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Dissertation no.63
Ann Britt Sandvin Olsson

Unrealized Potentials of Patient Participation in Primary Healthcare Service Development

A Qualitative Study of Collaboration, Context, and Impact.

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in Partial Fulfilment of the Requirements
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Scientific environment

The scientific environment of this thesis comprises several actors from the practice field, patient organizations, and academic environments. They have all contributed to the research process and my development as a researcher.

The Ph.D. project's research focus and objective were developed in a workshop facilitated by me. The process and those involved are described in Appendix 1.

The research team members offered their insights and support throughout the research process. Their titles at the start of the Ph.D. project were:

- Anita Strøm (main supervisor), associate professor Ph.D., Faculty of Health Studies, VID Specialized University
- Una Stenberg (co-supervisor), senior researcher Ph.D., Norwegian National Advisory Unit on Learning and Mastery in Health, Oslo University Hospital, and Frambu Competence Center for Rare Diseases
- Tor Slettebø (co-supervisor), Professor Ph.D., Faculty of Social Studies, VID Specialized University
- Mette Haaland-Øverby (co-researcher with experiential knowledge), experience consultant/special advisor MHSc, Norwegian National Advisory Unit on Learning and Mastery in Health, Oslo University Hospital
- Ann Britt Sandvin Olsson (Ph.D. student), Norwegian National Advisory Unit on Learning and Mastery in Health, Oslo University Hospital, and Center of Diakonia and Professional Practice, VID Specialized University, Oslo

The research team´s areas of expertise is displayed in Table 1. Later in the research process, the research team´s expertise was supplemented by my colleague and senior researcher André Vågan´s expertise concerning the science of philosophy and methodology.

Table 1. The research team´s areas of expertise at the start of the Ph.D. project.

Research team members	User involvement	Empower-ment	Patient education	Involvement in research	Public Health
Anita Strøm, PhD	x	x	x	x	x
Una Stenberg, PhD	x		x	x	x
Tor Slettebø, PhD	x	x		x	
Mette Haaland-Øverby, MHSc	x	x	x	x	
Ann Britt Sandvin Olsson, PhD candidate	x	x	x		x

The Ph.D. project started on March 1st, 2018, when I entered the Ph.D. program of the Center of Diakonia and Professional Practice at VID Specialized University in Oslo. There, I became a member of the research network “User Participation in Health and Welfare Services” (UPHEW)[1]. The members provided an academic environment for discussing and exploring issues concerning patient participation and for contributing feedback to article drafts and academic texts.

In September 2018, I joined the Researcher School of Municipal Healthcare Services[2]. Professor Marit Kirkevold headed the program. It was a partnership between the University of Oslo, Oslo Metropolitan University, the University of Bergen, Western Norway University of Applied Sciences, Norwegian University of Science and Technology (Gjøvik), Nord University, and the Arctic University of Norway. Participation in the research school contributed to an academic environment to explore and discuss primary healthcare issues and research. Regular interactive webinars led by professors and associate professors corresponding to the phases of the Ph.D. project´s research process enabled receiving feedback and contributing it to fellow Ph.D. students.

The Ph.D. project's mixed advisory panel was established in the spring of 2018. The panel comprised three patient representatives and three healthcare professionals with extensive experience in patient participation when developing health services. The members and their affiliations during the research process were:

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[1] See https://wo.cristin.no/as/WebObjects/cristin.woa/13/wa/presentasjonVis?pres=535427&type=GRUPPE&la=en

[2] See https://www.med.uio.no/helsam/forskning/forskerskoler/muni-health-care/

- Astrid Torgersen Lunestad, the Musculoskeletal Health Research and Dissemination Unit (FORMI), Oslo University Hospital, and the Norwegian Association for Women's Pelvic Joint Health (in Norwegian: Landsforeningen for kvinnelig bekkenleddshelse)
- Bente Sandvik*, Trondheim municipality
- Carina Kolnes, Indre Østfold municipality
- Edgar Wammervold, The Norwegian Rheumatist Association (in Norwegian: Norsk Revmatikerforbund)
- Ingeborg Kristiansen, Stange municipality
- Kari Fredriksen, the Learning and Coping Center, Stavanger University Hospital
- Øivind Skotland, Norwegian Association of the Hearing Impaired (in Norwegian: Hørselshemmedes landsforening)

*Bente Sandvik withdrew from the mixed advisory panel for personal reasons in December 2018. Kari Fredriksen replaced her from May 2019.

Meetings and workshops during the research process contributed to an environment for exploring and discussing the practice of patient participation in health service development.

Acknowledgements

Thank you, first, to the Dam Foundation and my workplace, the Norwegian National Advisory Unit on Learning and Mastery in Health, Oslo University Hospital, for making this doctoral work possible. It has been a privilege to conduct this research project.

Secondly, many thanks to my supervisors, Anita Strøm, Tor Slettebø, and Una Stenberg, for providing guidance, insights, and steady novice researcher support during this process. Many thanks also to the co-researcher, Mette Haaland-Øverby, for sharing knowledge, discussions, and companionship during the fieldwork and the work process. Thank you also to André Vågan for offering valuable supervision from the sideline.

