

# User participation through interest organisations

A qualitative study of representation, strategies and  
impact for people in vulnerable life situations

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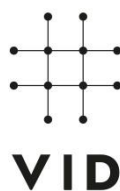
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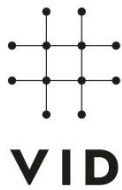
**Jan Marius Kristiansen Gathen**

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VID Specialized University

[post@vid.no](mailto:post@vid.no)

[www.vid.no](http://www.vid.no)

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Jan Marius Gathen, April 2023

## List of papers

### *Paper 1*

Gathen, J. M., Slettebø, T., & Skjeggstad, E. (2023). The participation of people in vulnerable situations in interest organisations: A qualitative study of representatives views. *Journal of Social Policy*, 1–18. <https://doi.org/10.1017/S0047279423000089>

### *Paper 2*

Gathen, J. M., Slettebø, T., & Skjeggstad, E. (Submitted manuscript). Three strategies of user participation. Interest organisation representatives' views on how they make an impact on service development.

### *Paper 3*

Gathen, J. M., Slettebø, T., & Skjeggstad, E. (2022). User participation among people in vulnerable situations at service level. A scoping review exploring impact for individual stakeholders and services. *Nordisk Velfärdsforskning* [Nordic Welfare Research] 7(1), 52–67. <https://doi.org/10.18261/nwr.7.1.4>



## Summary

This thesis explores collective user participation by focusing on interest organisations representing people in vulnerable life situations. In this thesis, collective user participation—or simply user participation—refers to activities where service users aim to affect the development of services provided by the welfare state. Service users' participation in developing better welfare services is a goal for service users, professionals and politicians and is anchored in legislation and national and supranational documents. However, user participation can be particularly challenging for people in vulnerable life situations, who may depend on support to participate or be represented by others. Hence, interest organisations are vital in promoting these groups' interests. With both collective user participation and interest organisations related to these groups having received little attention in research, the thesis provide new knowledge on these topics by focusing on representation, strategies and impact. The overarching research question in the thesis is as follows: *How do representatives in interest organisations perceive user participation?*

Paper 1 address the research following questions: *How do people in vulnerable life situations participate in interest organisations? What are the dilemmas related to the representation of people in vulnerable life situations?* The paper is based on interviews with 14 representatives of interest organisations. These people represented people with dementia, intellectual disabilities, substance use problems, asylum seekers, children in contact with the child protection service and children of parents with substance use problems. The thematic analysis resulted in the development of two main themes. The first, namely *participation as representatives of the organisations*, revealed that a spokesperson's role often depends on competence and that the users of public services rarely obtain such a position. However, people with experience in using public services participate as living examples in external activities, increasing the groups' visibility through their physical presence and their stories. The second theme was titled *participation in organisational activities*. The extent to which people with lived experiences participate in formal meetings varies, but they are often consulted by the organisations and attend events and informal gatherings. Notably, people in vulnerable situations interact with and, thus, influence the service-providing organisations.



Paper 2 addresses the following research question: *How are interest organisations for people in vulnerable life situations influencing public actors, and what are the perceived impacts?* The second paper is based on analysis from the same interviews as the first paper. In the analysis, three themes were developed related to how the informants described their organisations' dealings with services, municipalities, politicians and other public actors. *The cooperative strategy* refers to participation as an arena for collaboration and partnership in which they assumingly would share interests and goals. *The oppositional strategy* shows how the participants would use open conflict and confrontation as a tool for influence, often through the media and complaint systems. The third strategy—*negotiation*—illustrates how organisations would manoeuvre between being critical and constructive while maintaining a relationship with public actors.

Paper 3 addresses the following research question: *What types of impact are associated with collective user participation for people in vulnerable life situations in the research literature?* The paper is a scoping review of the research literature. The finding shows that, at the individual level, user participation could facilitate personal empowerment among the involved users and affect the involved professionals' knowledge. However, some users also experienced disempowerment because of their involvement in user participation activities. Impacts at the organisational level were that user participation resulted in changes in attitudes, knowledge, culture, professional practice, interventions, an increased number of employees, organisational development and changes in policies.

This thesis discusses how the participation of people in vulnerable life situations can be understood as direct, assisted, indirect and via others. It also addresses the terminology related to organisations representing people in vulnerable life situations. Here, I argue for describing them as interest organisations rather than service user organisations. Further, the thesis discusses how organisations manoeuvre in a landscape of power and tokenism. Finally, I discuss the challenges and opportunities to make and identify impacts associated with participation. The novel contribution of this thesis is that it provides new knowledge about user participation through interest organisations by focusing on representation, strategies and impacts concerning user participation for people in vulnerable life situations.

## Sammendrag

Denne avhandlingen utforsker kollektiv medvirkning gjennom interesseorganisasjoner. Med kollektiv medvirkning siktes det til aktiviteter gjennomført med hensikt om å forbedre velferdstjenester for alle brukere. I dag ansees medvirkning som en demokratisk rett og som sentralt for kvalitetsutviklingen av velferdstjenestene. Det å medvirke kan være vanskelig for mennesker i sårbare livssituasjoner, men interesseorganisasjoner kan her være viktige for å fremme disse gruppenes interesser. Kollektiv medvirkning og interesseorganisasjoner for personer i sårbare livssituasjoner har derimot fått lite oppmerksomhet i forskningslitteraturen. Med denne avhandlingen ønsker jeg å bidra med kunnskap som kan øke vår forståelse for det arbeidet som interesseorganisasjonene bidrar med i utviklingen av forbedrede velferdstjenester. Det overordnede forskningsspørsmålet i avhandlingen er: *Hvordan oppfatter representanter i interesseorganisasjoner medvirkning?*

Den første artikkelen i avhandlingen adresserer forskningsspørsmålene: *Hvordan deltar mennesker i sårbare livssituasjoner i interesseorganisasjoner? Hva er dilemmaene knyttet til representasjonen av mennesker i sårbare livssituasjoner?* Artikkelen er basert på intervjuer med 14 representanter for interesseorganisasjoner. Deltakerne representerte personer med demens, utviklingshemming, rusproblemer, asylsøkere, barn i kontakt med barnevernet og barn av foreldre med rusproblemer. Den tematiske analysen resulterte i utviklingen av to hovedtemaer. Den første, *deltakelse som representanter for organisasjonene*, viser at rollen som talsperson ofte er avhengig av kompetanse og at personer med brukererfaring sjelden har en slik rolle. Personer med brukererfaring deltar likevel ofte som levende eksempler i ekstern representasjon, og øker med det gruppens synlighet gjennom fysiske tilstedeværelse og personlige historier. Det andre hovedtemaet, *deltakelse i organisasjonens aktiviteter*, viser at det varierer i hvilken grad personer med brukererfaring deltar i de formelle møtene i organisasjonene. De blir likevel ofte konsultert av organisasjonene og representantene, og de deltar langt oftere på de uformelle arrangementene og samlingene. Noen interesseorganisasjoner tilbyr også tjenester til brukergruppen, og personer med brukererfaring kan også påvirke organisasjonene gjennom disse.

Den andre artikkelen i avhandlingen adresserer forskningsspørsmålet: *Hvordan påvirker interesseorganisasjoner for mennesker i sårbare livssituasjoner offentlige aktører, og hvilke*

*resultater fører det til?* Denne artikkelen bygger på de samme intervjuene som den første artikkelen. I analysen ble det utviklet tre temaer. Det første temaet, *samarbeidsstrategien*, beskriver medvirkning som en arena for samarbeid og partnerskap, der deltakerne antar at de deler interesser og mål med de offentlige aktørene. Det andre temaet, *den opposisjonelle strategien*, beskriver hvordan åpen konflikt og konfrontasjon blir anvendt som et verktøy for å påvirke, ofte gjennom media og ulike klagesystemer. Det tredje temaet, *forhandlingsstrategien*, illustrerer hvordan organisasjonene manøvrerer mellom å være kritiske og konstruktive, samtidig som de forsøker å opprettholde et godt forhold til de offentlige aktørene. Deltakerne beskriver også at det kan være vanskelig å se resultater av medvirkning, og at synlige resultater oftest ses i konkrete saker på tjenestenivå.

Den tredje artikkelen adresserer forskningsspørsmålet: *Hva beskrives i forskningslitteraturen som betydningen av kollektiv medvirkning for personer i sårbare livssituasjoner?* Artikkelen er en litteraturstudie designet som en scoping review. Funnene indikerer at medvirkning kan føre til for personlig empowerment blant de involverte brukerne, samt påvirke de involverte fagpersonenes kunnskap og holdninger. Imidlertid kan noen brukere også oppleve disempowerment på grunn av deltakelsen. På tjenestenivå indikerer funnene at medvirkning kan bidra til å endre holdninger, kunnskap, kultur og yrkesutøvelse blant fagpersoner, bidra til endringer i tjenestens organisering og prioriteringer, samt endringer i overordnede retningslinjer.

I denne kappen starter jeg med å diskutere hvordan medvirkning av mennesker i sårbare livssituasjoner kan forstås som direkte, assistert, indirekte og via andre. Kappen tar også for seg begreper forbundet med organisasjoner som representerer mennesker i sårbare livssituasjoner. Her argumenterer jeg for å benytte begrepet interesseorganisasjoner fremfor brukerorganisasjoner. Videre diskuterer jeg hvordan interesseorganisasjoner manøvrerer i et landskap av makt og avmakt. Avslutningsvis diskuterer jeg betydningen av kollektiv medvirkning og hvordan dette kan identifiseres. Denne avhandlingen bidrar til å øke vår forståelse om medvirkning gjennom interesseorganisasjoner for mennesker i sårbare livssituasjoner, med særlig fokus på deres representasjon, deres strategier og betydningen av interesseorganisasjonenes arbeid.

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## Terminology

*People in vulnerable life situations* – Groups of people who have less autonomy and depend more on the welfare system than the average service user because of a combination of their social circumstances and personal resources.

*Individual user participation* – Service users influencing their own service reception.

*Collective user participation* - User participation at collective levels, including service, system and politics, here aiming to improve services for more than individual service users. In this thesis, I alternate between this term and simply writing user participation or participation.

*Interest organisation* – An organisation representing the interests of a service user group. Other similar terms that are often used in the literature include service user organisation and patient organisation.

*People with service user experience* – refers to people who have personal experience using public services. Other similar terms used in the literature are expert by experience and experiential knowledge.



## Preface

The topic of this thesis—user participation—is a charged concept and is a topic of ongoing debate in the public sphere, the welfare state and its services and research. To better understand this thesis, this preface describes my educational and professional background, my motivation for studying user participation and the frame of the PhD project.

In 2010, I moved to Oslo and started the bachelor's programme in occupational therapy. During my initial studies, I developed a particular interest in mental health and started working at a hospital ward for people with severe mental illness. Here, I met people in great need of help who also had many personal resources. Unfortunately, I also saw that they had difficulties handling their life, and I was involved in several episodes where staff needed to use force toward patients. During one of these episodes, I was the one that was able to get in contact and calm down one of the patients, leaving me as an extra in charge of the situation. The patient's outburst was because he disagreed with some of his team's decisions regarding his treatment and restrictions. When I talked with the patient, I reflected on how his team could have done things differently and whether increased collaboration with the patient could have stopped the outburst. From this point, I became particularly interested in user participation because I believe that increased focus on this could have led to a different outcome in the mentioned case.

After graduating, I started working at an activity day centre for people with mental health problems. Here, the service users always asked about improving the food serving. We, the staff, partly met these requests, but we also considered it a less critical issue in improving the service. The service users especially expressed their wish for an expanded lunch during the weekly service user meetings, which was my first meeting with what can be labelled collective user participation.

When I wrote my master's thesis in health promotion and empowerment, I focused on user participation at a similar activity day centre. After interviewing seven service users, I realised that the lunch contributed to much more than just filling the stomach. The primary motivation for most was meeting other people, being part of a group and having a structure in their



everyday life besides eating healthy food. I felt embarrassed that we had not focused more on the lunch, but we believed involving the service users in preparing the lunch was more important than what was happening during the meal. Realising this, I saw how collective user participation might improve services in other ways than professionals think. Therefore, when I found a position as a PhD fellow related to user participation among people in vulnerable life situations, I became excited and saw this project as an opportunity to develop knowledge to improve welfare services. Moreover, my excitement increased when I read that the PhD position included participation in a large research project founded by the Research Council of Norway.

Since the fall of 2018, I have been fortunate to be part of the Challenges of Participation (CHAPAR) research project focusing on user participation for people in vulnerable life situations. CHAPAR—and thus my PhD project—have been founded by the Norwegian Research Council (grant number 273527) through the HELSEVEL work programme (Norges Forskningsråd, 2017). The HELSEVEL work programme highlights people with dementia, intellectual disabilities, substance use problems, children in contact with child protection services and asylum seekers as some groups that will be an increased priority for welfare services in the upcoming years. Thus, the programme favours research that focuses on these groups. The aim of the CHAPAR was to develop knowledge and models of user participation for these groups. The project includes five case studies focusing on service user groups like those mentioned above. Through involvement in the CHAPAR project, I have been interacting with researchers focusing on the same topic. By participating in the project, I have presented and discussed my project with researchers with expert knowledge of the different service user groups. These discussions and feedback have been of great value to the project because it has helped identify knowledge gaps, develop the project and validate the findings. I am grateful for the opportunity to participate in the CHAPAR project, which has been inspirational and valuable in writing this thesis.

## 1.0 Introduction

The current thesis explores collective user participation by focusing on interest organisations for people with dementia, intellectual disabilities, substance use problems, those in contact with child protection services and asylum seekers. In the present thesis, collective user participation, or simply user participation, refers to activities where service users aim to affect the development of services provided by the welfare state. Collective user participation relates to the democratisation and improvement of welfare services (Vedung & Dahlberg, 2013), aiming to affect services for all service users, whether it is individuals or groups participating (Elster, 1985; Seim & Slettebø, 2007). In contrast, individual user participation refers to service users' participation in their own service reception.

The concept of user participation emerged from the service user movements in the 1960s related to democratisation and participation in service development. Today, these movements have been transformed into more formalised organisations and are increasingly involved in formal channels of user participation. Interest organisations are crucial for promoting the voices of service users (NOU 2018:16; United Nations, 2006). How interest organisations promote the voices of the service users and the impact of their work are issues of particular importance related to people in vulnerable life situations because these often need help to promote their interests. However, there is little research on organisations representing people in vulnerable life situations.

The current thesis expands the knowledge base of these organisations and their work through interviews with representatives of interest organisations and a scoping review of the literature. In the following chapters, I briefly introduce what I understand with user participation and the term people in vulnerable life situations before presenting the thesis aim and research question(s).

