerna andra typer av frågor än riksförbundet exempelvis? Exempel!? (Har regioner mer vårdnära frågor (därmed mer

lämpligt på landstingsnivå) medan riks mer tillgänglighets, rättighetsfrågor (dvs högre politisk nivå)?)

6. (om bidrag till regioner/lokalföreningar): Hur ser beslutsprocesser ut bakom bidragen? Vilka arbetar med detta? Utifrån vilka riktlinjer?

Tema 3. Organisationens intressepolitiska arbete

7. Hur formuleras era intressepolitiska ståndpunkter? Var uppkommer idéerna om vilka frågor som ska drivas? Vem bestämmer om hur de ska drivas?

8. Hur formaliserat utformas detta arbete? Kan man följa arbetet i dokumentation (mötesanteckningar etc?) eller spånas det fram i mer informella sammanhang?

9. Exempel på kampanj: Hur såg processen bakom kampanj X ut? Var uppkom idén? Vem? Hur kommer ni fram till vad som ska göras – vilka är delaktiga i dessa processer? Var detta en typisk process vid arbetet med en sådan kampanj?

10. Hur skulle du beskriva er motpart i det intressepolitiska arbetet? Vem riktar ni er till? (politiker? Vårdgivare? Anhöriga? Tjänstemän? Allmänheten?)

11. I vilken utsträckning arbetar ni mot landsting/regioner? SKL? Hur ser den dialogen i så fall ut?

12. Vilka metoder använder ni främst för att driva opinion? Varför? Vilka metoder tycker ni är mest effektiva?

13. Vad är viktigast – att vara synlig inför allmänheten eller påverka direkt mot personer med makt att förändra?

Del 2) Representativitet; formella processer och karaktäristik av representanter

Tema 4: Formella processer för utnämnande av representanter och ansvarsutkrävande av representanter

14. Vem skulle du säga att ni representerar i riksförbundet? Organisationens medlemmar? Patienter med diagnosen? Lokala föreningar?

15. Har du någon uppfattning om hur stor del av personer med sjukdomen/sjukdomarna som är medlem i er organisation?

16. Många patientföreningar lider av medlemstapp – även ni. Hur påverkar det ert arbete på förbundet?

17. Vilka sitter i valberedningen och vad krävs för att bli invald där? Hur arbetar valberedning? Vad tänker man på när man nominerar personer? Hur många nomineras? Hur stor är konkurrensen om platserna?

18. Får ni feedback från medlemmar på ert arbete? Hur sker det i så fall? Exempel? Finns etablerade kanaler för det?

19. Har det hänt att medlemmar har reagerat negativt på ert arbete på riksförbundet och kommit med kritik? Hur reagerar ni om medlemmar kommer med kritik?

20. Hur försäkrar ni er om att ni och ert arbete på riksnivå representerar era medlemmars intressen? Hur självständigt kan styrelsen arbeta?

21. Hur sker tillsättningen av kansliets tjänstemän? Har alla erfarenhet av sjukdomen? Är sådan koppling viktig vid rekrytering?

22. Ser man kanslister som representanter?/ Upplever du som kanslist att du får en röst i utformandet av ert arbete?

Tema 5: Vem är representanten? Vad ligger bakom engagemanget?

23. Vad fick dig att söka dig till förbundet? Vad är drivet?

24. Har du någon uppfattning om vad som brukar ligga bakom varför man söker sig till kansliet?

25. Skulle du säga att medlemmar som engagerar sig på förbundsnivå skiljer sig på något sätt från andra medlemmar? Hur? Vad skiljer de nationellt engagerade från de på lokal nivå?

26. Hur stor erfarenhet av styrelsearbete har ledamöterna i allmänhet?

27. Vad tycker du krävs för att vara en god representant för diabetiker/psoriatiker/hjärt-lungsjuka?

Appendix 2. Survey Questions used in Article III.

In this appendix the questions that are included in the four indices (individual, community and organizational coproduction indices and index for service quality) from the patient and staff questionnaires are presented. The survey questions are developed within a research project led by Professors Yayoi Saito and Victor Pestoff. Sub questions or response options that are not included in the indices are in italics.

2a. Included Survey Questions for Patients.