Thirdly, thank you to the members of the mixed advisory table for sharing your knowledge, experience, and expertise and for enthusiastically supporting this doctoral work from start to end. Thanks for additional discussions and webinar contributions, Edgar Wammervold and Kari Fredriksen.

A special thank you goes to the contacts in the four municipalities participating in this project: you made participant recruitment and conducting fieldwork, focus groups, and individual interviews a breeze. Special thanks to every one of you 55 informants who shared your diverse experience to the benefit of this research project.

Thanks to the ever-helpful Oslo University Medical Library senior librarians Hilde Strømme, Josephine Jeanette Mikaela Aamodt, and Tarjei Fiskå Werner for conducting the literature searches. Thank you to Bjørg Kristin Haaland for your transcription help. Many thanks to Janet Holmén, the language consultant of the articles and extended abstract, for meticulously scrutinizing and clarifying formulations and for flexibility in the process. Thank you to the associate professors Ida Lillehagen (University of Oslo) and Marianne Rodriguez Nygaard (VID Specialized University) for their insights in the mid-way-seminar, to associate professor emerita Sissel Seim (Oslo Metropolitan University) for contributing her expertise in the so-called 90% Ph.D. seminar, and to professor emerita Magdalene Thomassen (VID Specialized University) for good philosophy of science discussions.

To my invaluable study group initially constituting Muni-Health-Care / the Western Norway University of Applied Sciences Ph.D. students: thank you for a supportive, forward-driving novice researcher environment and friendship, Kristine Berg Titlestad, Susanne Grødem Johnson, and Trine-Lise Dræge Steinskog.

Thank you to all experienced and novice researchers in the VID researcher network “User Participation in Health and Welfare Services” for sharing your expertise and knowledge, reading and debating my drafts of various qualities, and for good laughs. Thank you to Ingebjørg Haugen, associate professor (VID Specialized University), who took the time to provide insightful comments on the extended abstract draft, and to Jan Marius Gathen for Ph.D. student companionship.

To all my colleagues at the Norwegian National Advisory Unit on Learning and Mastery in Health: heartful thanks for your support, sharing of knowledge and expertise whenever needed, and friendship. Thank you for ongoing discussions about the meaning of involvement, Liv-Grethe K. Rajka. Thank you for podcast contributions, Hilde Blindheim Børve, and for webinar support, Anita Røyneberg Alvheim and Cecilia Sønstebø – and for help with the thesis´s layout, Cecilia.

Last, thanks to my family and friends for always reminding me of what is important in life. Thank you to Christian for always having my back and Abraham for adding spunk to my life.

Oslo, December 2023

Ann Britt Sandvin Olsson

Sammendrag

Denne avhandlingen bidrar med ny kunnskap om brukermedvirkning i utvikling av kommunale helsetjenester basert på tre perspektiver: brukerrepresentanter, fagpersoner og fasilitatorer. Avhandlingen har fokus på samarbeidet som brukermedvirkningen forutsetter og hvilken «impact» samarbeidet har. Fagpersoner som legger til rette for og leder dette samarbeidet kalles fasilitatorer. Hvert perspektiv er adressert i en egen artikkel. Avhandlingen inkluderer også en litteraturstudie om «impact» av medvirkning i utvikling av helsetjenester for voksne. I mangel av et dekkende norsk begrep brukes termen «impact» i det videre for å omtale hvilken betydning, effekt, nytte, utbytte, eller virkning brukermedvirkning kan ha.

Tradisjonelt er det en oppfatning at brukerrepresentanter har mindre makt enn fagpersoner når partene samarbeider. For å styrke kunnskapsgrunnlaget om brukermedvirkning og denne måten å utvikle helsetjenester på, fokuseres det i avhandlingen på den relasjonelle dynamikken som utspiller seg i dette samarbeidet. Overordnet forskningsspørsmål er:

> Hvilken betydning kan samarbeidet ved brukermedvirkning i utvikling av helsetjenester ha for brukerrepresentanter, fagpersoner og fasilitatorer, og hvilken impact kan samarbeidet ha?

Avhandlingen har et kvalitativt, utforskende og samarbeidsbasert forskningsdesign. Denne tilnærmingen anses som hensiktsmessig for å utforske og beskrive hvordan deltakere erfarer et fenomen. Designet er forankret i en hermeneutisk fenomenologisk tradisjon. Deltakerne ble inkludert basert på deres erfaringers relevans for å besvare forskningsspørsmålet. De kom fra fire norske kommuner som praktiserer brukermedvirkning i utvikling av helsetjenester. Ved å utforske og beskrive erfarne kommuners utfordringer kan funnene være overførbare til kommuner med mindre medvirkningsfokus.

De fire kommunene er lokalisert i ulike deler av Norge, har ulikt befolkningsgrunnlag og ulikt erfaringsgrunnlag med å praktisere brukermedvirkning i utvikling av helsetjenester. Det ble gjennomført én fokusgruppe med brukerrepresentanter og en fokusgruppe med fagpersoner i hver av de fire kommunene. I tillegg ble det gjennomført 12 individuelle

intervjuer med henholdsvis seks brukerrepresentanter og seks fasilitatorer. Fagpersonene og fasilitatorene hadde forskjellige administrative og kliniske stillinger innen somatikk, psykisk helse og rus, og representerte 11 ulike profesjoner. Brukerrepresentantene kom fra 15 organisasjoner og representerte helseutfordringer som autismespekterforstyrrelser, demens, hjerte- og lungesykdom, hørselshemming, kreft, metabolsk syndrom, osteoporose, revmatoid artritt og slag. Datamaterialet ble analysert ved hjelp av tematisk analyse.