## 1.1 An introduction to user participation

In modern democracies, the foundation of user participation is rooted in laws and official documents in each country. The documents from supranational organs, such as United Nations and World Health Organisation, are also vital in laying the foundation for user participation. Among these, both the Human Rights (United Nations, 1948) and Convention of the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) state that people have the right to participate in social and public life. The latter emphasises the rights of people with disabilities to participate in the political sphere and influence decisions that affect them directly or by freely chosen representatives. Regarding health services, the Alma Ata Deceleration (World Health Organization, 1978) has great importance, stating in article IV that ‘people have a right and duty to participate individually and collectively in the planning of their health care’.

User participation is essential in many countries because it is believed to democratise and improve the welfare state. According to Vedung and Dahlberg (2013), user participation can contribute to adjusting services to the service users’ needs, redistributing power to service users, contributing to the services’ efficiency and legitimacy and promoting citizenship. On the other hand, scholars have also been critical of user participation. Criticism of user participation includes that service users often do not know their own best interests, that they can make choices that harm others, that user participation requires resources, that it can lead to the professional helpers withdrawing and leaving too much responsibility to service users and that it may hide the power differences between service users and services (Banks, 2006; Mik-Meyer & Villadsen, 2007; Slettebø, 2009).

Norway is a social democracy characterised by an egalitarian society and provides generous welfare services for all citizens compared with many other welfare regimes (Kautto, 2010). User participation is an essential value in Norway, which has been underscored in a range of white papers and laws (Forvaltningsloven, 1967; Kommuneloven, 2018; Meld. St. 7 (2019–2020); Meld. St. 10 (2012–2013), 2012; Meld. St. 34 (2015–2016); Meld. St. 38 (2020–2021); Pasient- og brukerrettighetsloven, 1999); this influences professional practice, professional practice education, service development, politics and research. Accordingly, a range of procedures and models have been developed in services, institutions and political bodies to meet the demand for user participation (Bjørger, 2013). These channels are often councils and

committees, where people with personal experience using public services or representatives of organisations representing service users are recruited or elected to participate.

In official documents, organisations representing service users have been underscored as crucial regarding user participation (NOU 2018:16, 2018). Because Norway has an extensive civil society sector, some service users are represented by several organisations, for example, in the substance use field. Organisations representing service users often consist of people with both current and previous service user experiences, next of kin, idealists, professionals and a combination of these. This variety is also reflected in the definition of a service user representative in White Paper 34 (1996–1997), which states that a representative can be a person with personal experience, a next of kin or an employee or spokesperson in an organisation representing service users. Besides heterogeneity among representatives and members, these organisations also have great differences regarding structure, activities and goals (Markström & Karlsson, 2013). Because the Norwegian welfare state provides comprehensive services, user participation is one of the main concerns for interest organisations, and many of them have become prominent actors in service development and the political arena.

The organisations representing service users have often been labelled service user organisations in Norway and in the international research literature. However, because these organisations often consist of people with different backgrounds, the term may be imprecise or misleading. These issues are particularly present regarding people in vulnerable life situations. Therefore, I use the term interest organisation in the present thesis, which I will return to in the discussion.

## 1.2 People in vulnerable life situations

What to call people using public services is part of ongoing debates (McLaughlin, 2009, 2020). In the current thesis, I use the term people in vulnerable life situations (shortened to people in vulnerable situations in the papers). Other frequently used terms are vulnerable groups, vulnerable populations, populations at risk and marginalised groups (Kuran et al., 2020). Terminology could be particularly challenging when dealing with groups of people who usually have less influential societal positions than the average person because it can lead to increased stigmatisation and marginalisation. However, it can also provide these groups with rights and resources, and it may draw society's attention and make the group's struggles visible. The United Nations (2006) Convention of People with Disabilities states the following in article 1:

*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

I would argue that such a definition—or to point to some groups as more vulnerable than others—is not necessarily oppressing. Instead, I would argue that using the term people in vulnerable situations highlights that something can change and to society's obligation to fulfil these people's human rights.

By using the term people in vulnerable life situations, I underscore that a combination of personal and social circumstances creates the particular challenges. This implies a view of vulnerability as a general human condition that changes during one's life and is affected by both individual and societal factors. Thus, both individual factors and social categories affect people's life chances and living conditions. The latter includes factors such as gender, class, ethnicity, family situation, disability, health and citizenship. Being part of multiple social categories can lead to more severe marginalisation than the sum of the single factors imply. Therefore, the term people in vulnerable situations underscores that it is a combination of individual factors and social structures that influence people's degree of vulnerability (Fjetland et al., 2022). This approach to vulnerability makes it open to whom people in vulnerable situations are. However, Peroni and Timmer (2013) underline that some people experience more vulnerability than others, arguing that legal documents describe people in vulnerable situations as people who experience particular inequality, discrimination and a lack of fundamental human rights.

In a Nordic context, authors have described people with dementia, intellectual disabilities, mental health problems and substance use problems as being in particularly vulnerable situations (Fjetland et al., 2022; Frank et al., 2012). Moreover, migrants, children, the elderly and the poor are often described as vulnerable (Kuran et al., 2020). These groups also resembles the groups mentioned in the HELSEVEL programme plan (Norges Forskningsråd, 2017). In the present study, I have chosen to focus on people with dementia, intellectual disabilities, substance use problems, mental health problems, asylum seekers, people in contact with the child protection service and children with parents with substance use problems. Despite these groups' apparent differences, they all seem to experience challenges that arise from more than one factor of marginalisation. Some factors include, but are not limited to, health problems, addictions, intellectual capacity and a lack of language skills. These factors might be considered individual traits and can make everyday life and social participation harder than for the average person. However, other factors include socioeconomic status, living conditions, formal citizenship, family and social network and access to education and the job market, which have much to do with structures in society. Hence, a combination of individual and societal factors often affects their situations.

I have chosen to use the term people in vulnerable life situations rather than terms like vulnerable groups and marginalised groups because I deem it more inclusive and because it underscores that both individual and societal factors are vital for creating vulnerable life situations. Furthermore, by applying the term people in vulnerable situations, one also turns the attention from the individual's lack of resources towards increasingly exploring societal barriers. This turn may increase the possibility for changes because it may be addressed at a societal rather than individual level.

### 1.3 Aim and research question(s)

Collective user participation among the groups included in the present thesis has yet to receive much attention in research compared with many other groups of service users, which I will show in chapter 2. Notably, there is a need for more research on interest organisations and the impacts associated with collective user participation for these groups. Therefore, the overall aim of the present thesis is to develop knowledge about collective user participation among people in vulnerable life situations by focusing on interest organisations. In particular, the current thesis explores representation, strategies and impacts. The overarching research question in the thesis is the following:

*How do representatives in interest organisations perceive user participation?*

To help answer the main research question, the included papers address the following research questions:

1. How do people in vulnerable life situations participate in interest organisations, and what are the dilemmas related to representation? (paper 1)
2. How are interest organisations for people in vulnerable life situations influencing public actors, and what are the perceived impacts? (paper 2)
3. What types of impact are associated with collective user participation for people in vulnerable life situations in the research literature? (paper 3)

The current thesis focuses on how, combined, the findings from the papers address the overarching research question. To answer this, the discussion focuses on representation, strategies and impacts in separate chapters. These three perspectives are together crucial in answering the overarching research questions and will engage in a critical discussion, where I aim to develop new theoretical insight. The reader will also notice that paper 3—the scoping review—started working on and the first published. This choice was made to improve the chronology of the present thesis because I deemed it better to address representation and strategies before impacts in the discussion. However, the work with paper 3 greatly influenced the second part of the project, which I will describe in the methods chapter.

## 1.4 Outline of the thesis

The present thesis has been submitted to the interdisciplinary PhD programme Diakonia, Values and Professional Practice at VID Specialized University. The present thesis addresses both the value and professional practice dimension in the PhD programme. User participation is a charged concept viewed as a value, goal and means by governments, professionals and service users believed to contribute to improved and more democratic welfare services. Consequently, user participation is intertwined in the ideology of the welfare services, thus affecting professional practice directly and indirectly.

This introduction has described the background of user participation, people in vulnerable life situations and the aim and research questions addressed in the current thesis. In chapter two, I present the literature review by giving the rationale for conducting this project. Chapter three presents the theoretical perspectives in the study. Chapter four presents the design, methods and analysis chosen; it also includes a reflection on the study concerning the philosophy of science and provides ethical considerations regarding the project. Chapter five presents the findings from the papers. In chapter six, I discuss the findings related to the overarching research question. Finally, chapter seven presents the conclusion and implications of the thesis.





## 2.0 Research on User Participation

The purpose of this chapter is to describe the research field regarding collective user participation for people in vulnerable life situations. In the fall of 2022, I performed a search using Scopus, Academic search elite, Cinahl and SocIndex to identify relevant articles. The searches were limited to peer-reviewed articles published in English after the year 2000. The search terms had to be in the articles' title, abstract or keywords. In all the searches, I included search terms for the groups included. Like in paper 3, I also included people with mental health problems because most literature concerns this group. I also did fewer systematic searches on google scholar and searched for publications by relevant academics. In the following chapters, I present the research mainly without specifying which service user group the research concerns. Most of the literature concerns people with mental health and substance use problems, an area that seems to have received the most attention in research. However, there is increasing research on collective user participation and organisations for the other groups as well.

The chapter starts by giving an overview of the literature concerning collective user participation among people in vulnerable life situations in general. The second chapter focuses on interest organisations for people in vulnerable life situations. The third chapter describes the impact associated with collective user participation but is more general in tone than the scoping review.

### 2.1 Collective user participation among people in vulnerable life situations

Collective user participation among people in vulnerable situations is a broad topic, and the research focuses on both concrete practices and overarching ideologies. User participation has become widespread and is often perceived by professionals and service users as a good policy (Omeni et al., 2014; Rosenberg & Hillborg, 2016). Studies also show how user participation is connected to both democracy and consumer ideology in the welfare state (Askheim et al., 2017; Christensen & Pilling, 2019). Although user participation seems valued by both service users and professionals, studies underscore the importance of developing new participation channels to enhance the pathways through which the service user's perspectives reach policymaking processes (Restall et al., 2011). A recent review shows how research tends to focus on specific

channels of collective user participation in various welfare services (Ineland, 2022). These services are often health services, and the included studies in the present review indicate that research primarily addresses the participation of people with mental health problems and, to some degree, people with substance use problems. For example, Strøm and Slettebø (2021) state that research on collective user participation of people with dementia in nursing homes seems nonexistent.

A recurring topic in the research literature is the development of new channels that aim to increase user participation in various welfare services (Boyden et al., 2009; Coates & Howe, 2016; Seim & Slettebø, 2011). These studies suggest further development and list the various factors promoting or hindering user participation, which are often related to professional attitudes and knowledge, power dynamics, information, organisational structures, competence and support and unclear processes. Thus, professionals play a key role in promoting or hindering participation because these are often the ones with the opportunity to change current practices or services (de Freitas & Martin, 2015). Thus, power dynamics between professionals and service user representatives are a major factor that can hinder or promote user participation because professionals often control both the participation channels and decision-making processes in services (Broer et al., 2014; Brosnan, 2013; Rosenberg & Hillborg, 2016; Seim & Slettebø, 2011). For example, Broer et al. (2014) have studied improvement teams in health services, describing that professionals and service users alike struggled with the contributions service users could make and what functions they should fulfil. This mutual powerlessness partly disappeared when service users helped to determine and execute specific actions instead of participating in the improvement teams they studied. Thus, the culture in the participation forums influences the service users' opportunity to participate (Harding et al., 2010; Mugisha et al., 2019).

General stigma and disempowerment of service users are also underscored as major barriers to user participation, and facilitation by professionals is often required to make user participation successful (Abayneh et al., 2017; Gurung et al., 2017; Petersen et al., 2012; Tang et al., 2018). These studies also indicate that, when facilitation is successful, user participation can result in individual and collective empowerment. Therefore, providing groups with opportunities and incentives that attract, retain and enable them to build and release capacity and competence might be important to facilitate participation (de Freitas & Martin, 2015; Harding et al., 2010; Mugisha et al., 2019). Other factors restricting or promoting participation include

discrimination, poor economic conditions and policy frameworks and initiatives (Gurung et al., 2017; Kleintjes et al., 2013; Mugisha et al., 2019). In addition, time might be a vital factor in promoting participation. For example, Keogh et al. (2021) have found that time and creativity are crucial factors in promoting user participation.

## 2.2 Interest organisations representing people in vulnerable life situations.

Markström and Karlsson (2013) write that the development of interest organisations moves towards professionalisation and hybridisation (e.g., providing services and doing advocacy work). However, interest organisations might need help with sustainability (Patterson et al., 2009). Research also suggests that organisations may depend on facilitation and support from public actors to survive and that financial support can increase participation in interest organisations (Anker, 2008; Bardwell et al., 2018; Billsten & Benderix, 2021; Davies et al., 2022; Mugisha et al., 2019). Thus, many interest organisations can have close relationships with public actors.

Interest organisations adjust their agendas in response to current practices and policies and use a range of channels to influence services and politics (Mitra & Schick Tanz, 2020). These channels can be invited, claimed and popular channels (e.g., arenas created independently of authorities for activism, self-help initiatives or social activities), and here, interest organisations might have a parallel presence in these (Näslund et al., 2018). Interest organisations can have different roles and levels of acceptance and influence according to different political and legal situations (Johansson et al., 2015). Thus, they can be involved in high-level discussions on policymaking and local discussions about service improvement. Näslund et al. (2018) suggest that interest organisations have shifted their focus from accessing participatory spaces to critically examining the opportunities for influence. Like with other forms of collective user participation, power dynamics and service users' historical disempowerment might provide barriers to participation (Ardila-Gómez et al., 2019). Therefore, interest organisations might need to form alliances with other actors to gain influence, and scholars suggest that a lack of strong leadership and unity among interest organisations is a barrier to gaining influence (Gurung et al., 2017). Brown et al. (2019) find that having an effective policy influence only partly depends on the quality of the arguments: it also relies on alignment with other organisations in the organisational field and their policy network. Moreover, Montenegro and Cornish (2019) argue that the welfare system's incorporation of the service users' voices can

result from the policy needs for service user representation more than the status of interest organisations.

Interest organisations evolve through engagements with the welfare services, state and broader society, which affect their goals, behaviour and self-understandings (Montenegro, 2018). Close ties to governmental actors, combined with a consensus-oriented culture in the participation channels, could reduce interest organisations' critical role (Näslund et al., 2020). Eriksson (2015, 2018) examines how the relationship and interaction with public actors affected representatives and their organisations. Eriksson suggests that the logic of the representatives may be affected by what he describes as a co-option process, meaning that their goals, reasoning and arguments start to align with that of the public actors. This process might again result in less critical representatives and organisations. Other scholars have found that interest organisations adjust their criticism of welfare services to maintain their positions as insiders (Jones et al., 2021). Aligning with this, Mossberg (2016) writes that service user representatives consciously manoeuvre between using their voices and adapting to other stakeholders' views. However, Johannesson and Weinryb (2021) argue that, under certain conditions, heavy criticism can be a successful strategy to gain policy influence.