Individual coproduction index

Q8. How can you express your opinions/ideas about the service provided here? Please circle all applicable.

1. *Using the suggestion (rainbow) box*
2. Talking to professional staff (doctors, nurses, etc.)
3. *Talking to administrative staff*
4. *Talking with board members*
5. *Attending local cooperative member meetings*
6. *Voicing opinions in committee meetings*
7. *Participating actively in the hospital/facility's activities*
8. *No way to communicate opinions*
9. *Never tried to communicate opinions*
10. *Other   (Please specify:)*

Q12. Do you agree with the following statements about medical and elderly care services here? Please circle one for each.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree - Disagree

1. The staff takes time to answer your questions and talk with you about your conditions situation

2. The staff discusses your conditions and treatment/care plan in a clear and understandable way
3. *The staff is very busy and they don't have much time for patients and can't talk with them.*
4. The staff is courteous and friendly and take their time with you.
5. You meet the same person day after day or time after time and get to know them.
6. Information about medical treatment and elderly care are shared with patients/users
7. Efforts are made to improve patients'/users' understanding about their medical/elderly care
8. Explanations are made clearly to facilitate understanding among patients/users and their consent is sought
9. Efforts are made to establish support systems for patients/users and to improving communication

Community coproduction index

Q4. Please circle up to 3 alternatives which best describes this hospital/facility

1. *Creates jobs in the local area*
2. Promotes patient and user participation in health promotion
3. Engages in preventive health /elderly care
4. *Provides health care and elderly care in areas in short supply of these services*
5. *Provides training and job opportunities for women in the local area*
6. *Provides high skilled jobs (doctors, nurses etc.) in the local area*
7. *Prevents depopulation of the local community*
8. Promotes community-based integrated care
9. *Promotes local development*
10. *Provides health and elderly care to uninsured patients (Eg. Free/low cost medical service)*
11. *Don't know*

Q7. Do you participate in the activities provided here? Please circle one alternative for each.

Often – Sometimes – Rarely – Never - Not applicable (activity does not exit)

1. Hospital events (e.g. health festival)
2. Community activities (e.g. Han group, flea market)
3. *Local membership meetings for cooperative members*
4. Activities and study groups for health
5. *Volunteer activities (e.g. helping out at festivals, distributing newsletters, etc)*
6. *Make investments and donations*
7. *Other (Please specify   )*

Q14. Do you agree with the following statements about medical and elderly care services at this facility? Please circle one for each.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree
Disagree

1. Provides information about medical/elderly care services to the community
2. Understands medical/elderly service functions of the community
3. Actively participates in community activities
4. Contributes to health promotion of the community

Organizational coproduction index

Q3. Why did you choose this hospital/facility? Please circle all applicable.

1. *Easy to access*
2. *Lowest costs*
3. *Has special medical services*
4. Wanted to participate more actively in the management of the hospital/facility
5. *Recommended by my local co-op / JA*
6. *Member of the co-op / JA*
7. *Recommended by acquaintance, friend or family*
8. *Staff are competent*
9. *Staff are kind and helpful*

10. *Only one available*
11. *Other reasons (please specify:)*

Q7. Do you participate in the activities provided here? Please circle one alternative for each.

Often – Sometimes – Rarely – Never - Not applicable (activity does not exit)

1. *Hospital events (e.g. health festival)*
2. *Community activities (e.g. Han group, flea market)*
3. Local membership meetings for cooperative members
4. *Activities and study groups for health*
5. Volunteer activities (e.g. helping out at festivals, distributing newsletters, etc.)
6. **Make investments and donations**
7. *Other   (Please specify   )*

Q8. How can you express your opinions/ideas about the service provided here? Please circle all applicable.