Medvirkning i forskning danner grunnlag for kunnskapen som er utviklet i denne avhandlingen. Forskningsteamet inkluderte en medforsker med brukererfaring. Et panel med rådgivende mandat har også bidratt i kunnskapsutviklingen. Panelet består av tre brukerrepresentanter og tre fagpersoner. Alle diskuterte sine fordommer og forestillinger om brukermedvirkning i utvikling av helsetjenester for å kunne bruke dette aktivt inn i forskningsprosessen. Samtlige anså medvirkning både som nødvendig for å forbedre kvaliteten på helsetjenester og som en demokratisk rettighet.

Artikkel 1, litteraturstudien, utforsket hvordan forskningslitteraturen beskriver impact av voksne brukerrepresentanters medvirkning i utvikling av helsetjenester. Funnene viste at samarbeidet hadde både positiv og negativ på de involverte partene, samt impact på måten de samarbeidet. Funnene viste også at medvirkningen hadde impact på sluttbrukernes opplevelse av helsetjenestene, fagpersoners kliniske utøvelse og organisasjonens prioriteringer, tjenesteleveranser og medvirkningskultur. Litteraturstudien bidro til å identifisere kunnskapshull om hvordan brukerrepresentanter og fagpersoner opplever det å samarbeide om å utvikle helsetjenester, samt om impact av og kontekstens rolle for samarbeidet.

Artikkel 2 undersøkte fagpersoners opplevelser av å samarbeide med brukerrepresentanter for å utvikle kommunale helsetjenester. Funnene antydet at fagpersonene anså det å samarbeide med brukerrepresentantene som sine kollegaer, noe som kompliserte samarbeidet. Samtidig som de så nytten av medvirkningen, var det utfordrende å balansere mellom rollen som autoritet og likeverdig samarbeidspartner. Dette opplevdes som utfordrende. Fagpersonene strevde også med å skille mellom hva som var brukerrepresentantenes kollektive innspill og deres private erfaringer i arbeidet med å utvikle en helsetjeneste som de selv kunne stå inne for og deres kollegaer ville støtte opp om.

Artikkel 3 handlet om hvordan fasilitatorer så på sin rolle som tilretteleggere for medvirkning. Funnene viste at fasilitatorenes oppgaver krevde kontinuerlig og systematisk arbeid på mange organisatoriske nivåer. Funnene viste at før fasilitatorene kan utvikle helsetjenester med brukermedvirkning, måtte de etablere et nettverk av personer med brukererfaring. Disse personene måtte kunne samarbeide godt med andre og bidra med erfaringer på vegne av flere enn seg selv. Fasilitatorene brukte også mye tid på å oppmuntre til brukermedvirkning i kommunen og til å finne fagpersoner som vil samarbeide med brukerrepresentanter. Sist, men ikke minst, måtte fasilitatorene vise lederne nytten av brukermedvirkning for å få deres støtte, ressurser og nok tid til å utvikle tjenester på denne måten. Én kommune hadde et eget budsjett for brukermedvirkning. De andre manglet både støtte og ressurser.

Artikkel 4 utforsket kontekstuelle faktorer som brukerrepresentanter opplever har betydning for deres medvirkning i utvikling av kommunale helsetjenester. Funnene viste at brukerrepresentantene mente primærhelsetjenesten manglet en overordnet plan for brukermedvirkning, noe de oppfattet som et lederansvar. Mangelen på en slik plan hadde betydning for hvilke ressurser som ble brukt på medvirkning og for fagpersoners forståelse av hvem de skal involvere når og hvordan. Brukerrepresentantene opplevde også at primærhelsetjenesten manglet en kultur som støtter opp om medvirkning. De understrekte at om fagpersoner ikke verdsetter deres bidrag eller inkluderer dem som fullverdige samarbeidspartnere i prosessen, gjør det medvirkning mindre meningsfylt, mer komplisert og mer arbeidskrevende.

Avhandlingens diskusjon er tredelt og belyser relasjonelle og kontekstuelle forhold fra brukerrepresentanters, fagpersoners og fasilitatorers ståsted. Det første temaet handler om kompleksitet og spenninger i samarbeidet mellom brukerrepresentanter og fagpersoner. Det andre omhandler kontekstuelle barrierer for brukermedvirkning ved utvikling av helsetjenester. Det tredje temaet retter fokuser mot potensialet for å oppnå positiv impact av medvirkning og å unngå negative følger av samarbeidsbasert helsetjenesteutvikling.