Their claim for collective representation often legitimates the work done by interest organisations. However, interest organisations might be both of and for people with service user experience (Schicktanz et al., 2018). This means it varies how much people with service user experience participate in the organisations that represent them. Jongsma et al. (2017) have studied this related to people with dementia and autism spectrum disorder. Their findings indicate that persistent stereotypes reduce people with service user experiences' participation within interest organisations and on the political level. The authors describe that the stereotypes lead to a situation where those who can represent themselves are deemed 'not affected enough', and those who struggle to express themselves are excluded because of these challenges. Because service users have varying vulnerabilities and needs, research has also found that interest organisations might represent only a part of a service user group and that there is a need for more efficient procedures for including all service users (Raz et al., 2018). The organisations involved in collective user participation processes might also only be viewed to promote the view of some service users (Bartoszko, 2021). This might be particularly challenging in fields

with significantly differing normative assumptions and political views, such as within substance use.

In interest organisations, the service user's experiences are viewed as complementary to established medical and expert knowledge and an essential component in improving the welfare services (Jones et al., 2021; Näslund, 2022). However, there might be differing views between professionals and service user representatives on the representative's independence and accountability and if they promote collective or individual perspectives (Mossberg, 2020). Representativeness is also an issue when welfare services recruit service user representatives. El Enany et al. (2013) suggest that unrepresentative user participation can occur because of self-selection by those wanting to participate and professionals actively selecting, educating and socialising certain service users. The authors further write that selected service users tend to be more articulate and able to work with professionals than the average service user. The most active service user representatives are commonly motivated by a desire for social justice, social conscience and personal development (Patterson et al., 2009). This aligns with Neech et al. (2018), who find that being a service user representative is linked to wellness and that making a difference to others and giving back are motivating factors. However, these experiences depended on feeling valued and supported by professionals, and participation could also trigger mental health difficulties.

### 2.3 Impacts associated with user participation.

Research on the impacts associated with user participation has often focused on individual user participation, such as shared decision-making (Stiggelbout et al., 2015), user empowerment (Castro et al., 2016) and user satisfaction (Ng & Luk, 2019), in addition to participation in research (Malterud & Elvbakken, 2019). However, there is also growing interest in the impacts associated with collective user participation (Ineland, 2022). Crawford et al. (2002) have conducted one of the first reviews on the impact of collective user participation. The authors show that collective user participation was associated with changes in organisations' attitudes to involving patients, positive responses from involved patients and changes in the provision of services across various settings. However, they also state that there is no evidence for collective user participation influencing the use of services, quality of care, patient satisfaction or the health of patients.

More recently, several scholars have conducted extensive reviews of the impact of collective user participation in different settings and with a slightly different focus (Mockford et al., 2011; Olsson et al., 2020; Rosenberg & Hillborg, 2016); these studies indicate that user participation empowers those involved, affects professionals' attitudes and knowledge, contributes to organisational development, changes professional practice and affects policies. However, studies also suggest that user participation could harm participants, lack impact and be challenging to evaluate (Daykin et al., 2007; Ocloo & Matthews, 2016; Usher & Denis, 2022). Studies have shown that it is difficult to measure the impact of implementing channels for user participation at the service level (Rise et al., 2014; Rise & Steinsbekk, 2015). Regarding interest organisations, studies have aimed at evaluating these organisations' participation in health policy by focusing on the stakeholders' perceptions of the degree of participation and its form (Souliotis, Agapidaki et al., 2018; Souliotis, Peppou et al., 2018). Researchers have also examined the perceived impacts of the participation of interest organisations, reporting many of the same impacts as described above (Patterson et al., 2010). In addition, the authors describe that the interest organisations can develop their structures based on involvement in participation processes. Moreover, participation in interest organisations could also offer potential improvements in well-being for those involved through the activity itself and via extended social networks (Weetch et al., 2021).

## 2.4 Summary of the literature review

Collective user participation among people in vulnerable life situations is a broad topic encompassing both tangible practices and overarching ideologies. Service users and professionals widely perceive user participation as a beneficial policy. Consequently, studies have often focused on studying what promotes and hinders participation besides the development and implementation of new channels of participation. Furthermore, professionals are described as crucial actors in promoting or hindering user participation, as are addressing power dynamics between the stakeholders in the user participation processes.

Furthermore, the review suggests that interest organisations for people in vulnerable life situations use various channels to influence services and policies. It also suggests that interest organisations have become increasingly formalised and professionalised and that their sustainability might be challenging without public actors' support. Moreover, research has found that the background of members and representatives in interest organisations varies. Although interest organisations may claim collective representation, they could sometimes be more *for* than *of* people in vulnerable life situations.

This review suggests that the impact associated with user participation is multifaceted. User participation can empower those involved, change professionals' attitudes and practices, contribute to organisational development in the welfare services and influence policies. However, research also describes how user participation might harm participants and lack impact and that impacts can be challenging to identify.

This literature review illustrates that there has been increasing attention in research on collective user participation among people in vulnerable life situations, particularly among those with mental health and substance use problems. However, the review also shows a need for more research on interest organisations and the impact associated with collective user participation among people in vulnerable life situations. Therefore, the present thesis addresses these topics.





## 3.0 Theoretical Perspectives

People's participation in developing health and welfare services has many names: user participation, user involvement, patient and public involvement, patient participation, consumer participation, user empowerment, user engagement and citizen participation. I have chosen to use the term participation because this term is more open than involvement, which indicates a more passive form, at least when looking at a literal understanding of the word. Participation is also more connected to the welfare state than other terms like empowerment, engagement and advocacy. Moreover, the terms used to describe those affected by or using public services differs (for a broader discussion, see McLaughlin (2009, 2020)). In the present dissertation, the term service user refers to the experience of using or being affected by public services (Rønning & Solheim, 1998).

This chapter describes the current thesis' overarching theoretical perspective: user participation. In addition to user participation, the papers apply and describe different theoretical perspectives related to representation (paper 1), insider and outsider strategies (paper 2) and impact (paper 3). I have chosen not to repeat these and have instead focused on describing the theoretical perspective on user participation. I start by elaborating on ideological perspectives on participation and how user participation can be understood as an extension of representative democracy. After this, I describe the perspectives of power related to user participation. Then, I describe different participation channels, arguing for the benefits of the term collective user participation. Finally, I describe the levels of user participation.

### 3.1 Ideological perspectives on user participation

According to Wistow and Barnes (1993), user participation can be traced to four origins: managerialism, public service orientation, the normalisation philosophy and user movements. The two first are usually referred to as the consumerist understanding of user participation, while the other aligns with the democratic understanding (Askheim et al., 2017). The point of departure for the present thesis is the democratic understanding of user participation.

The consumerist understanding of user participation is founded on neoliberalism and reflects a tendency for marketisation and the rise of choice. A central concept in the consumerist tradition is new public management. New public management emphasises economic efficiency and adopting market models, principles and ideas (Busch et al., 2003). The people using services are viewed as consumers and as active and competent rather than as passive and dependent (Stamsø, 2009). From a consumerist perspective, service user satisfaction becomes both a goal and indicator of quality and success. Tritter (2009) argues that the consumerist approach could reduce involvement in a tick-box activity; he further argues that opportunity of choice is the mechanism used to promote individual consumerism in health systems.

Wistow and Barnes (1993) describe that the democratic understanding of user participation originated from the normalisation philosophy and service user movement and that it emphasises rights, democratisation and shared power. The normalisation philosophy originated from professionals' focus on organising the services to the service users' needs. According to this, the service user would receive extended rights, the opportunity to make choices and the opportunity to participate in ordinary society, rather than be isolated in specialised institutions. The user movements focused on the power to define problems and were explicitly political, where there was increased power in decision-making processes and a focus on barriers created by society. Today, citizenship and empowerment are crucial ideological underpinnings and goals in the democratic understanding of user participation. Citizenship is rooted in human rights (United Nations, 1948) and focuses on increasing citizens' civil, political and social rights (Marshall, 2003). Like many other countries, Norway has gone through a continuous democratisation process over the past century, where citizens have expanded rights and opportunities, such as women's right to vote. Today, the understanding of citizenship has expanded to focus on the rights of discriminated and oppressed groups to participate in society equally as others (United Nations, 2006). This understanding promotes increased participation in society and welfare service development by people in vulnerable life situations.

Empowerment is a concept closely connected to and a vital part of user participation. At the collective level, empowerment is famously described by Freire (2000) and revolves around a group's capacity to influence and improve their living conditions. This is often related to the social movement's struggles for improved rights and living conditions, such as the service user

movement. Later, these movements transformed into more formalised organisations, such as interest organisations, which I focus on in the present thesis. The importance of these organisations is underscored in the convention of people with disabilities (United Nations, 2006). The declaration highlights that people with disabilities—thus also people in vulnerable life situations—should have political rights and opportunities on an equal basis with others. United Nations (2006) states in article 29 that countries should:

*(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected,*

and

*b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including: (i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties; (ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.*

The convention is particularly concerned with the political interest of persons in vulnerable life situations and how their interests are represented. Thus, the goal is to promote citizenship and empowerment at the individual and collective levels.

The practice of user participation may vary depending on ideological underpinnings. However, these can be difficult to identify or separate in practice as the ideologies promote user participation through many of the same arguments and means. Moreover, user participation is likely to be founded through both ideologies simultaneously in practice because they have different strengths and weaknesses related to improving quality in service delivery and efficient management of resources.

### 3.2 User participation as an expansion of the representative democracy

For thousands of years, democracy has been subject to debate and development. As such, democracy has meant different things at different times and places (Dahl, 2020). Today, many countries are described as representative democracies, including Norway. Representative democracy is often described as an indirect democracy because the voting-eligible citizens (which have varied across time and space) choose representatives that govern on their behalf. Thus, people place power in the hands of representatives through elections. Although representative democracy has its benefits, some criticism towards it includes that it is believed to provide a gap between the decision-makers and people, not holding representatives accountable to their premises and that it is insufficient for promoting the voices of all people (Dahl, 2020). Therefore, the participatory and deliberative elements are believed to compensate for some of these deficiencies and help deepen democracy, often in the form of user participation (Vedung & Dahlberg, 2013).

The participatory dimension is about increasing people's proximity to decision-making processes and, thus, including them in debates about matters that concern them (Dahl, 2020). This could include voting over issues on a national level or including groups in matters that concern them through councils and committees. Nevertheless, the idea is that those concerned with the issue should be closer to the decision-making process and be able to voice their opinions. Moreover, there is a belief that deliberation will improve the quality and legitimacy of subsequent decisions, which emphasises the importance of thoughtfully scrutinising all relevant arguments around an issue (Habermas, 1984). Therefore, all people have the right to participate, particularly those concerned with the issues. Habermas (1984) also states that deliberation should seek to decrease power asymmetries by increasing competence among weaker groups, which can be achieved through assistance in representation. Thus, user participation can be understood as a way of deepening democracy through the representative, participatory and deliberative dimensions.

### 3.3 Perspectives on power

The central element in a democracy is the sharing of power. Consequently, power has been central in the study of user participation and is often understood through a combination of the structure (Marx, 1971) and actor (Weber, 2000) perspectives. Weber (2000, p. 51) defines power as the ability to make something happen or to promote one's will despite resistance within a social relationship. According to Dahl (1957), power should be studied through decision-making, which has been centrally related to user participation (Arnstein, 1969; Tritter, 2009). As such, the service user movement and interest organisations have aimed at gaining power by getting access to decision-making forums in the welfare services and at the political level.

Lukes (2005) approaches power through three dimensions: decision-making power, nondecision-making power (agenda setting) and ideological power. The latter is the ability to influence wishes and thinking and resembles the concept of governmentality, which focuses on how knowledge, social structures and discourses are connected and used to control and possibly manipulate people (Dean, 2010, 2013). Foucault's perspective on power offers an understanding where power is not defined or described in a general theory; instead, he sees power as subtle and all-encompassing (Foucault, 1984, 2008). Rather than seeing power as a resource, he describes that power first unfolds through action and that power is relational, fluid and contextual and must be studied in concrete situations (Bröckling et al., 2010). Foucault's point is that power characterises all human relationships, that we cannot escape it, that it is productive and that knowledge and power are closely related. Therefore, Foucault speaks of power produced through thinking systems and the organisation of society and its institutions. Thus, the concept of governmentality describes how individuals incorporate established discourses and discipline and govern themselves according to these (Dean, 2010, 2013). According to this understanding, society can control and govern individuals and populations by developing techniques that influence discourses and normativity. Therefore, interest organisations often seek to affect the discourses and perceptions of normativity in society by exposing injustice and discrimination. This again might result in improved social inclusion and improved service provision.

### 3.4 Channels of user participation

User participation can occur at the individual, service, system or political levels (Vedung & Dahlberg, 2013). The term collective user participation is seldom used in the literature. Instead, scholars have often used the term user participation, specifying the level or activity of participation (e.g., service level, service development, service user council). In the following, I elaborate on the topic and describe commonly used participation channels.

Slettebø and Seim (2007) write that the purpose of user participation determines if it can be classified as individual or collective user participation. Collective user participation is when participation aims to improve service reception for all users. This builds on Elster's (1985) understanding on how both individuals and groups can work towards obtaining collective goals. In this understanding, the term collective has nothing to do with the number of involved persons. Instead, the term reflects the collective goal with participation: namely service improvement for the service user group as a whole. In the present thesis, I use the term collective user participation in line with Elster's (1985) and Seim and Slettebø's (2007) description.

Changes at the service, system and policy levels can occur because of the participation of individual users, user representatives or interest organisations. At the political level, the most commonly used channels are the parliamentary channel, the corporative channel through interest organisations, mass media and political actions (Rønning & Solheim, 1998). Today, a range of channels exists to affect services and politics, and it would be challenging to list them all. Some channels that have been mentioned by the informants in the interviews and in the writings of scholars in the field (Rønning & Solheim, 1998; Vedung & Dahlberg, 2013) include the following:

- Councils and committees
- Dialogue conferences
- Consultation meetings
- Using different types of media
- Complaint systems in services
- The legal system
- Petitions

Norwegian laws also highlight collective user participation, and the Local Government Act (Kommuneloven, 2018) states the following in section 1-1:

*The purpose of this Act is to promote local self-government and provide the necessary frameworks for this. The Act shall facilitate the local representative government and a strong representative local democracy with active inhabitant participation.* (English translation <https://lovdata.no/lov/2018-06-22-83>)

As indicated above, the law aims to promote representative local democracy and underlines that inhabitants should actively participate in these processes. Laws and official documents (Forskrift om medvirkningsordninger, 2019; Kommuneloven, 2018) also state that the municipalities are required to have councils for older people, people with disabilities and young people. Thus, collective user participation can occur at service, system and political levels (Haukelien et al., 2011). In the literature, these terms are often used to specify the level of participation. However, in practice, there is no clear-cut distinction between these levels, so I use the term collective user participation to refer to participation at all levels. The benefit of using this term is that it opens a perspective across the levels because participation rarely aims to or affects just one of them. This fact is particularly prominent regarding interest organisations, which are the focus of the current thesis. In addition, user participation in research has become an important topic and issue of debate. Although user participation in research can be seen as a form of collective user participation, this is not included in the present thesis.