1. Using the suggestion (rainbow) box
2. *Talking to professional staff (doctors, nurses, etc.)*
3. Talking to administrative staff
4. Talking with board members
5. Attending local cooperative member meetings
6. Voicing opinions in committee meetings
7. Participating actively in the hospital/facility's activities
8. *No way to communicate opinions*
9. *Never tried to communicate opinions*
10. *Other   (Please specify:)*

Index of service quality

Q11.Are you satisfied with the following in this hospital/facility? Please choose

one of the alternative.
Satisfied - Somewhat satisfied - Neither satisfied nor unsatisfied - Somewhat
unsatisfied - Unsatisfied

1. Professional staff (doctors, nurses)
2. Administrative staff （reception, accounting, information etc.)
3. Management
4. Accessibility
5. Healthcare

Q13.Do you agree with the following statements about medical and elderly care
services at this facility? Please circle one for each.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree -
Disagree

1. Higher standard compared to other providers
2. *High quality equipment and facilities are in place*
3. *Technical skills of staff are high*

Q15.Would you recommend this hospital/facility/service to your friends and
acquaintances? Please circle one alternative.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree
Disagree

2b. Included Survey Questions for Staff.

Individual coproduction index

Q21.Do you think your workplace makes active effort to engage in dialogue with the following people? Please circle one for each.

Active - Rather active - Somewhat inactive – Inactive - Don't know

1. Patients/users
2. *Volunteers*
3. *JA/Health Coop members*
4. *Other healthcare and care service providers*
5. *Local community members　(neighborhood association, local commercial businesses, social welfare council)*
6. *Local government officials*
7. *Other　(Please specify:　　　　　　　　)*

Q24.Do you agree with the following statements about your workplace? Please circle one for each.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree
Disagree

1. Patients'/users' rights are clearly stated and protected
2. *Patients'/users' personal information is protected*
3. *Patients'/users' dignity and privacy are protected*

Q25.Do you agree with the following statements about medical and elderly care services at your workplace? Please circle one for each.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree
Disagree

1. Information about medical treatment and elderly care are shared with patients/users
2. Efforts are made to improve patients'/users' understanding about their medical/elderly care
3. Explanations are made clearly to facilitate understanding among patients/users and their consent is sought

4. Efforts are made for establishing support systems for patients/users and for improving communication

Community coproduction index

Q21.Do you think your workplace makes active effort to engage in dialogue with the following people? Please circle one for each.

Active - Rather active - Somewhat inactive – Inactive - Don't know

1. *Patients/users*
2. *Volunteers*
3. *JA/Health Coop members*
4. *Other healthcare and care service providers*
5. Local community members （neighborhood association, local commercial businesses, social welfare council）
6. *Local government officials*
7. *Other （Please specify: ）*

Q31.Please circle up to 3 of the below which best describes your workplace

1. *Creates jobs in the local area*
2. *Promotes patient and user participation in health promotion*
3. Engages in preventive health /elderly care
4. *Provides health care and elderly care in areas in short supply of these services*
5. *Provides training and job opportunities for women in the local area*
6. *Provides high skilled jobs (doctors, nurses etc.) in the local area*
7. *Prevents depopulation of the local community*
8. Promotes community-based integrated care
9. *Promotes local development*
10. *Provides health and elderly care to uninsured patients (Eg. Free/low cost medical service*
11. *Don't know*

Q36. Do you participate in the activities provided by your workplace? Please circle one for each.

Often – Sometimes – Rarely – Never - Not applicable (activity does not exist)

1. Hospital events (e.g. health festival)
2. Community activities (e.g. Han group, flea market)

3. *Local membership meetings for cooperative members*
4. Activities and study groups for health
5. *Volunteer activities (e.g. helping out at festivals, distributing newsletters, etc.)*
6. *Make investments and donations*
7. *Other* （*Please specify* 　　　　　）

Q8. Were each of the following aspects of this workplace when you first chose this job? Please circle one for each.

Important - Somewhat important - Neither important nor unimportant - Not very important - Not important - Doesn't apply

1. *Cooperative form*
2. Commitment to community activities
3. *Provides stable work*

Q9. How important are each of the following aspects of your workplace for you currently? Please circle one for each.

Important - Somewhat important - Neither important nor unimportant - Not very important - Not important - Doesn't apply

1. *Cooperative form*
2. Commitment to community activities
3. *Provides stable work*
4. *Easy to commute*
5. *Working hours fit your lifestyle*
6. *Friends and acquaintances work here*
7. *Friends and acquaintances work here*
8. *High salary*

Organizational coproduction

Q21.Do you think your workplace makes active effort to engage in dialogue with the following people? Please circle one for each.