Avhandlingen belyser hvordan brukerrepresentanter, fagpersoner og fasilitatorer må manøvrere i grensesnittet mellom politiske idealer om brukermedvirkning og slik dette i realiteten utspiller seg i praksis. For å samarbeide konstruktivt må samtlige kjenne på usikkerhet og håndtere en rekke hindringer. Funnene indikerer at å likestille fagpersoner og brukerrepresentanter i samarbeidet bidrar til å komplisere relasjonen mellom dem. Fagpersoner er usikre på hvordan inkludere innspill fra brukerrepresentanter, og partenes ulike kunnskapsbehov kan ytterligere komplisere prosessen. Samtidig er brukerrepresentantene usikre på hva deres innspill vil bety for prosessen og det endelige resultatet. Funnene tyder videre på at kommunens kultur og støtte for medvirkning i helsetjenesteutvikling kunne vært bedre. Ledere og fagpersoner synes å trenge kunnskap om hva brukermedvirkning er. Det kan også være hensiktsmessig at brukerrepresentanter har kunnskap om hvordan håndtere situasjoner som oppstår grunnet fagpersoners begrensede kjennskap til medvirkning og dens eventuelle negative konsekvenser. For å utnytte mulighetene som ligger i å utvikle helsetjenester i et partnerskap mellom brukerrepresentanter og fagpersoner, er det viktig å forstå impact av både samarbeidsprosessen i seg selv og resultatene av denne, samt kjenne til eventuelle negative følger. Fagpersoner og brukerrepresentanter kan jobbe sammen for å forbedre helsetjenester på forskjellige måter. Ved å ta hensyn til målet med tjenesteutviklingen, kontekstuelle faktorer, ønsket impact og tilgjengelige ressurser, kan man finne gode måter å samarbeide på.

Avhandlingen bidrar til en dypere forståelse om hvilke utfordringer, usikkerheter og kontekstuelle barrierer brukerrepresentanter, fagpersoner og fasilitatorer må overvinne for å samarbeide konstruktivt. Samarbeidets kompleksitet understreker viktigheten av at kyndige fasilitatorer leder prosessene – med støtte fra ledelsen. Det synes nødvendig å ta samarbeidsutfordringene på alvor for å styrke kommunal medvirkningspraksis. En diskusjon på politisk og kommunalt nivå om prioritering og implementering av brukermedvirkning i helsetjenesteutvikling synes også å være behov for. Denne avhandlingens funn indikerer at kommunen er lite forberedt på å inkludere brukerrepresentanter i arbeidet med å forbedre helsetjenester.

Summary

The thesis contributes new knowledge about patient participation in primary healthcare service development from three perspectives: healthcare professionals, patient representatives, and internal facilitators. The thesis focuses on the collaboration among these parties and its impact. Each perspective is covered in one article. The thesis also includes a scoping review of the research literature on the impact of adult patient participation in the development of health services.

This thesis shifts the focus from the binary view of power dynamics between professionals and representatives to emphasize relational dynamics. Aiming to strengthen the practice of involvement, the thesis seeks to explore the following overall research:

> What meaning can the collaboration in health service development with patient participation have for healthcare professionals, patient representatives, and internal facilitators, and what impact can their collaboration have?

The thesis design is qualitative, explorative, and collaborative. It is inspired by a hermeneutic phenomenological tradition. The research approach is considered appropriate to explore how participants perceive a research phenomenon. The participants were purposely sampled from four Norwegian municipalities that practice patient participation in primary healthcare service development. The assumption was that their challenges were representative of others with less focus on involvement. While the findings cannot be generalized, they may thus be transferable to other contexts.

The municipalities are located in different parts of Norway and have different population sizes, and different types and amounts of experience of conducting patient participation in health service development. Four focus groups with a total of 23 patient representatives, four focus groups with a total of 26 healthcare professionals, and 12 individual interviews with six facilitators and six representatives were conducted locally. The professionals and facilitators had different administrative and clinical positions within somatic and mental healthcare services and represented 11 professional backgrounds. The representatives were affiliated with 15 patient organizations representing conditions such as autism spectrum

disorders, cancer, dementia, hearing impairment, heart and lung disease, osteoporosis, metabolic challenges, stroke, and rheumatoid arthritis. The data were analyzed by applying a thematic analysis.

The knowledge presented in this thesis has been developed based on involvement in research. The research team included a co-researcher with experiential knowledge. In addition, a mixed advisory panel of three patient representatives and three healthcare professionals contributed to exploring, scrutinizing, and developing the knowledge presented in this thesis. All those involved discussed their preconceived notions of patient participation in health service development to use these in the research process actively. All saw patient participation both as a means to enhance the quality of health services and respond to the public's needs, and as a democratic right.

Article 1, the scoping review, explored the impact of adult patient participation in health service development described in the research literature. Findings include positive and negative process-based impact on those involved and the organization´s practice of patient participation. Also, patient participation impacted service users´ perceptions of the health services, healthcare providers´ clinical practice, and the organizational culture, and delivery and provision of health services. The scoping review further identified research gaps concerning how patient representatives and healthcare professionals perceive their collaboration, the impact of the collaboration, and the role of context.