### 3.5 Levels of user participation

In addition to different channels, user participation is also described at different levels, which is often related to how much the service users affect the decisions made. Arnstein (1969) has developed the most influential model called ‘a ladder of citizen participation’. Using a ladder metaphor, she describes eight levels of participation depending on how much decision-making power the citizens have. The steps in the ladder include manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control. Arnstein calls the two first steps (manipulation and therapy) nonparticipation. The three next steps (informing, consultation and placation) are described as degrees of tokenism. Only steps six to eight (partnership, delegated power and citizen control) are deemed real participation, which are labelled degrees of citizen control.

Arnstein’s (1969) model has received criticism over the years for being rigid, normative, inflexible and lacking nuances (Carpentier, 2016; Tritter & McCallum, 2006) Tritter and McCallum (2006) argue that greater emphasis must be placed on the merits of the process and importance of the various knowledge and experience professionals and users have acquired. Carman et al. (2013) propose that user participation be viewed as a continuum. The models include consultation and involvement at the lower end of the continuum. The higher end of the continuum includes sharing power and responsibility, which is called partnership and shared leadership. However, Carman et al. (2013) state that reaching the higher end is not the primary goal because such an intensive form of participation is not necessarily better for everyone.

Another influential model distinguishes between direct and indirect involvement (Tritter, 2009). Direct involvement is about having actual power in decision-making processes, and indirect is about bringing information and opinions to those who make the decisions. Tritter’s (2009) model also includes a collective and individual dimension, describing if individuals or groups participate. Moreover, the model describes proactive and retroactive participation. Proactive participation is creating new suggestions, while retroactive is responding to existing ones.

Despite the criticism, Arnstein's ladder can be understood as a continuum without normative underpinnings. The central point of the model is to illustrate that different levels of participation exist. Thus, the ladder can be understood as an analytical tool rather than hierarchical and normative. As such, many other models that have been developed can be seen as variations of Arnstein's ladder. However, Tritter's (2009) model offers a helpful perspective through the direct/indirect and proactive/reactive distinctions, helping us understand user participation as a process that includes or informs decisions and is more or less prescribed or negotiated.

Related to the present thesis, the distinction between real and tokenistic participation and direct and indirect participation are of major relevance in two ways. First, the perspectives can illuminate how interest organisations can participate in service development and what type of influence they gain. Second, they can shed light on how people with service user experience participate in their organisations and how they are represented. I will return to these topics in the discussion.



## 4.0 Design and Methods

This chapter presents the design and methods of the PhD project. Because the project consists of qualitative interviews and a literature review, I describe these separately. At the end of the chapter, I reflect on ethical issues and discuss the strengths and weaknesses of the project.

### 4.1 Design

As the introduction and literature have shown, there is a need for more knowledge on collective user participation for people in vulnerable life situations. Because this topic is little described and the terminology is often unclear, I have chosen a qualitative design for the PhD project. Qualitative research focuses on getting in-depth knowledge about a phenomenon (Creswell & Creswell, 2018) and is appropriate when the purpose is to investigate the participants' experiences, values and thoughts (Kvale & Brinkmann, 2015). The emphasis of the project is on both explorative and descriptive elements.

### 4.2 A critical realist approach

Ontological and epistemological considerations are central in developing research projects and guide choices regarding research questions and methods. The present PhD project has aimed to study collective user participation using explorative and qualitative approaches. The overall approach aligns with a critical realist approach. In the following, I describe how this position has influenced the project.

Critical realism is a tradition that focuses on both the ontological and epistemological levels. On an ontological level, critical realism assumes that much of reality exists and operates independently of our knowledge (Danermark et al., 2019). An essential assumption is that ontology cannot be reduced to a question of epistemology and that these should be dealt with at different levels (Bhaskar, 1998). Critical realism's central position is that reality exists and, thus, actors and social structures exist, but we only have access to knowledge about this reality through interpretation (Danermark et al., 2019). Therefore, a critical realist epistemology shares many traits with—and has been inspired by—other interpretative traditions such as hermeneutics and constructivism. Thus, knowledge depends on the context, concepts and activities and are historically, socially and culturally situated (Kjørstad, 2020). Nevertheless,

critical realism underscores that some interpretations and explanations—based on their arguments and evidence—can be more reasonable and acceptable than others. Thus, our knowledge might become increasingly certain. Critical realism is also concerned with causality, here assuming these can be revealed in closed systems like the natural sciences. However, because the social world is an open system with endless factors influencing a phenomenon, the best we can hope for is to understand and describe tendencies using cause and effect (Danermark et al., 2019). In particular, the philosophical assumptions have implications for how I understood vulnerability, conducted the interviews and the analysis and approached impact, something I will elaborate on below.

The position within a critical realist tradition has several implications for the present project. First, regarding vulnerability, the position of a critical realist implies that vulnerability is both embodied in individuals and culturally constructed at the same time. Thus, vulnerability is real and emerges as a product of the interaction between the person and environment in a specific context. Thus, laws, politics and institutions are of importance. Related to the groups in the present thesis, the combination of people's embodied vulnerability and societal structures creates vulnerable life situations.

I have approached the interviews through what Kvale and Brinkman (2015) describe as the traveller's metaphor. This approach underlines that the choices and interpretation of the researcher are central in all phases of a research project. In the interviews, I have aimed to explore the informant's perceptions (including experiences, opinions and views) of collective user participation. Hence, I conducted semistructured interviews, focusing on getting the informants to talk about what concerned them. This approach has also resulted in revising the research questions and adjusting the theoretical perspectives in the project. In the analysis, this became particularly apparent because there were other questions and theoretical perspectives that were more interesting and provided greater explanatory power of the material than the initial questions and perspectives. As such, I have applied an abductive approach in the analysis, leaning on interpretation through different theoretical perspectives.

Moreover, the value dimension is central to critical realism, assuming that research is always value laden and has solid political potential. The concept of user participation is charged and has strong normative assumptions. The belief in democratising and improving the welfare state

is also one of my motivations for studying the topic. Thus, these values and assumptions have influenced how I have conducted this research project.

Finally, understanding and identifying impact is an issue of debate regarding user participation. Impact is often understood as a linear process. However, collective user participation occurs in the social world, which is an open system. Thus, I have approached impact through a circular understanding, emphasising that there are impacts *associated with*, not *of*, user participation. Moreover, collective user participation is relational, usually involving the interactions between the stakeholders over a more extended period. Thus, the interaction between the stakeholders is complex because they mutually affect and are affected by each other.

### 4.3 Scoping review

The third paper in the present thesis is a scoping review. I have put this as the third paper because the chronology provides the best structure. The paper was the first I started working on and the first one published. The work on the paper helped me develop the second part of the project, which was valuable in developing the focus and interpretation in the interviews. The paper thoroughly describes the method and research process. In this chapter, I elaborate on the method itself and how I have approached it.

When I started planning the review and conducting the initial searches, the study focused on the impacts associated with both collective and individual user participation. However, it soon became apparent that the research field was somewhat unclear in its terminology, particularly regarding individual user participation. Thus, as the review process progressed, I found it necessary to limit the scope of the review. In addition, I also saw a need for more summarised knowledge regarding collective user participation and impact, particularly in the literature concerning people in vulnerable life situations. Simultaneously, I worked on recruiting and conducting the interviews, which increasingly drove my attention towards collective user participation in the review. However, there was little research on interest organisations among people in vulnerable life situations. Thus, the study needed a broader scope than focusing on interest organisations. I decided to focus on collective user participation more broadly.

Because of the unclear field regarding terminology, focus and study designs, it would be challenging to conduct a systematic review, so I decided that a more explorative approach would be necessary. I then chose a scoping review method to review the literature. This method is systematic but open, allowing for flexibility and creativity for the researchers. Arksey and O'Malley (2005) first described the scoping review method, and it is now a common approach to conducting literature reviews. Davis et al. write the following on scoping reviews:

*Scoping involves the synthesis and analysis of a wide range of research and non-research material to provide greater conceptual clarity about a specific topic or field of evidence.* (2009, p. 1386)

The initial framework developed by Arksey and O'Malley (2005), with the modifications of Levac et al. (2010), is still the most common approach to conducting this type of review. The popularity of these papers might be because of the frameworks being open and flexible yet systematic. The framework consists of six steps:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting results
6. Consultation (optional)

Later, the terminology was further developed by a range of scholars (e.g., Colquhoun et al., 2014; Daudt et al., 2013), and how to conduct scoping reviews is a current topic of debate. The discussion goes on between those who approach the method quantitatively, in line with the systematic review approach, and those in favour of a more exploratory and qualitative way, in which I will place my approach. In the more qualitative approach, one must also be systematic and give a thorough method description. However, one should protect the method's strengths, notably the room for flexibility and creativity. The latter elements are crucial for exploring and providing new perspectives on an understudied topic.

Today, multiple checklists exist to make the review process more stringent, and I used Tricco et al. (2018) to support the review, although not stringently. Applying checklists for assessing the included studies for scientific quality has also become a norm. In the review, I applied the mixed methods appraisal tool (MMAT) (Hong et al., 2018), which is used to assess the quality of a range of study designs. The main strength of this tool is that it includes different quality measures for different study designs, which I found helpful in reading and assessing the articles.

In the review process, the distinction between the data collection and analysis was not clear-cut, resembling the process of other qualitative research methods. When reading and assessing the full-text articles, I started to get a clearer picture of what the literature was about. I also started to develop and refine a data charting form, ending up with many versions before the final form. In analysing the included articles, I conducted a thematic analysis aligning with the approach I used in analysing the interviews. This included an abductive approach, where theory was central in interpreting the data.

Finding out how to sort the material was one of my main challenges when working on the paper. At first, I tried to understand the material through classical perspectives related to user participation, such as Arnstein's (1969) ladder or Tritter's (2009) conceptualisation. However, this did not fit particularly well with the data. After several rounds of coding, I found applying Banks et al. (2017) concept of co-impact helpful in understanding and sorting the material. The concept helped me focus on and describe the process and perceived impacts of these processes at different levels. Moreover, as I presented the analysis and findings in several meetings in the research group at VID and the CHAPAR project, I realised that harmful or no impact of participation was a topic I should highlight. Thus, this was developed as a separate theme in the article.



### 4.3 Qualitative interviews

As part of the project, I conducted interviews with interest organisations' representatives. In this part of the project, I wanted to explore the perspective of the service users on collective user participation. However, during the interviews, the project focused increasingly on the organisations and representatives. In the following, I elaborate on parts of the research process that have been less described in the papers.

#### 4.3.1 Method

In the present dissertation, I chose to conduct qualitative interviews, often referred to as in-depth interviews. Interviews are one of the most widely used methods in qualitative research. In line with a critical realist approach, my interests, values and preunderstanding have played an essential role in conducting the interviews and the following analysis (Brinkmann, 2014; Kvale & Brinkmann, 2015). However, the informants have also affected the interviews and focus and development of the project. In my interaction with the informants, I gained new knowledge that affected the research process, including vital phases such as recruitment, interviews and analysis. This interaction with the informants can also be understood as a form of user participation in research (Feiring et al., 2016). For example, I adjusted the research questions and the interview guide after the first couple of interviews because of new insights from these interviews, and representatives from the organisations helped recruit informants for the study.

When I started to recruit informants and conduct the interviews, my focus was mainly on the impact associated with both individual and collective user participation. However, during the first couple of interviews, my focus and interest also turned towards the organisations, how they worked and how people with service user experience participated. Moreover, it became clear that I needed to limit the project to focus on collective user participation. This also affected my work with the scoping review because I decided to narrow the scope to concern collective user participation. During the interview process, I gained new insights, and many of my preassumptions were challenged. In particular, I will mention two things that surprised me, which also became central in the two articles I have written based on these interviews.

The first was how professional the organisations appeared to me and who the members and representatives were. Before the interviews, I expected the organisations to be more loosely organised and work less systematically. Moreover, the competence of the representatives and varying participations of people with experience were also surprising to me as an outsider. Thus, these were also things that I found interesting to write about, resulting in the themes presented in the first paper.

The second surprise was how the informants described the public services and their relation and interactions with them. I expected the informants to be more critical, maybe almost hateful, towards services, professionals, politics and policy. The informants expressed criticism and frustration towards these, but this criticism was nuanced and constructive. Moreover, my main impression after the interviews was that the informants had a positive view of public actors and acknowledged their work and struggles toward delivering good services. Most of the informants also described their interaction and relations with public actors as positive, even though they talked of room for improvement. These experiences led to the development of the second article, where I have described how different strategies seem to be applied in influencing public actors.

#### 4.3.2 Recruitment and sample

A strategic sample was recruited to explore the research topic. I consulted other academics, read public documents and searched the web to identify potential interest organisations and informants. In addition, I consulted professionals working in some of the fields.

Through this process, I found relevant organisations and contacted them by email. The people I came into contact with either suggested themselves for an interview or put me in touch with others or arranged appointments. In several cases, the informants also recommended and put me in contact with other people after the interviews. Thus, the organisations and informants have influenced the sampling.

The organisations I contacted were mainly positive about participating in the study and were easy to contact. Still, some organisations did not respond to my e-mails, or I could not make an

appointment. Afterwards, I understood that one organisation that did not respond underwent major organisational upheavals. Regarding the two other organisations, I have yet to gain further knowledge of their reasoning. Interviews with these actors could have produced different perspectives and stories than those contained in the data material obtained. Nevertheless, it is also conceivable that they receive many requests and have prioritised other things. After conducting the interviews, my impression was that interest organisations received many requests and have many things they want to prioritise. I decided to stop recruiting more informants when I considered that the materials collected had provided enough information power to address the research questions (cf. Malterud et al., 2016).

The final sample of informants consisted of 14 representatives. The sample included 10 women and four men. These informants were people between 20 and 75 years of age, while most between 40 and 60 years old. The informants had different roles in the organisations. Eight of them were employees, and six were volunteers. They were also part of different levels of the organisations. Some informants were representatives at the national level, some at the local level and some at both. Regarding the informants' backgrounds, 3 out of the 14 had personal service user experiences. Besides these, two had experience as next of kin, seven had a relevant professional background, and two were next of kin with a professional background. The people with professional backgrounds had health, sociology and law education specialities, among others.