Active - Rather active - Somewhat inactive – Inactive - Don't know

1. *Patients/users*
2. *Volunteers*

3. JA/Health Coop members
4. *Other healthcare and care service providers*
5. *Local community members（neighborhood association, local commercial businesses, social welfare council）*
6. *Local government officials*
7. *Other（Please specify: ）*

Q36. Do you participate in the activities provided by your workplace? Please circle one for each.

Often – Sometimes – Rarely – Never - Not applicable (activity does not exit）

1. *Hospital events (e.g. health festival)*
2. *Community activities (e.g. Han group, flea market)*
3. Local membership meetings for cooperative member
4. *Activities and study groups for health*
5. Volunteer activities (e.g. helping out at festivals, distributing newsletters, etc.)
6. Make investments and donations
7. *Other（Please specify   ）*

Q8. Were each of the following aspects of this workplace when you first chose this job? Please circle one for each.

Important - Somewhat important - Neither important nor unimportant - Not very important - Not important - Doesn't apply

1. Cooperative form
2. *Commitment to community activities*
3. *Provides stable work*

Q9. How important are each of the following aspects of your workplace for you currently? Please circle one for each.

Important - Somewhat important - Neither important nor unimportant - Not very important - Not important - Doesn't apply

1. Cooperative form
2. *Commitment to community activities*
3. *Provides stable work*
4. *Easy to commute*
5. *Working hours fit your lifestyle*
6. *Friends and acquaintances work here*
7. *Friends and acquaintances work here*
8. *High salary*

Index of Service quality

Q23.How would you rate the overall quality of health and elderly care services of your workplace? Please circle one of the below.

Good - Rather good - Neither good nor bad - Rather bad - Bad

Q15.Do you agree with the following statements about your workplace? Please circle one for each.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree - Disagree

1. Sufficient structures and opportunities are in place for expressing your opinions
2. Your suggestions and opinions are reflected
3. It's easy to express your opinions

Q27. Would you recommend this hospital/facility/service to your friends and acquaintances? Please circle one of the below.

Agree - Somewhat agree - Neither agree nor disagree - Somewhat disagree – Disagre

Thesis from
Ersta Sköndal Bräcke University College

Nr 1. Anna Holmqvist (2019). Integritet på undantag? En studie av barns röst i patientlagen och patientorganisationer.

Nr 2. Megan Weber Falk (2020). Development and Evaluation of the Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden.

Nr. 3. Lilian Pohlkamp (2020) Bereaved mothers and fathers. Grief and psychological health 1 to 5 years after losing a child to cancer.

Nr 4. Bodil Holmberg (2020) Assisterad kroppslig omvårdnad i livets slut på vård- och omsorgsboende. När kroppen inte räcker till.

Nr 5. Rakel Eklund (2020). Barns erfarenheter av "The Family Talk Intervention". Att leva med en svårt sjuk förälder som vårdas inom specialiserad palliativ hemsjukvård.

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Collective Patient Participation:
Patient Voice and Civil Society Organizations in Healthcare

The importance of engaging patients in the development of healthcare has received increasing attention over the last decades. However, this attention has mainly been directed towards various forms of involvement of individual patients. While involving individual patients in healthcare has great benefits, there are distinct values of collective forms of patient participation as well. This dissertation shifts focus to the collective forms of patient participation. Through four independent studies, with different methodological and theoretical approaches, the dissertation increases our knowledge of how collective forms of patient participation are shaped in an increasingly individualized and marketized society. Furthermore, the dissertation contributes to a better understanding of the diversity of patient participation in general, the distinct values and purposes of individual and collective participation and how they all play important yet different roles in improving democratic and quality aspects of healthcare.

Anna Mankell received her Master's Degree in Political Science in 2012. Since then, she has worked as a research assistant within the field of Health Services Research at Uppsala University and, since 2016, a PhD candidate at Ersta Sköndal Bräcke University College. Her main research interest has been the relationship between civil society and welfare services such as health- and social care.

Ersta Sköndal Bräcke University College has third-cycle courses and a PhD programme within the field The Individual in the Welfare Society, with currently two third-cycle subject areas, Palliative care and Social welfare and the civil society. The area frames a field of knowledge in which both the individual in palliative care and social welfare as well as societal interests and conditions are accommodated.

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MÄNNISKAN I VÄLFÄRDSSAMHÄLLET