Article 2 explored how professionals perceived collaboration with patient representatives to develop primary healthcare services. The findings implied they regard the representatives as their colleagues, possibly further complicating their collaboration. The professionals seemed to operate between a position of authority and collaboration. While they saw the need for participation, they also found it challenging. The difficulties included understanding whether representatives' input was based on personal experience or collective representation, and figuring out how to integrate their input and develop a health service that the participating professionals and their colleagues would endorse.

Article 3 concerned the internal facilitators´ perspective on their role in enabling collaboration between healthcare professionals and patient representatives to develop primary healthcare services. The facilitator role was understood as requiring continuous and systematic work on multiple organizational levels, especially since senior managers and supervisors appeared not to fully understand the potential of patient participation or how to support facilitators' work. The findings confirmed that to practice patient participation when developing health services, facilitators must establish and maintain a network of persons with experiential knowledge, engage professionals willing to be involved, and gain senior management's understanding and support. One municipality had a budget for involvement, while the others lacked the necessary support and resources.

Article 4 explored the contextual factors that were perceived as affecting patient representatives' involvement in primary healthcare service development in Norway. Representatives found primary healthcare to lack an overall plan for practicing involvement. They considered it a leadership issue that affected resource allocation and professionals' understanding of whom to involve, when, and how – and to what degree they were involved. They also perceived primary healthcare as lacking a culture supporting patient participation. When healthcare professionals did not value representatives´ contributions and failed to fully include them as team members in processes, involvement became less meaningful, more complicated, and laborious.

The thesis´s discussion centers around three main topics that shed light on relational and contextual aspects that matter for participatory health service development, based on the perspectives of professionals, representatives, and facilitators. Firstly, complexities and tensions that characterize the collaboration between professionals and representatives are addressed. Secondly, contextual barriers that can hinder patient participation as a way of working to develop health services are discussed. Thirdly, the potential of realizing positive and avoiding negative impacts from the collaboration is considered.

The findings highlight how relational dynamics and contextual factors put healthcare professionals, patient representatives, and facilitators in a tight spot at the interface between policy ideals and the actual practice of patient participation. Professionals,

representatives, and facilitators must tackle challenging situations and uncertainties and overcome several obstacles to collaborate constructively. The findings suggest that repositioning professionals and representatives as colleagues may raise issues that disrupt achieving a partnership. For example, professionals are uncertain about incorporating input from the representatives. Also, the parties' different knowledge needs can complicate collaboration. Representatives are uncertain of being able to impact the process and its result. The findings imply that the organizational culture and support for patient participation in primary healthcare service development could be better. Primary healthcare senior managers, supervisors, and professionals could benefit from knowledge about patient participation. Additionally, representatives need knowledge to handle situations arising from limited knowledge about involvement. Realizing the potential of developing health services in a partnership between professionals and representatives requires understanding both process-based and findings-based impacts, including possible drawbacks. Norwegian laws and regulations leave room for interpretation concerning how municipalities may obtain and apply experiential knowledge to improve health services. The findings indicate that working together in various ways can enhance healthcare services. Taking into account the purpose, contextual factors, desired impact, and available resources of the health service development may guide the best course of action.

This thesis adds to the current knowledge base a more nuanced and profound understanding of difficulties, uncertainties, and contextual barriers that healthcare professionals, patient representatives, and internal facilitators must overcome to collaborate constructively. The complexity of the collaboration underlines that it is crucial that competent facilitators lead the processes – with support from leadership. Addressing these challenges is necessary for strengthening patient participation in primary healthcare service development. There also seems to be a need for a discussion at the policy and local levels regarding prioritizing and implementing patient participation. Overall, the findings indicate that municipalities are unprepared for patient participation aimed at improving the health services.

List of publications

1. Sandvin Olsson, A. B., Strom, A., Haaland-Overby, M., Fredriksen, K., & Stenberg, U. (2020). How can we describe impact of adult patient participation in health-service development? A scoping review. *Patient Education and Counseling*, *103*(8), 1453-1466. https://doi.org/10.1016/j.pec.2020.02.028

2. Sandvin Olsson, A. B., Haaland-Øverby, M., Stenberg, U., Slettebø, T., & Strøm, A. (2022). Primary healthcare professionals' experience with patient participation in healthcare service development: A qualitative study. *PEC Innovation*, 1, 100068. https://doi.org/10.1016/j.pecinn.2022.100068

3. Sandvin Olsson, A. B., Stenberg, U., Haaland-Øverby, M., Slettebø, T., & Strøm, A. (2023). Enabling Primary Healthcare Service Development with Patient Participation: A Qualitative Study of the Internal Facilitator Role in Norway. *Primary Health Care Research and Delivery*, 24, e57. https://doi.org//10.1017/S1463423623000488

4. Sandvin Olsson, A. B., Haaland-Øverby, M., Stenberg, U., Slettebø, T., & Strøm, A. Contextual Factors that Matter for Participation in Developing Primary Healthcare Services. *Submitted for publication*.