The informants represented eight different organisations that represented the following groups: people with dementia (three informants), substance use problems (two informants), asylum seekers (two informants), intellectual disabilities (three informants), children in contact with welfare services (two informants) and children of parents with substance use problems (two informants). The organisations all had democratic structures, such as general assemblies and elections. The organisations were more or less formalised, but all but one informant represented organisations with employed staff. However, the number of employees varied significantly. The seven organisations with staff received some funding from the government or public organisations. In addition, they often had membership fees. In addition, the organisations also had websites with varying degrees of available information. Regarding the members of the organisations, this number ranged from below 50 to several thousand. The members were said

to be both current service users, past service users, next of kin, professional practitioners, idealists or people with a combined background. Most of the members were a combination of these, but this greatly varied between the organisations.

When conducting a research project, there is often a question of whom one should include as informants. Related to the service user groups in the current thesis, there is a range of organisations where many have differing views and agendas. This relates to how representative they are and how it has affected the findings. Because I have conducted a qualitative study with various service user groups, it would have been difficult to include all organisations with differing views. Even identifying these differences is demanding. Including other organisations could have provided different stories and perspectives. However, the present thesis focuses not on the actual politics or opinions of the organisations but on the organisations themselves and their relationship and interaction with public actors.

Another question is if I should have focused more on including people with service user experience themselves. Interest organisations were deemed service users' most legitimate representatives when designing the project. Interestingly, one crucial finding is that few people currently use public services that are representatives of the organisations. If I had emphasised this more in the recruitment process, I could have included more informants with personal experience as service users. Perhaps this could have provided another insight and enlightened the research questions in new ways. However, there could also have been a question about consent competence for some of the groups. In addition, language barriers and reduced cognitive capacity could have been issues that would have to be addressed. Based on this, I believe my choices regarding recruitment has suited this project, but I also believe future research can—and perhaps should—address this differently.

### 4.4.3 Interviews

The interviews in the present study were conducted in autumn 2019 and autumn 2020. Eleven interviews were conducted physically and two over the phone. The telephone interviews were the last two in 2020 and were chosen because of the Covid-19 situation and geographical distances. The physical interviews mainly took place in the interviewees' offices, which was my conscious choice. The intention was that it would be easier to participate because of travelling time and the inconvenience it entails for the informants. I also believed meetings in the organisation's offices would provide me valuable information and a possibility to meet more people from the organisations. Another element was to equalise the balance of power in the relationship by meeting the people in the surroundings the informants chose.

The audio recordings from the interviews were between 65 and 100 minutes. Nevertheless, the conversations usually lasted longer, and I noted things of importance before and after turning on the audio recorder. Thus, the meetings in their entirety lasted between 90 and 120 minutes. The interview started with some informal chat and information about the PhD project. I read up on the organisation's website and relevant documents before each interview and mentioned this for the informants to create a relationship and provide a frame for the interviews. The interviewees were engaged in the topic of the project, so the interviews got off to a natural start. Thus, before I turned on the audio recorder, the informants spoke about the organisation and user participation. After the interviews, there was more focus on the PhD and CHAPAR projects. Moreover, many informants mentioned people I could interview.

One interview was conducted with two people at the organisation's request. One of the informants was a new volunteer representative, and the other was an employee in the central part of the organisation. The request was based on guidelines in the organisation, where all new representatives were to receive enough support and follow-up to feel secure in their new role. Methodologically, this could have challenges because a third person can influence what is said. Both participants may feel bound by the other's presence and cover up or modify their opinions and experiences. In addition, power and relationship outside the interview setting could have influenced how the participants related to each other in the interview. Despite these potential pitfalls, I found the interview fruitful and did not feel any apparent restrictions on what could be said. The informants had different backgrounds and experiences; one had a professional

background, and the other had experience as a service user, which helped the participants complement each other.

In general, interest organisation representatives should represent more than themselves. Therefore, there will probably be guidelines for what they can or should say from the organisations they represent. This issue was also something several informants mentioned, stating that there were different opinions within the organisations and between the various interest organisations in the field. Furthermore, many informants were also trained to speak to politicians and professionals where they operate as strategic actors. Therefore, their descriptions and the topics raised could have been influenced by their organisation's agenda and, thus, affected the interviews.

Because the interviews aimed to explore user participation and view on their organisation work, I let the informants speak freely about their experiences and views related to the interview topic. However, as a researcher, I probably still mostly controlled the conversation, and the topic was clearly defined beforehand. I also changed and narrowed the project's focus during the interview process. Thus, the interview guide was refined based on experiences and insights from the previous interviews. Therefore, the later interviews became more focused on the topics in the final project.

#### 4.3.4 Analysis

The formal part of the analysis in the project occurred after transcribing the interviews. However, the analytical process started when planning the project and was an ongoing process until finalising the papers. During the interviews, I developed new insights, which affected the research focus and made me search for new theoretical perspectives. Besides reading up on the literature, the work on the scoping review had a major impact on the focus and interpretation of the interviews. The work with the review provided me with new knowledge and made me limit the scope as I started to gain an overview of the knowledge gaps in the research literature. In addition, the knowledge I obtained by reading the studies in the review helped me see new things in the material.

I chose thematic analysis to analyse the data material. This analytical method is flexible and open, but the researcher must still be systematic and describe the process rigorously. According to Braun and Clark (2013), researchers need to describe their analysis thoroughly, including, but not limited to, all steps in the process, how they apply theory and their philosophical considerations. The framework developed by Braun and Clarke (2006, 2012, 2013, 2019) is an often applied approach to thematic analysis. The framework consists of the following steps: familiarising oneself with the data, generating initial codes, searching for themes, reviewing the themes, defining and naming themes and producing the report. The authors highlight that this process is not linear, and I have repeatedly jumped between these steps. However, I have found the framework helpful in providing a systematic way of conducting and presenting the analytical process, thus making my results and conclusions more transparent.

Initially, Braun and Clarke (2006, 2013) have described their approach to thematic analysis as atheoretical in the way that it could be used with all epistemological underpinnings. However, more recently, they have placed their approach in what they call the qualitative tradition, contrasting it with what they label the quantitative approach to thematic analysis (Braun & Clarke, 2019). I approach thematic analysis in line with Braun and Clark (2019) because I understand they place their approach within an interpretative spectre without connecting it to a specific tradition. Thus, in my view, their framework aligns with a critical realist approach because it highlights interpretation of the data.

In the analysis, I have deliberately used theory to interpret and understand the material. However, when the initial theory did not sufficiently explain the material, I searched for and applied new theoretical perspectives that provided a better explanation power related to the data. The theoretical perspectives also changed during the research process because of new insights, adjusted research focus and questions and input from my supervisors and other academics.

The analysis was an iterative process, where I found Braun and Clark's (2006, 2013, 2019) framework helpful for systematising the process. I started the formal analysis by reading the transcriptions thoroughly. After reading the material several times and writing down things of

potential interest, I started coding the material. The coding process started with a broad research question, where I developed hundreds of codes. Thus, the focus of the analysis pointed in many directions, even though I adjusted, combined or discarded codes between coding each interview. While working with the initial coding, it soon became clear that the research questions needed to be adjusted and specified. Based on feedback from supervisors and other scholars, I performed a new reading of the material and revised the research questions.

I used pen and paper and NVIVO (a software program for organising text) in the initial coding. However, I felt I lost oversight of the material and tended to code too broadly and inclusively when using NVIVO. Therefore, when I did a complete coding based on the revised research questions, I did this with pen and paper. This change gave me better insights into the material, improved my thinking and made me more creative. This approach also helped me better reaction the focus of the research questions, leading to more precise coding. Here, the codes were both semantic and latent, meaning they were descriptive and more interpretive. However, most codes can be deemed latent, implying they were theory laden.

The refinement of codes continued until all interviews were coded. However, the codes were also adjusted and changed later because coding, developing themes and writing are not separate processes. Therefore, after developing the initial themes, and also later, I went back and did a more narrowed coding of specific parts of the material—for example, codes related to how people in vulnerable life situations participated as living examples.

The coding and initial themes were discussed in numerous supervisions. Moreover, I presented these at research group meetings at VID and seminars in the CHAPAR project. I also presented the analysis, findings and article drafts in these forums. Presenting my analysis and initial themes provided essential feedback that pointed to weaknesses and contradictions. This feedback helped me generate new ideas and perspectives, allowing me to move beyond the superficial level by asking new questions and applying new theoretical perspectives. This again led to developing new codes and themes because I realised that some were too broad and others too narrow. Moreover, I decided that some themes were not interesting or could be combined



in new ways. The development of themes continued until the finalisation of the papers, even though in the later phase, it was more about how to present them in an exciting way.

As with all research, putting it together is a difficult thing and takes a lot of revision. Even though I had developed and described the themes and linked them to the research questions, they were still revised and changed until I finalised and sent in the papers for peer review. In this phase, some new understanding of theory and feedback from other scholars helped develop the themes and analysis further, providing more depth. In addition, I selected citations I believe have helped illustrate the findings and have tried to present the data in interesting way.

#### 4.3.5 Ethical reflections

It is essential to not harm participants in research. To avoid harming, I have read and followed national and international legislation and standards for good research ethics within the social sciences (NESH, 2021). I have also applied for permission to conduct the project in relevant institutions, and the Norwegian Centre for Research Data recommended the study (reference number 505481). When I started planning the project, the first idea was to talk to people with service user experience. However, as I have mentioned earlier, there could have been concerns about consent competence, cognitive capacity and language barriers. Because I wanted to include a range of different groups, I chose to recruit informants from interest organisations. I believe these had knowledge about the phenomenon, were legitimate representatives of the groups and had consent competence and ability to communicate effectively around the research topic.

Another step to avoid harm is to inform potential participants about the study and what participation would mean to them. The participants were given oral and written information about the study before participation and then signed an informed consent form. The two participants that were interviewed over the phone gave written consent over email and oral consent at the beginning of the interview. The consent forms and recordings were stored separately and locked in. These were shredded and deleted at the end of the project period. All informants were informed that participating was voluntary and that they could withdraw at any point and get their information deleted without giving a reason to the researcher. I also informed

them that I would anonymise them as individuals and the organisations they represented in the final report. The interviews were anonymised during the transcription, removing information that could lead back to any of them; this was done by altering or deleting certain parts of the interviews that revealed specific characteristics or processes they had taken part in. Although the interviews focused on the organisations and informant's perception of collective user participation, the informants sometimes spoke of experiences related to their own care or experience as a next of kin. Because the project aimed to explore collective user participation, I excluded or rewrote these parts of the material in the transcription. Despite this, the connection between personal experiences and collective user participation became interesting in the analysis and is a topic in paper 1. However, the focus here is on how the informants perceived that personal or next of kin experience affects collective user participation, not on the personal experiences themselves.

#### 4.5 Quality criteria and reflexivity

Validity, generalisability and reliability are terms that have been linked to quantitative research but have been given new content related to qualitative research in recent decades. In the following, I use these concepts aligning with Kvale and Brinkmann's (2015) description.

In a qualitative context, validity is about credibility and trustworthiness. This means the topic, research question, method and results are relevant and appear probable. Involving others in the research can increase validity, which is often called communicative validation (Kvale & Brinkmann, 2015). I have deemed academia as the most suitable validation community because the purpose has been to develop theoretical knowledge about of user participation (Kvale & Brinkmann, 2015). This goal implies a need for theoretical knowledge at a high level, so it has been vital to involve and present my work for other academics. My supervisors have been crucial in obtaining this and involved in the entire research process, especially the analysis. It has been vital to receive feedback on the project, especially preliminary findings, throughout the project. This has included frequent presentations in the research group and at seminars in the CHAPAR project, conferences, PhD courses, colloquium groups, the mid-term evaluation, the final seminar and other academic settings. I have also had contact and conversations with people from the practice field—both my informants and others—where I have discussed my project and the field in general. In addition, many researchers have read and given feedback on

article drafts, for which I am grateful. The papers have also been revised based on feedback from peer reviewers, a process which has improved the papers significantly.

Knowledge developed through qualitative research can have transferable value. A central element in developing transferable knowledge has been to validate interpretations and results to previous research and theory and critically discuss different ways of understanding the findings. The literature has both challenged or coincided with my interpretations, which have helped develop the analysis further. As such, the papers and this extended abstract have aimed to theorise the findings to be relevant outside the context of this particular study. I have tried to do this in the papers and the present thesis, and it will then be up to the critical reader to assess whether I have succeeded.

Reliability is about the verifiability of research. In qualitative research, the researcher can describe the research process in detail so that others can judge how reliable the findings seem. Therefore, it is vital to show transparency in all parts of the research process so that the reader can assess the quality and logic of everything from research questions, design, analysis, findings and conclusions. It is also crucial that the researcher is reflexive throughout the research process and is aware of and demonstrates how the researcher's preconceptions, background and assessments have influenced the informants, the research process and results (Creswell & Poth, 2016). Important choices I have made during this project are the design of the project, which research question to ask and methods to use, whom to recruit for the interviews, how to conduct the analysis and how to interpret the data. These are some of the choices that have been necessary to make, and I could, of course, have made choices which would have taken the project in a different direction.

Despite these efforts to improve the validity, generalisability and reliability, I see that the current thesis also has several weaknesses. Some of these are addressed in the papers, but I will briefly mention some the most important. The present thesis does not describe the practice of collective user participation. Instead, the findings describe my interpretation of the informants' descriptions of their perception of user participation, which again reflects their interpretation of their experiences and views and the research setting. In paper 3, the findings describe my

interpretation of the research literature. Thus, the findings and discussions in the present thesis do not reflect the practice in the real world. There is also a question if the included groups are ideal of including in the same research project. As shown, there is great variety in challenges, interests and goals among these groups, and the organisations differ regarding structure, professionalisation, preferred means and relationships with public actors. As such, limiting the number of groups could have provided more depth to the material because there are just two or three informants per service user among the informants. However, I believe that this variation is also a strength of the study and that it enabled me to look across these groups and identify similarities and differences. It also led me to seek for and use new perspectives, which helped me develop new insights that could have been overlooked if I had included just one or two groups. Another benefit is that the material describes different settings. This forced me to focus on theoretical development, which could increase the transferability and usefulness of the findings to other contexts.



## 5.0 Summary of Papers

In this chapter, I summarise the main findings from the three papers, which will form the basis for the discussion in chapter 6.

### 5.1 Paper 1

The first paper is based on interviews with 14 representatives in organisations representing people in vulnerable situations. The paper is titled 'The participation of people in vulnerable situations' in interest organisations: A qualitative study of representatives views' and was published in the *Journal of Social Policy*. This article aimed to explore how people in vulnerable situations participate in organisations by addressing the following questions: (1) *How do people in vulnerable situations participate in interest organisations?* (2) *What are the dilemmas related to the representation of people in vulnerable situations?*

The first main-theme is *participation as representatives in the organisation*. The first subtheme, *participation as spokespersons*, describes that it was challenging for people using or affected by public services to be spokespersons. The role of a spokesperson was connected to competence and knowledge. These requirements were most often described when the spokesperson had it as a job, and the situation was more nuanced in the case of unpaid spokespersons. For all the groups, the informants highlighted the professional language and culture in user participation channels as barriers to becoming spokespersons. Furthermore, many informants conveyed that the organisations had become more strategic in ensuring that their spokespersons were qualified through educating and preparing new representatives. The informants emphasised that people with lived experiences of using public services should be spokespersons of relevant interest organisations. However, obtaining the necessary qualifications and language skills may be difficult for people with illnesses, disabilities or strenuous life situations. The second subtheme, *participation as living examples*, describes how people with service user experience participate in external activities, making the group visible through physical presence and telling their own stories. This role were perceived to increase the groups' visibility, transfer knowledge to public actors and society, reduce stigma and influence concrete cases. Many informants emphasised that individual stories should be used carefully to

form a framework of understanding because they may contribute to cementing people's established perceptions of the group. Moreover, it was different views regarding the impact of presenting individual stories: some believed that the audience was only emotionally impacted at that particular time and place, while others believed it had a more significant effect.

The second main-theme is *participation in organisational activities*. The first subtheme, *participation in meetings, events and gatherings*, describes that it varies how much people with lived experiences participate in formal meetings, but they are often consulted and attend events and informal gatherings. Some reasons for this were time, resources and the background of the organisations members. However, the degree and type of participation varied between the organisations. In fact, some described models that had been developed to ease the participation of people with service use experience. Moreover, consulting experienced people at events and gatherings were seen as more accessible than formal meetings. This was also seen as essential for staying in touch with people at the grassroots. The second subtheme, *service reception and participation by proxy*, describes that people with lived experiences influence the organisation through interaction when using the organisations' services and through their next of kin. Here, the organisations' service provisions was reported as making it possible to develop knowledge about the current issues faced by people in vulnerable situations. This affected the representatives' work and contributed to unique knowledge about the groups' experiences, needs and perspectives. In addition, several informants underlined the importance of next of kin in promoting the voices of people in vulnerable situations, either on those people's behalf or together with them. Here, the informants often functioned as interpreters.

The article discusses these different types of participation, both the opportunities and challenges. In particular, the findings have been discussed in light of representation theory and points to possible implications of the current practice in the organisations. Regarding representation, the article argues that representation for these groups can be understood as both descriptive and substantive. This paper makes three major contributions to the field of knowledge. First, the paper contributes knowledge about interest groups that have been little studied. Second, the article provides knowledge of how people in vulnerable life situations participate in organisations and in how they participate in collective user participation activities.

Finally, the article contributes a critical perspective on the representation of both interest organisations and public services.

## 5.2 Paper 2

The second paper is titled ‘Three strategies of user participation. Interest organisation representatives’ views on how they make an impact on service development’. This article aimed to develop knowledge about user participation by interest groups for people in vulnerable situations. More particularly, we focus on the strategies they apply and impacts they seem to have by addressing the following research question: *How do interest organisations influence public actors, and what are the perceived impacts?* The article is based on the interviews conducted with representatives of organisations for people in vulnerable life situations. The analysis led to the development of three themes reflecting tendencies in how the informants described their interest organisations’ interaction with public actors: a cooperative strategy, an oppositional strategy and a negotiation strategy. Even though these strategies may have overlapped in practice, the organisations seemed to manoeuvre between them consciously, and some appeared to prefer specific strategies over others.

*The cooperative strategy* was often chosen at the service level and in municipalities, where the informants described being insiders and having a good relationship with public actors. Many described similar or shared goals, which resulted in constructive dialogue in direct channels such as councils, committees, meetings and informal interaction with public actors. In addition, the informants described that they and the public actors participated in each other’s arrangements, collaborated in providing services and sometimes providing services financed by public actors. The informants expressed that dialogue, trust and respect were vital for what they often labelled as collaboration or partnership. These factors were perceived as promoting mutual understanding and goals and commitments, thus improving relationships between stakeholders. Identifying impacts from the cooperative strategy was often straightforward because it involved providing concrete services. One way to identify impact was to find if a service had been delivered. Another was to see if the services met the service user group’s needs. Moreover, some had started collaborating with the government in service provision, and in rare cases, the government had taken over the service provision permanently. Furthermore, the informants expressed how the cooperative strategy contributed to the interest organisations



by obtaining better relationships with public actors, receiving more information, expanding their network, being given access to new user participation channels and sometimes receiving more funding.

*The oppositional strategy* describes how interest organisations could engage in open conflict with and exert pressure on public actors at the service, system and political levels. The informants mainly chose this strategy from outsider channels such as the media, publishing reports and through complaints systems. This strategy often included conflict based on frustration towards public actors, services and policies. The informants expressed that outsider channels were often effective and that they could identify visible results from them because these channels revolved around concrete issues and where they, as an organisation, had clear goals. Outsider channels were also used to create attention and affect public discourse where identifying impacts was difficult. In addition, some informants described that their organisations developed services to meet their service user groups' needs because a public service had failed to do so. The effects of these activities were often easy to identify because they met a need among service user groups. However, these activities were also perceived to affect others' perceptions of the organisation and service user group, increasing their status and making the need for their service user group visible.

*The negotiation strategy* illustrates how organisations would manoeuvre between being critical and constructive while maintaining a relationship with public actors. With this strategy, the interest groups mainly use insider channels, often combined with moderate criticism in outsider channels. Here, the involved actors often had different goals and priorities, but there were rarely overt conflicts. The informants believed their negotiation strategies contributed to creating legitimacy among public actors. Being viewed as competent and constructive was vital for bringing about impact; on the other hand, promoting grassroots voices could also increase the organisations' legitimacy and influence. It could be challenging to see results and identify cause-and-effect relationships from a negotiation strategy. Despite this, the informants were confident that this work had an impact and claimed that they noticed whether or not they were being listened to. To identify their results, the informants suggested asking involved service users, studying documents and following issues over time. Many expressed that a lack of visible changes did not mean user participation did not have an impact because it could take time to

achieve changes. Nevertheless, many had also experienced a lack of impact, which could be particularly visible in councils and committees where they had a consultative role. The informants also expressed that the strategy could result in tokenistic participation and a reduced critical voice.

The paper discusses these strategies, the impacts associated with participation and how interest groups may prefer different strategies. The paper states that the study contributes to theoretical development by building on the insider/outsider distinction. The informants seemed to prefer the negotiation strategy and mainly chose to use insider channels to gain influence. However, it also seems as though the oppositional strategy provides groups with a second opportunity if the negotiation strategy does not provide the desired impacts. The risk of co-option may be present in the cooperative and negotiation strategies but could also provide significant impacts if the goal and critical thinking are maintained.

This study makes three significant contributions to the research field. First, the paper expands the knowledge base of interest groups' work, their strategies, and how they interact with public actors. Second, the article uses empirical data to explore the understudied field of perceived impacts associated with collective user participation. Third, the article expands our understanding of collective user participation by focusing on both insider and outsider activities. Consequently, the article contributes to theoretical development by applying a more dynamic understanding of the insider and outsider distinction.

### 5.1 Paper 3

The third paper is a scoping review of the literature entitled 'User participation among people in vulnerable situations at service level. A scoping review exploring impact for individual stakeholders and services' and was published in *Nordic Welfare Research*. This article aimed to explore the impact of user participation at service level among people in vulnerable situations and how this process affects the involved stakeholders. The review addressed the following questions: (1) *What are the characteristics of the studies, study participants and user participation activities?* (2) *What types of impact are associated with user participation in the studies?*

The first theme describes *the included studies' characteristics*. The included studies were mainly conducted in Western countries, and most had a qualitative design. The study's stakeholders were users (e.g., users, user representatives, next of kin) and professionals (e.g., health professionals and social workers, managers, government officials, politicians). Thirteen of the studies dealt with the user participation of people with mental health problems. The activities described in the studies were user participation in developing or modifying interventions, user surveys, guideline development, consultations about information materials or interventions and general service development. However, some studies did not specify the act of user participation.

The second theme describes *impact at the individual level*, relating to how users and professionals are individually affected by their engagement in the user participation activities and how the process affects the interaction and relationship between the stakeholders. Among the users, engagement was reported as being associated with an increased feeling of empowerment, increased self-esteem, new skills and knowledge development, expanded social networks and a positive effect on health and well-being. For professionals, the studies reported that the user participation process resulted in increased knowledge about the users' perspective and that this insight improved the professionals' understanding of the users' situation, expanded their knowledge foundation and enhanced the user–professional relationship. In the collaboration process, user participation was associated with increased access to and focus on the users' perspective, expanding the professionals' knowledge for decision-making and making the discussions more fruitful.

The third theme describes *impact at the organisational level*, referring to the uptake and use of knowledge acquired in the user participation process. The reported impacts were improved attitudes towards users and user participation among professionals, improved information materials and change in professional practice and organisational rearrangements in services because of user participation. In addition, the studies provided vague descriptions of service development and reported increased participation in the existing user participation activities, establishing new channels for user participation at service level. Finally, a few studies reported

changes in overarching policies because of user participation, affecting the guidelines' focus, language and content.

The fourth theme, *harmful or no impact*, refers to the potential for user participation to have unintended impacts or failing to have any impact. At the individual level, the studies indicated that user participation led to some users experiencing disempowerment, worsening their mental health, frustration and feelings of vulnerability in the user participation process. At the organisational level, the internalisation of the norm of user participation among professionals led the professionals to accuse one another of unnecessary use of power towards the users, thus worsening the working environment, and government officials were afraid of being viewed as incompetent if they did not meet the users' outcome expectations. User participation can also lead to resistance from professionals who do not believe the users are representative and think that users are overly critical of the service. At the policy level, one study described that user organisations withdrew from the process of developing new guidelines because they disagreed with the content.

Using Banks et al.'s (2017) concept, the article provides a theoretical contribution to the field of research by expanding the perception of the impact associated with user participation, emphasising a circular understanding. The article further discusses how users can be understood as having power in the participation process, and the possibility of co-optation may result in less critical users, manipulating user participation into becoming nonparticipation. The article concludes that user participation can be more than an empty ritual and that service users and service providers should be encouraged to participate in these activities to develop and improve services. However, it also recommends that, in facilitating user participation, service providers pay attention to the possible harm the process may cause the participants

This paper makes two crucial contributions to the field of knowledge besides illuminating collective user participation for people in vulnerable life situations. First, the paper expands our knowledge of the impact of collective user participation and contributes to theoretical development by applying Banks et al.'s (2017) concept of co-impact. Second, the paper

emphasises the potential pitfalls of collective user participation, an issue that has received minimal attention in the research literature.

## 6.0 Discussion

The overarching research question in the present thesis is as follows: *How do representatives in interest organisations perceive user participation?* The papers address this question by focusing on the participation of people in vulnerable life situations in the organisations (paper 1), the strategies the organisations apply to influence the welfare services and their perceived impacts (paper 2) and what the research literature describes as the impact associated with collective user participation (paper 3). In the following discussion, I combine the findings from the papers in an overarching discussion of the findings. As I see it, the findings illuminate three overarching topics: representation, strategies and impact.

First, the findings show that people in vulnerable life situations participate directly, assisted, indirect and via others in their organisations and user participation processes. However, the findings also illuminate dilemmas and challenges related to representation. Thus, I will discuss how people in vulnerable life situations are represented and whether this is real or tokenistic participation. Second, the findings from the papers address the interaction and relationship between interest organisations and public actors and how different channels and strategies are used to gain influence. Interest organisations manoeuvre in a landscape of power and tokenism, and I will discuss how they and their representatives obtain power or become powerless. Third, the findings show that collective user participation might impact individual stakeholders, services and organisations, systems, policies and politics. However, the findings also suggest that it is challenging to identify these impacts and that participation may have no or even harmful impacts. This knowledge is vital to understanding how collective user participation may contribute to service development. Thus, I will discuss how this knowledge can be applied to help service development. Based on these findings, the following is discussed:

1. Representation *of* and *for* people in vulnerable life situations
2. Interest organisation's strategies to manoeuvre in a landscape of power and tokenism
3. Collective user participation: The challenge of making and identifying impact

## 6.1 Representation *of* and *for* people in vulnerable life situations

In this chapter, I discuss representation related to people in vulnerable life situations. This topic concerns whom the representatives are and the relationship between the organisations and whom they represent.

The findings presented in paper 1 show that people in vulnerable life situations can participate in interest organisations in various ways. However, the findings also suggest that it can be challenging, particularly being a spokesperson. These findings align with previous research that has illustrated how organisations might be *for* and not *of* people in vulnerable life situations (Jongsma et al., 2017; Raz et al., 2018; Schicktanz et al., 2018). Andreassen et al. (2014) suggest that interest organisations are increasingly focusing on developing competence among their representatives to be influential, which might exclude some people with service user experience from obtaining the role of a spokesperson. Thus, papers 1 and 2 suggest that the focus of interest organisations might be on the most effective way of promoting a group's interests rather than who the representatives are, which is often labelled substantive representation (Pitkin, 1967). Consequently, the representatives might be recruited based on their perceived ability to impact the services. This ability can be connected to competence; thus, people in vulnerable life situations might be perceived to have difficulties in fulfilling the role as a spokesperson.

Beresford (2013, 2020) describes this as the othering of user participation, meaning that people other than those with personal experiences represent the service users. The sample of informants of my interviews illustrates this because few had personal service user experience. Few representatives with personal experience could be a challenge for the organisations because it might reduce the accuracy of the representation of interests and affect the internal and external legitimacy of the organisation (Gnes & Vermeulen, 2018). Moreover, it may reduce the participation of people in vulnerable life situations to degrees of tokenism (Arnstein, 1969). However, in official papers, service user representatives are defined as those who represent the users of services, which can be either a person with a disability, a next of kin or an employee or elected representative in an organisation representing service users (White Paper 34, 1996–1997). This definition underscores that people without service user experience are seen as legitimate representatives of service users.

Despite the barriers to becoming a spokesperson, papers 1 and 3 show that some people with service user experience are indeed spokespersons. However, most of them participate through what I have labelled living examples. In these roles, people with service user experience often share their own stories, which can help interest organisations appear authentic. Simultaneously, paper 2 suggests that interest organisations focus on appearing competent and promoting the accumulated experiences of the group they represent, as exemplified by how they often cite reports and research. The informants also described that professionalisation and competence were the prerequisites for exerting influence in many settings. Thus, interest organisations seem to wish to appear professional and authentic simultaneously. The balance between appearing authentic and professional has been described as a challenge for interest organisations because authenticity and professionalism may undermine each other (Andreassen et al., 2014; Bartoszko, 2021; Martin, 2008). However, support in representation processes may also help build the required competence among people with service user experience and make use of the different experiences and competencies in the organisations.