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Articles

Tables

Figures

Abbrevations

AS	Anita Strøm
ABSO	Ann Britt Sandvin Olsson
NK LMH	Norwegian National Advisory Unit for Learning and Mastery in Health (in Norwegian: Nasjonal kompetansetjeneste for læring og mestring innen helse)
MH	Mette Haaland-Øverby
MUNI-HEALTH-CARE	The Research School of Municipal Healthcare Services
OECD	Organisation for Economic Co-operation and Development
OUS	Oslo University Hospital (in Norwegian: Oslo universitetssykehus)
TS	Tor Slettebø
US	Una Stenberg
WHO	World Health Organization

1. Introduction

This thesis concerns patient participation in health service development and its impact. The thesis explores how healthcare professionals, patient representatives, and internal facilitators perceive the collaboration that is necessary to develop or improve primary healthcare services with patient participation.

Patient participation is a recognized means of creating high-quality health services (Andreassen, 2018a; Fredriksson & Tritter, 2017). Global policy documents (OECD, 2020; WHO, 1978, 2018, 2021) have over time decreed that patient participation should be applied to help tailor health services to the public's needs. Norwegian (Meld. St. 19 (2024-2025), Meld. St. 38 (2020-2021)) policies also decreed involvement to develop health services.

Apart from representing a health service quality issue, patient participation is also thought to help reduce inequality in health by strengthening the possibilities for all, and especially for vulnerable groups in the population to voice their needs and impact the form and content of local healthcare services (Andreassen et al., 2014; Gathen et al., 2022). Patient participation on service and system level is meant to contribute to patients, service users, next of kin, or informal carers experiencing autonomy and shared decision-making on an individual level (Tritter & McCallum, 2006). Nevertheless, the practice of patient participation in health service development is not widespread (Abayneh et al., 2022; Biddle et al., 2021; Bombard et al., 2018; Semrau et al., 2016; Tierney et al., 2016).

Primary healthcare was under pressure to improve service quality and organize and deliver high-quality healthcare services before the COVID-19 pandemic (Bergstrom et al., 2020; Siantz et al., 2021; Walunas et al., 2021). However, the COVID-19 pandemic continues to challenge global health: the availability of and access to high-quality services within primary healthcare, rehabilitative, palliative, and long-term care – specialties that serve some of the most vulnerable individuals – are affected especially hard (OECD, 2023; WHO, 2023). Impact of involvement depends on professionals´ ability and willingness to include patients, service users, patient representatives, or informal carers in the micro, meso, or macro level processes (Strøm & Fagermoen, 2014; Strøm et al., 2011; Tritter & McCallum, 2006).

Therefore, exploring how to constructively and efficiently develop primary healthcare services suited to the public's needs appears more pertinent than ever.

In this thesis, multiple terms are used to describe patient participation in health service development. These are typically understood in several ways and need clarification before moving on.

1.1. Applied terms

Within healthcare, various terms and concepts are used to refer to “patient participation”, such as “user involvement”, “patient engagement”, and “patient and public involvement”. Patient participation in the development of care and social services may also be referred to as “co-production”, “co-creation”, “social innovation”, or “service design”. Thus, Halabi and colleagues (2020) propose a way to clarify the terms and concepts related to patient participation. Since all forms of patient participation aim to involve patients in the healthcare system, they suggest using “patient participation” as a generic term that is followed by an explanation of its meaning in the specific research context.

Complying with Halabi and colleagues (2020), the term “patient participation” is used in the four articles and this thesis. The term refers to patients, service users, patient representatives, next of kin, or informal carers´ participation in the development of health services. How the concept of patient participation is understood in this thesis is elaborated on in Chapter 3. The term “patient representatives” (hereafter called “representatives” for short) refers to persons with experiential knowledge about living with health challenges in the role of patients, service users, or next of kin. Their experiential knowledge emanates from subjective and lived experience, not professional training. Representatives may or may not be members of a patient organization. Some may thus have been trained in the patient representative role, while others have not received such training. Nevertheless, they actively contribute their experiential knowledge and expertise when involved in health service development. “Healthcare professionals” (hereafter called “professionals” for short) refers to persons with professional training employed within primary healthcare. In this thesis, the professionals typically belong to the practice environment where the new health service is to be implemented. Professionals actively use their professional knowledge and expertise when involved in health service development.

An “internal facilitator” is a healthcare professional who is employed within primary healthcare (hence “internal”, hereafter called a “facilitator” for short) and who is tasked with leading the development or improvement of health services with patient participation. A facilitator invites patient representatives and professional healthcare colleagues to contribute to developing or improving health services. They facilitate the process from start to end. Some facilitators also contribute to implementing the health service into practice; others leave it up to the professionals who have been involved and their practice environment.

The term “impact” is understood broadly. It is regarded as any change, meaning, effects, outputs, outcomes, experience of not having an impact, and added value from patients, service users, patient representatives, and the public as potential patients, next of kin, or informal carers collaborating with professionals in health service development and research. Impact includes both “soft” outcomes (i.e., changes in attitudes, empowerment) and “concrete” outcomes (i.e., changes to service provision or alteration of the language in patient information pamphlets) (see van Deventer et al., 2015). The understanding of the concept of impact is elaborated on in Chapter 3.

“Primary healthcare” commonly represents the first point of contact that a person has with the healthcare system when experiencing a health problem. However, primary healthcare incorporates a wide range of services provided by professionals in the municipality. Primary healthcare professionals, such as general practitioners, nurses, and physical therapists, offer ongoing support to help persons maintain good health. This includes diagnosing and treating health conditions, managing chronic conditions, and conducting regular health check-ups.