Paper 1 also suggests that participation in formal parts of the organisations, such as decision-making processes and elections, is scarce. Nevertheless, people with personal experience participate in organisational activities and the informal organisation and are described as influencing the interest organisations through these. A lack of connection between an organisation's top and grassroots could be a dilemma for interest organisations (Pijl & Sminia, 2004). On the one hand, interest organisations need to be well managed to have an impact on services. On the other hand, they must also be authentic and listen to the grassroots to accurately promote their members' voices (Jones et al., 2021). Combining these factors is essential to creating internal and external legitimacy (Gnes & Vermeulen, 2018). As such, the participation of people in vulnerable life situations in both formal and informal arenas in organisations may be crucial. Strictly indirect or informal participation may increase the risk of tokenism (Arnstein, 1969) and the othering user participation (Beresford, 2013, 2020) because people with service user experience do not obtain any direct influence on decision-making. The findings illustrate how some have addressed this issue by developing procedures to increase the participation of people with lived experiences in the organisations. These procedures increase the ability of people in vulnerable life situations to participate and raise awareness in the organisations.



The distinction between interest organisations *of* or *for* people with service user experiences (Schick Tanz et al., 2018) became a central perspective in the interviews and following analysis. This resulted in the topic in paper 1 and in changing the terminology from service user organisation to interest organisations in the project. The distinction was also raised and discussed with the informants. Many informants raised the issue or identified themselves as representatives of an interest organisation rather than a service user organisation. The terminology might have implications for how we think about people and organisations. By using the term interest organisations, I highlight that the representatives and members are not necessarily service users. In contrast, the term service user organisation implies that the service users themselves are representatives or members of the organisation. This might be the case in many organisations, but as paper 1 illustrates, the representatives and members are often a combination of people with different backgrounds. Representatives without service user experience may be a concern if not clarified, which might reduce the legitimacy of the organisations and representatives (Bartoszeko, 2021; Jones et al., 2021; Martin, 2008). The term service user organisation also connects the member's and representatives' identity to that of being a user of public services. This is not necessarily negative because we all use public services. However, it can restrict the focus of the organisations to the services, thus reducing work to affect other parts of the welfare state and society. As paper 2 illustrates, interest organisations often focus on other parts of society than just welfare services.

In sum, my findings illustrate that representation and participation in interest organisations for people in vulnerable life situations can be both direct, supported, indirect and by proxy. These types of representation and participation may have benefits and pitfalls, but the findings also suggest that different types of representation are needed to promote these groups' voices effectively. Returning to the distinction of organisations *of* and *for* people in vulnerable life situations, perhaps interest organisations should and need to be both.

## 6.2 Interest organisations strategies to manoeuvre in a landscape of power and tokenism.

The findings suggest that interest organisations seek to influence welfare services through different channels and strategies. Most research concerning user participation focuses on insider channels, such as councils, committees and informal contact with professionals. The present thesis contributes to expanding the view of user participation by including outsider channels, such as the media, publishing reports and conducting campaigns. In this chapter, I discuss power dynamics in these in user participation processes and how interest organisations seem to manoeuvre in a landscape of power and tokenism with the risk of being co-opted.

Paper 2 describes how interest organisations apply and combine different channels and strategies. In line with other restudies, the present paper suggests that interest organisations often seek to obtain a good relationship with public actors (Jones et al., 2021), which is illustrated in *the cooperative* and *negotiation strategies*. The findings from papers 2 and 3 suggest that most insider channels have a consultative role with little decision-making. Thus, interest organisations seem to participate in channels that could be labelled degrees of tokenism (Arnstein, 1969) or indirect participation (Tritter, 2009). However, Lukes (2005) describes how power can be understood through the non-decision-making (agenda setting) and ideological dimension, and paper 2 suggests that interest organisations prefer using insider channels, where the organisations try to raise concerns for their service user group and give input that enlightens the other stakeholders. Although non-decision-making and ideological power can be difficult to measure, meeting public stakeholders and promoting one's opinions contributes to deliberation, where the best arguments should, but not always, prevail. Of course, this is Habermas' (1984) ideal version of deliberation forums, and power relations and the self-interest of the stakeholders might hinder this outcome.

Paper 2 also illustrates how working through outsider channels and with a more conflict-oriented strategy can be effective. In these channels, interest organisations may seek power by affecting public opinion and expose what they see as injustice, malpractice or discrimination. For example, paper 2 illustrates how criticism in the media resulted in an improved living facility for people with intellectual disabilities. As such, interest organisations often connect and explain their actions in accordance with a social justice frame, which is often referred to as a type of master frame (Benford & Snow, 2000), used to gain sympathy and recognition in

society by creating external pressure on services and governments. However, paper 2 suggests that organisations prefer maintaining good relationships with public actors. Although this seems logical and may lead to desired results, this development and emphasis on collaboration could result in reducing interest organisations' critical role (Dean, 2010, 2013). Perhaps the increased access to and development of insider channels and interest organisations emphasising competence are signs of the welfare state transforming and reducing interest organisations' criticism.

Papers 1 and 2 illustrate how interest organisations develop formal structures and competence in their organisations and among their representatives. These findings indicate that to increase their influence, interest organisations learn from other organisations and adapt to the field. Thus, they could become more similar to the welfare services and professionals because this might increase the possibility of gaining influence and legitimacy (DiMaggio & Powell, 1983). When service user representatives and public actors interact, their different logic, means and goals will be affected (Andreassen, 2018a, 2018b), and scholars have argued that civil society logic is more fragile to external pressure than professional, which can lead to co-option (Eriksson, 2015, 2018). Selznick (1949) describes co-option as taking others' perspective, understanding and logic as one's own, which has proven to be an issue in the interaction between public actors and interest organisations (Eriksson, 2015, 2018). For example, papers 1 and 2 show that the informants seek to generalise their groups experiences, often by producing reports and that representatives familiarise themselves with research and reports. In this sense, the organisation's logic may be influenced and start to resemble the logic of the professionals (Eriksson, 2015, 2018; Ocasio et al., 2017).

Because representatives of service users usually are less in numbers and resources in this interaction, the chance that they are affected by the professional logic might be more significant than the other way around. This again might lead to less critical organisations. For example, paper 2 describes how the informants preferred strategies that maintained a good relationship with public stakeholders and, thus, were cautious with direct criticism and confrontations. However, the informants also expressed much criticism and room for service improvement in the interviews. It could also be that the interest organisations and public actors often have similar goals and prefer similar means, making collaboration a natural choice (Najam, 2000).

Moreover, the findings also illustrate that interest organisations are not always concerned with cooperation and presenting generalised and research-based experiences. The oppositional strategy (paper 2) and people telling their own stories (paper 1) may illustrate this. As such, in my view the informants seemed very conscious about the organisations' goals and how to go about to gain influence.

To summarise, the findings illustrate how interest organisations use insider and outsider channels to gain influence but still prefer maintaining a good relationship with public actors. Furthermore, interest organisations seem to emphasise developing competence in their organisation and among their representatives. In this development, there might be a risk of co-optation. However, the findings also suggest that interest organisations can be critical and use open conflict strategically. Thus, they may consciously manoeuvre between strategies to impact the welfare services.

### 6.3 Collective user participation: The challenge of making and identifying impact

The findings from papers 2 and 3 illustrate how collective user participation may have various impacts, but it may be challenging to identify. In the following, I discuss the potential benefits and pitfalls of collective user participation, how I understand the concept of impact in the present thesis and potential indicators that can be used to identify the impacts associated with collective user participation.

The findings from papers 2 and 3 suggest that collective user participation might benefit the participating service users, improve public services and increase a groups' inclusion in society. These align with previous research, highlighting empowerment among service users, professional development and improved services as benefits of collective user participation (Mockford et al., 2011; Olsson et al., 2020; Rosenberg & Hillborg, 2016). However, the findings also illustrate how collective user participation might have a harmful or no impact and be challenging to identify, the latter of which can result from tokenistic processes. These findings align with other literature (Daykin et al., 2007; Ocloo & Matthews, 2016; Usher & Denis, 2022), but harmful or no impacts have been little addressed in the research literature related to the service user groups included in the present thesis.

Papers 2 and 3 illustrate that collective user participation is often a process without decision-making power, often understood as indirect participation (Tritter, 2009) or degrees of tokenism (informing, consultation, placation) (Arnstein, 1969), which can make it challenging to identify impacts. However, papers 2 and 3 also suggest that these channels might provide beneficial results and align with research describing the relationship with the public actors as pivotal in promoting or hindering participation (Andreassen et al., 2018b). As such, papers 2 and 3 suggest that the user participation process can affect these professionals' attitudes and knowledge towards service users and user participation, which is a vital goal for interest organisations. In addition to affect the involved professionals, papers 2 and 3 suggest that collective user participation may impact the involved service users, services, overarching policies and politics. These findings align with previous reviews, which have highlighted that both the process and outcome of the process should be considered regarding impacts (Mockford et al., 2011; Olsson et al., 2020; Rosenberg & Hillborg, 2016). However, few scholars discuss how to identify the

impacts of user participation, and a crucial contribution of the papers is to expand the knowledge of how one could address this.

In the papers, I have written impacts *associated* with—and not impacts *of*—collective user participation. This distinction is founded in how I have approached the concept of impact in this project. In the papers, I have addressed impacts through a circular approach inspired by Banks et al. (2017). Banks et al.'s (2017) concept co-impact was developed in participatory action research context and highlights the nonlinear connection between processes and outcomes; the authors argue that the iterative interaction between stakeholders makes a linear understanding challenging, perhaps impossible. In papers 2 and 3, the findings illustrate how the process might affect the stakeholders and their organisations and impact overarching societal levels. Moreover, in paper 2, the informants describe the process of user participation processes in more detail than their impacts, illustrating that identifying the impacts associated with user participation can be a challenge. Because user participation is a phenomenon occurring in the social world with numerous elements to consider, it might be challenging to study as a linear process. Danermark et al. (2019) describe the challenges of identifying causality in the social world, which they note as an open system. Accordingly, it can be challenging to study the impacts associated with collective user participation as a linear process. Therefore, I believe that applying a circular understanding of impact and seeking to identify tendencies might be a useful approach.

Knowledge of the impacts associated with user participation have been underscored as vital for genuine democratisation and service improvement (McKinley & Yiannoullou, 2012). Therefore, indicators of success or failure would be helpful. The findings from the papers provide knowledge of potential indicators that, in combination with other research literature, can be used to develop a framework for identifying the impacts associated with collective user participation. Developing a framework for this is outside this thesis' scope. However, papers 2 and 3 point to some potential indicators to include in such a framework. The findings from these papers describe a range of impacts, highlighting both the participation process' impact on the involved stakeholders and how these have made changes at services, organisations, system, policy and politics. As such, developing indicators that focus on both the process and how it has affected other levels can be helpful. However, as discussed above, one should also be aware of harmful and no impact.

Related to the process of user participation, papers 2 and 3 illustrate that the indicators for the involved service users could include them developing knowledge and skills, an increased feeling of empowerment, change attitudes towards services and increase their network. In addition, papers 2 and 3 suggest that participation may lead to development in interest organisations. For the professionals involved, papers 2 and 3 describe improved knowledge about and attitudes towards service users and user participation. In addition, the papers describe improved relationships and interactions between the stakeholders as a result of the participation process. At the organisational level, papers 2 and 3 illustrate that user participation might lead to adjusting service delivery and professional practice, organisational arrangement (e.g., relocating a service, more staff), policy changes and new or adjusted participation channels. Papers 2 and 3 suggest that the impact on political and societal levels are vaguer, and there were many general descriptions of affecting the attitudes of politicians, the public opinion and creating attention around and visibility of the service user group. However, paper 2 suggests that user participation may impact municipalities' budgets, political agendas, legislation and official documents. As such, the findings from papers 2 and 3 show that there are some potential indicators, even at these levels.

In sum, the findings suggest that collective user participation can impact the involved stakeholders, interest organisations, welfare services and policy. However, these impacts could also be challenging to identify. Therefore, the present thesis provides helpful knowledge for developing indicators to identify impacts associated with collective user participation. This knowledge may help improve user participation and contribute to service improvement, democratisation and avoiding the mentioned pitfalls.

## 7.0 Conclusion

The current thesis has addressed the overarching research question: *How do representatives in interest organisations perceive user participation?* The major findings concern representation, strategies and impacts. The findings suggest that it varies how people in vulnerable life situations participate in organisational activities in interest organisations and that participation through providing personal stories is more common than being a spokesperson. Consequently, I have used the term interest organisation rather than service user organisation to illustrate that service users participate and are represented in different ways. Furthermore, the findings illustrate that interest organisations seek to influence service development through various channels, including outsider channels. Interest organisations also seem to manoeuvre between different strategies, including cooperation, opposition and negotiation, to gain influence. Thus, interest organisations may have several ways of obtaining influence, but tokenism and co-optation are the potential pitfalls besides not accessing channels of influence. The present thesis also suggests that the impacts associated with participation include empowering involved service users and their organisations, changing professionals' attitudes and practices, contributing to organisational development in the welfare services and affecting policies. However, the findings illustrate that the impacts can be challenging to identify and that participation has potentially harmful or no impacts.

This thesis has several limitations. The present thesis addresses several groups of people in vulnerable life situations. Even if this has provided a range of valuable perspectives, only two or three informants from each group are included. Hence, there is a lack of depth in the represented group. There are also limitations related to which organisations have been included. There exists a range of organisations representing the included groups; hence, only a minor part of the relevant organisations has been included. Because interest organisations are not neutral actors, there may be different perceptions of user participation among other organisations. Many groups are not represented or participate in organisations, and these voices are not included in the material. The present study also addresses the phenomenon indirectly, and thus, it does not describe the actual practice of user participation or its impacts.

Despite these limitations, the findings in the present thesis may have implications for future research and practice. The thesis contributes to theoretical development by expanding the



understanding of collective user participation to include outsider channels, for example, using the media. Moreover, the present thesis provides knowledge of how better to understand interest organisations and the representation of people in vulnerable life situations and how to approach impacts associated with user participation. Regarding the latter, the thesis introduces a point of departure for developing a framework for identifying impacts. Because the present study has explored the research topic indirectly, future research should study the practice of user participation through interest organisations directly. Researchers should also pay more attention to the impacts associated with user participation because this seems like an often-neglected topic. In addition, future research could explore how people in vulnerable life situations could participate more directly, for example, by developing new models of collective user participation in collaboration with interest organisations and public actors. There is also a need for more research on interest organisations for people in vulnerable life situations, for example, related to the implications of organisational structures, professionalisation, participation of people with service user experience and funding.

For practice, the findings from the present thesis provide valuable knowledge for interest organisations and welfare services. The findings can contribute to an increased focus on the direct participation of people with service user experience in both the interest organisations and the welfare services. At the same time, the findings point to challenges, emphasising the importance of the interest organisations' work to ensure participation for people in vulnerable life situations. Furthermore, the findings can inspire interest organisations to expand their repertoire and practice by illuminating different channels and strategies to make impacts. For the welfare services and society, the findings illustrate how user participation might be little accessible for people in vulnerable life situations and sometimes also for representatives of interest organisations. This implies a need for adjusting existing or developing new models of participation. Interest organisations and public actors should also be aware of how the dynamics between the stakeholders affect them and expand the room for criticism. Finally, all stakeholders should pay more attention to impacts. This may increase the likelihood of democratisation and service improvement while reducing the risk of tokenistic user participation processes and potentially harmful side effects for stakeholders.

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## Appendix 1



# Mennesker i sårbare situasjoner i helse- og sosialtjenester. Hvordan beskrives og evalueres medvirkning?

**Referanse**

505481

**Status**

Under forhåndsvurdering

Åpne Meldeskjema

☰ Vurdering

Skriv melding her. Vær oppmerksom på at meldingen du skriver blir synlig for din institusjon i Meldingsarkivet og alle som får delt tilgang til prosjektet ditt.

Send melding

**Underveisvurdering**

04.02.2021 09:00

Etter avtale med institusjonen din skal NSD hvert andre år avklare status for behandlingen av personopplysningene.

Vi ber deg derfor om å sjekke meldeskjemaet og bekrefte at opplysningene er korrekte ved å trykke «Bekreft innsending» på siden «Send inn».

Dersom det er endringer i behandlingen som kan ha betydning for vurderingen må meldeskjemaet oppdateres før du sender det inn. Spørsmål kan stilles i meldingsdialogen. [Les om hvilke endringer som må meldes.](#)

Institusjonen din blir varslet hvis du ikke sender inn meldeskjemaet innen 30 dager.

**Melding fra Eva Payne**

23.09.2020 16:08

Hei, takk for meldingen. Vi har tatt informasjonen til orientering.

**Melding fra Jan Marius Kristiansen Gathen**

22.09.2020 12:34

Hei.

På grunn av koronasituasjonen vil jeg nå i avslutningen av datainnsamlingen gjennomføre noen intervjuer via telefon.

Hilsen,

Jan Marius

**Melding**

04.02.2019 14:45

Det innsendte meldeskjemaet med referansekode 505481 er nå vurdert av NSD.

Følgende vurdering er gitt:

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med

personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 04.02.2019, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

#### MELD ENDRINGER

Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringer gjennomføres.

#### TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle alminnelige kategorier av personopplysninger frem til 30.11.2022.

#### LOVLIG GRUNNLAG

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

#### PERSONVERNPRINSIPPER

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke behandles til nye, uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

#### DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

#### FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og/eller rådføre dere med behandlingsansvarlig institusjon.

#### OPPFØLGING AV PROSJEKTET

NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!

Kontaktperson hos NSD: Eva J B Payne  
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

#### Melding fra Eva Payne

04.02.2019 14:42

Hei,

Vi minner om at informantene dine har taushetsplikt, og at de ikke kan gi opplysninger som kan identifisere en

enkeltperson direkte eller indirekte, med mindre det blir innhentet samtykke fra den enkelte til dette. Det er svært viktig at intervjuene gjennomføres på en slik måte at taushetsplikten overholdes. Intervjuer og informant har sammen ansvar for dette, og bør innledningsvis i intervjuet drøfte hvordan dette skal håndteres. Vi forutsetter at dere er forsiktige ved å bruke eksempler.

Vurderingen sendes innen kort tid.

Med vennlig hilsen,

Eva J B Payne  
Rådgiver  
55 58 27 97

**Melding**

17.12.2018 15:29

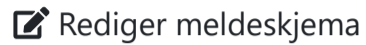
Kvittering på at meldeskjema med referansekode 505481 er innsendt og mottatt.

dd11d2d3

# Meldinger

**Status**

Avsluttet



Skriv melding...

Send melding

**Avsluttet**

07.12.2022 09:45

Vi har mottatt bekreftelse på at behandlingen av personopplysningene er avsluttet og at data enten er anonymisert, slettet eller arkivert.

**Sluttvurdering**

06.12.2022 09:00

*Skjult melding***Vurdert**

23.03.2021 14:01

Behandlingen av personopplysninger er vurdert.

[Les vår vurdering](#)**Sendt til vurdering**

19.02.2021 09:07

**Underveisvurdering**

04.02.2021 09:00

**Melding fra Eva Payne**

23.09.2020 16:08

Hei, takk for meldingen. Vi har tatt informasjonen til orientering.

**Melding fra Jan Marius Kristiansen Gathen**

22.09.2020 12:34

Hei.

På grunn av koronasituasjonen vil jeg nå i avslutningen av datainnsamlingen gjennomføre noen intervjuer via telefon.

Hilsen,

Jan Marius

*Skjult melding***Vurdert**

04.02.2019 14:44

Behandlingen av personopplysninger er vurdert.

[Les vår vurdering](#)**Melding fra Eva Payne**

04.02.2019 14:42

Hei,

Vi minner om at informantene dine har taushetsplikt, og at de ikke kan gi opplysninger som kan identifisere en enkeltperson direkte eller indirekte, med mindre det blir innhentet samtykke fra den enkelte til dette. Det er svært viktig at intervjuene gjennomføres på en slik måte at taushetsplikten overholdes. Intervjuer og informant har sammen ansvar for dette, og bør innledningsvis i intervjuet drøfte hvordan dette skal håndteres. Vi forutsetter at dere er forsiktige ved å bruke eksempler.

Vurderingen sendes innen kort tid.

Med vennlig hilsen,

Eva J B Payne

Rådgiver

55 58 27 97

*Skjult melding***Sendt til vurdering**

17.12.2018 15:29

## Appendix 2

## Vil du delta i forskningsprosjektet

”Helse- og sosialtjenester for personer i sårbare situasjoner. En studie av representanter for interesseorganisasjoners perspektiver på individuell og kollektivt medvirkning.”?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å utvikle kunnskap om medvirkning for mennesker med i sårbare situasjoner, sett fra perspektivet til representanter i bruker- og interesseorganisasjoner. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

### Formål

Studien er del av et doktorgradsprosjekt ved VID vitenskapelig høyskole. Medvirkning er en sentral rettighet og et ideal i helse- og sosialtjenestene. Likevel er det vanskelig å gjennomføre og evaluere. Formålet med prosjektet er å utvikle kunnskap om hva medvirkning er og hvordan dette kan evalueres, relatert til mennesker i sårbare situasjoner i helse- og sosialtjenester. Med mennesker i sårbare situasjoner, menes det mennesker som på grunn av sykdom, livssituasjon o.l. har utfordringer med å utøve autonomi i eget liv. Dette kan gjelde i mange situasjoner, men handler i prosjektet om medvirkning i helse- og sosialtjenester. På grunn av kronisk sykdom, livssituasjon eller samfunnsmessige barrierer kan en ha utfordringer med å medvirke i tjenester en benytter seg av. Medvirkning ses som den demokratiske retten borgere har til å være med å påvirke sitt eget liv. Dette innebærer at mennesker ses som ekspert på seg selv. Studien fokuserer på perspektivet til representanter i bruker- og interesseorganisasjoner. Forskningsspørsmålet i studien er:

- Hva opplever representanter i brukerorganisasjoner som medvirkning?

Forskningsprosjektet er finansiert av Norges Forskningsråd gjennom det overordnede prosjektet Challenges of Participation. Dette er et samarbeidsprosjekt mellom VID vitenskapelig høyskole, OsloMet Storbyuniversitetet og Høgskolen på Vestlandet. Informasjon om denne studien finnes på:

<https://www.vid.no/forskning/forskningsgrupper/>

<https://www.chapar.no/>

### Hvem er ansvarlig for forskningsprosjektet?

VID vitenskapelig høyskole er ansvarlig for prosjektet.

### Hvorfor får du spørsmål om å delta?

Utvalget i studien representerer bruker- og interesseorganisasjoner som primært arbeider innen helse og velferdssektoren. Du er spurt fordi du representerer en av disse, og kan tenkes å bidra med å utvikle kunnskap i tråd med formålet i prosjektet. Det er planlagt å rekruttere mellom 8 og 15 deltakere i studien.

### Hva innebærer det for deg å delta?

Hvis du velger å delta i prosjektet, innebærer det at du deltar i et intervju. Det vil ta deg ca. 60 minutter. Intervjuet inneholder spørsmål om hvilke tanker og erfaringer du har om medvirkning for gruppen du representerer i helse og velferdstjenester. Det vil bli brukt lydopptaker i intervjuet, dette vil senere bli transkribert til tekst.

### Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake

uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

### **Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger**

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Følgende personer vil ha tilgang til opplysningene:  
Jan Marius Gathen, PhD-kandidat.  
Tor Slettebø, Professor, hovedveileder.  
Erik Skjeggstad, Førsteamanuensis, biveileder.  
Torgeir Sørensen, Førsteamanuensis, biveileder.
- Navnet og kontaktopplysningene dine vil lagres innelåst og adskilt fra datamaterialet. Datamaterialet vil anonymiseres i transkripsjonen og lagres på sikker server ved VID vitenskapelig høgskole og utilgjengelig for andre en prosjektansvarlig og veiledere.
- Du vil ikke kunne gjenkjennes i en publikasjon.

### **Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?**

Prosjektet skal etter planen avsluttes i august 2022. Alle personopplysninger og lydopptak makuleres/slettes innen prosjektslutt.

### **Dine rettigheter**

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

### **Hva gir oss rett til å behandle personopplysninger om deg?**

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra VID vitenskapelig høgskole har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

### **Hvor kan jeg finne ut mer?**

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- VID vitenskapelig høgskole ved Jan Marius Gathen, på epost ([jan.marius.kristiansen.gathen@vid.no](mailto:jan.marius.kristiansen.gathen@vid.no)) eller telefon: 22 96 38 15.
- Vårt personvernombud: Nancy Liu, på epost ([nancy.yue.liu@diakonhjemmet.no](mailto:nancy.yue.liu@diakonhjemmet.no)) eller telefon 93 85 62 77.
- NSD – Norsk senter for forskningsdata AS, på epost ([personverntjenester@nsd.no](mailto:personverntjenester@nsd.no)) eller telefon: 55 58 21 17.

Med vennlig hilsen

Jan Marius Gathen  
Prosjektansvarlig



---

## Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *Mennesker i sårbare situasjoner i helse- og sosialtjenester. Hvordan beskrives og evalueres medvirkning?*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

- å delta i intervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. august 2022.

---

(Signert av prosjektdeltaker, dato)

## Appendix 3

## Intervjuguide

Organisasjon:

Rolle i organisasjonen:

Bakgrunnsinformasjon:

### **Innledning**

Informasjon om tema, studien og samtykke.

### **Hoveddel**

1. Hva er målet med organisasjonen?
2. Hvilken erfaring har organisasjonen deres med medvirkning?
3. Hvilken betydning har denne medvirkningen hatt?
4. Hva tenker du er gode resultater for dere?
5. Hvordan ser du om dere har lykkes/mislykkes?
6. Hvordan medvirker de dere representerer?
7. Hva fremmer og hemmer medvirkning for gruppen du jobber med?
8. Hva tenker du om forutsetninger for å medvirke?
9. Har medvirkning noen begrensinger eller negative sider?
10. Hvordan tenker du at man kan evaluere medvirkning/se resultater?
11. Hvis du skulle laget en evaluering, hvordan ville den sett ut?

### **Oppsummering**

12. Er det noe du ønsker å ta opp som er viktig å formidle?
13. Hvordan opplevde du å være med på intervjuet?

## Papers

### ***Paper 1***

Gathen, J. M., Slettebø, T., & Skjeggstad, E. (2023). The participation of people in vulnerable situations in interest organisations: A qualitative study of representatives views. *Journal of Social Policy*, 1–18. <https://doi.org/10.1017/S0047279423000089>

### **Abstract**

People in vulnerable situations have the same right as others to participate in public spheres and influence health and welfare services. However, organisations that support these people and promote their interests are essential to their participation. This study investigated how people in vulnerable situations with lived experiences of using public services participate in organisations representing their interests. Fourteen representatives from eight interest organisations were interviewed. The first theme we developed - namely, *participation as representatives of the organisations*, revealed that a spokesperson's role is connected to competence and that users of public services rarely obtain such a position. However, people with experience of using public services participate as living examples in external activities, increasing the groups' visibility through their physical presence and their stories. The second theme was titled *participation in organisational activities*. The extent to which people with lived experiences participate in formal meetings varies, but they are often consulted by the organisations and attend events and informal gatherings. Notably, people in vulnerable situations interact with and, thus, influence the serviceproviding organisations. This article discusses the findings in light of representation theory and their implications for practice.

## ***Paper 2***

Gathen, J. M., Slettebø, T., & Skjeggstad, E. (2023) Three strategies of user participation. Interest organisation representatives' views on how they make an impact on service development, *Nordic Social Work Research*, DOI: 10.1080/2156857X.2023.2256742

### **Abstract**

This study explores how interest organisations for people in vulnerable situations participate in the development of welfare services. We interviewed 14 people from interest organisations in Norway. To get a broad perspective on the topic, we recruited people from organisations representing people with dementia, intellectual disabilities and substance use problems, asylum seekers, children in contact with child welfare services and children of parents with substance use problems. In the thematic analysis, we developed three themes related to how the informants described their organisations' dealings with services, municipalities, politicians and other public actors. The cooperative strategy refers to participation as an arena for collaboration and partnership in which they assumingly would share interests and goals. The oppositional strategy shows how the participants would use open conflict and confrontation as a tool for influence, often through the media and complaint systems. The third strategy, negotiation, illustrates how organisations would manoeuvre between being critical and constructive while maintaining a relationship with public actors. The article discusses how interest organisations manoeuvre between these strategies and the benefits and disadvantages of each strategy. Furthermore, we discuss how interest organisations may prefer different strategies depending on their goals and relationship with public actors.

### ***Paper 3***

Gathen, J. M., Slettebø, T., & Skjeggstad, E. (2022). User participation among people in vulnerable situations at service level. A scoping review exploring impact for individual stakeholders and services. *Nordisk Velfärdsforskning* [Nordic Welfare Research] 7(1), 52–67. <https://doi.org/10.18261/nwr.7.1.4>  
*Velfärdsforskning*

#### **Abstract**

User participation is an attempt to democratise and improve health and welfare services. Although central political guidelines emphasise user participation, there is limited knowledge of its impact, especially regarding user participation at service level, where the aim is to improve services in general. This knowledge gap applies particularly to groups of users who face difficulties in exercising autonomy. This scoping review aimed to explore the impact of user participation at service level for people in vulnerable situations and how this process affects the involved stakeholders. From a literature search that yielded 4,964 hits, 22 articles were included in the final review. The finding shows that, at the individual level, user participation could facilitate personal empowerment among the involved users and affect the involved professionals' knowledge. However, some users also experienced disempowerment due to their involvement in user participation activities. Impacts at the organisational level were that user participation resulted in changes in attitudes, knowledge, culture, professional practice, interventions, an increased number of employees, organisational development and changes in policies. This review also contributes to theoretical development by expanding the knowledge of how the impact of user participation may be perceived, and argues for a circular understanding of impact.