Lastly, the phrase “health service development with patient participation” is applied when the focus is on the development of health services with patient participation as a means to tailor health services to the public´s needs. Conversely, when issues or aspects concerning the practice or experience of patient participation are in the foreground, the phrase “patient participation in health service development" is used. As stated above, the term "patient participation" is the chosen term in this thesis. While "patient participation" and "involvement" may be perceived to offer nuances and not to be overlapping terms, there is no consensus on the differences between them (Halabi et al., 2020). Therefore, "involvement" is used interchangeably to offer variation in the language, as well as less wordy sentences. The term "participatory health service development" is used for the same reason.

The term "participatory" may be defined as "characterized by or involving participation" (Merriam-Webster Dictionary, https://www.merriam-webster.com/dictionary/participatory) and as referring to situations where decision-making is shared among all participants (The Content Authority, https://thecontentauthority.com/blog/participative-vs-participatory). As will be described in Chapter 3, participatory health service development aligns with this thesis's understanding of a partnership between professionals and representatives when developing health services and is thus used in this thesis.

For the sake of brevity, "patient participation" in this thesis also sometimes refers to "patient participation in primary healthcare service development". Additionally, health service development is understood to include improving or enhancing health services.

1.2. The development of the Ph.D. project

The Ph.D. project initiative sprang out of the Norwegian National Advisory Unit on Learning and Mastery in Health (in Norwegian: Nasjonal kompetansetjeneste for læring og mestring innen helse, NK LMH) at Oslo University Hospital. The NK LMH practices patient participation systematically in service development and research projects aiming to improve the quality of patient education and self-management programs in hospitals and primary health care. An important motivation for the Ph.D. project stems from experiences that patient participation in health service development can work well but does not always do so. Also, a mapping (NK LMH, 2016) indicated that few Norwegian municipalities practiced patient participation when developing health services and that the understanding of what was considered patient participation varied.

Against this background, the Ph.D. project´s objective was developed in a workshop with healthcare professionals, persons with experiential knowledge, and researchers. I facilitated the workshop. The process is described in Appendix 1. The workshop resulted in the following statement:

> *The Ph.D. project will explore municipal arenas where patient participation in health service development is practiced and describe how patient participation is practiced. The objective is to contribute new knowledge that informs constructive collaboration between healthcare professionals and patient representatives in health service development.*

Staniszewska and colleagues (2012) state that to strengthen patient participation in health service development, there is a need to expand knowledge of what does not work well. Those involved in the workshop agreed and assumed that if the Ph.D. project would contribute knowledge about difficulties in involvement, this could inform constructive patient participation and help strengthen its practice.

1.3. Calls for research about patient participation in health service development

When planning the workshop to develop the focus and objective of the Ph.D. project, a senior librarian helped identify reviews about patient participation in health service development. A summary of the reviews´ findings and calls for research was presented toward the end of the workshop (see Appendix 1; Table 1). The summary indicated that the multiple terms and concepts complicated how to understand patient participation in health service development (Conklin et al., 2015; Mockford et al., 2012). The reviews further confirmed a need for research concerning the experiences of those involved in patient participation in health service development (Bombard et al., 2018; Ocloo & Matthews, 2016; Tierney et al., 2016), its impact (Bombard et al., 2018; Boström et al., 2017; Conklin et al., 2015; Groene & Sunol, 2015; Mockford et al., 2012), and context (Bombard et al., 2018; Conklin et al., 2015; Groene & Sunol, 2015; Mockford et al., 2012). The summary contributed to finalizing the Ph.D. project´s focus and objective.

1.4. Aim and research questions

This thesis applies a bottom-up approach to creating knowledge with involvement of those that the research is about. The thesis´s objective is to strengthen patient participation by contribute to informing constructive collaboration when developing health services that suit the public´s needs. The thesis' overall research question is:

> What meaning can the collaboration in health service development with patient participation have for healthcare professionals, patient representatives, and internal facilitators, and what impact can their collaboration have?

The overall research question is operationalized into answering the following four sub-questions:

1. How is the impact of adult patient participation in health service development described in the research literature?
2. How do healthcare professionals perceive collaborating with patient representatives to develop primary healthcare services?
3. How do internal facilitators perceive their role in developing primary healthcare services with patient participation?
4. How do contextual factors in primary healthcare matter to patient representatives' participation in developing health services?

Responses to each sub-question are presented in one of the four articles constituting this thesis. Each article´s research question, purpose, and main findings are presented in Table 2.

Table 2. Overview of the four articles' research questions, purposes, and main findings.

Article	Research question	Purpose	Main findings
1	How is the impact of adult patient participation in health service development described in the research literature?	To provide a comprehensive overview of the research status in the field – by synthesizing findings of primary studies concerning the described approaches to, and impact of, patient participation in health service development. To identify knowledge gaps that this thesis can contribute to fill.	• Identify that reported approaches to patient participation in health service development were diverse. • Identify process-based impact of participatory health service development on the involved healthcare professionals, patient representatives, and the patient participation practice itself. • Identify findings-based impact of patient participation in health service development on the service users, the healthcare providers, and the organization´s delivery and provision of services, and culture.
2	How do health-care professionals perceive collaborating with patient representatives to develop primary healthcare services?	To explore how healthcare professionals perceive the collaboration with patient representatives when developing primary healthcare services.	Healthcare professionals: • Value a complementary interprofessional relationship. • Navigate between a position of authority and collaboration. • Reconcile the need for patient participation with its challenges. • Identify collective representation to ensure a more evidence-informed result.
3	How do internal facilitators perceive their role in developing primary healthcare services with patient participation?	To explore how primary healthcare professionals tasked with facilitating health service development with patient participation perceive their role.	Internal facilitators: • Establish a network of patient representatives. ○ Locate, select, and train suitable patient representatives. ○ Establish good relations to ensure patient representatives´ future involvement. • Encourage healthcare professionals to engage with patient participation. ○ Promote patient participation. ○ Locate and engage healthcare professionals. • Call upon senior managers and supervisors to take responsibility. ○ Tackle barriers to patient participation. ○ Counter senior managers' and supervisors' involvement hesitancy.
4	How do primary healthcare contextual factors matter to patient representatives' participation in developing health services?	To explore contextual factors that matter to patient representatives´ practice of patient participation in health services development.	Patient representatives perceive a: • Lack of an overall plan for practicing involvement. • Lack of an organizational culture supporting involvement.

1.5. Contextualization of thesis at VID Specialized University´s Ph.D. program

This thesis was submitted to the interdisciplinary Ph.D. program Diakonia, Values and Professional Practice at VID Specialized University, Oslo, Norway.

The thesis is set within a primary healthcare context, representing health services research. Patient participation is a crucial aspect of global and Norwegian policies regarding health and welfare services. Involvement is considered a democratic principle, a legal right, and a means to develop health services that suit the public´s needs. The involvement of patients is believed to lead to better and more democratic services, and it is closely linked to the ideology of health and welfare services, as well as the professional practice of those working in these services.

1.6. Thesis outline

This thesis is organized into six chapters. Chapter 1, Introduction, has addressed the terms applied, the thesis' aim and research questions, justified its placement within the chosen Ph.D. program, and presented this thesis´s outline. Chapter 2 Background addresses the global and local context for this thesis research focus and provides a overview of the research developments within the field. Chapter 3 describes the thesis´s conceptual framework. The concepts of patient participation in health service development and impact are elaborated on. Models that help establish how patient participation is understood in this thesis and that enable exploring involvement further are introduced. Chapter 4 addresses the applied methodology, research design, and methods for data generation and analysis, which includes a methodological discussion. Chapter 5 contains a summary of the articles, including their findings. Chapter 6 discusses the four articles´ combined findings and describes their potential implications for practice and policy. The need for future research is also addressed. Last, it provides concluding remarks and answers the main research question.

2. Background

This chapter first addresses patient participation in health service development at global and Norwegian levels. Next, the recent research developments concerning patient participation when developing health services are provided.

2.1. Patient participation – a work in progress globally and locally

The Alma Ata Declaration, established by the World Health Organization with support from 134 countries in 1978, put public health and social determinants of health on the agenda (WHO, 1978). The declaration highlights the importance of individual and collective participation of people in planning and implementing their healthcare. However, it was only in the late 1980s, with the introduction of consumer-oriented reasoning and New Public Management (NPM), that the interests of patients, service users, next of kin, and informal carers were brought to the forefront in the public services (Elvbakken & Malterud, 2020). NPM refers to business finance ideas and reforms aimed at providing efficient and profitable services in the public's best interests (Ekeland, 2021).

In 2018, WHO hosted a global conference in Astana, Kazakhstan. Those present established that primary healthcare services should be accessible, safe, and affordable for all and provided with compassion and respect by well-trained healthcare professionals (WHO, 2018). This means professionals worldwide must provide high-quality patient care while improving healthcare services (Mortimer et al., 2018). However, despite long-term global encouragement (OECD, 2020; WHO, 1978, 2018), involving individuals with experiential knowledge in the development of health services is not a common practice (Abayneh et al., 2022; Biddle et al., 2021; Bombard et al., 2018; Semrau et al., 2016; Tierney et al., 2016). Additionally, after the COVID-19 pandemic, primary healthcare globally is under more pressure than ever (OECD, 2023; WHO, 2023).

Patient participation is considered a democratic principle (Askheim et al., 2016). However, its introduction into Norwegian policies may be understood as a response to a market ideology and an increasing political need for coordinating and making health services relevant to the public (Elvbakken & Malterud, 2020). This dualistic reasoning behind patient participation in a healthcare context is addressed more thoroughly in Chapter 3. However, the introduction of NPM in Norway contributed to establishing a focus on patients and their next of kin or informal caretakers as consumers. It allowed for a broad approach to patient orientation. For instance, a Norwegian white paper, “The Patient First” (NOU 1997:2), decreed involvement in decision-making concerning a patient's treatment and the delivery and provision of health services. It enabled patients and service users to choose among different healthcare providers (Elvbakken & Malterud, 2020).

Later white papers (Meld. St. 38 (2020-2021); Meld. St. 29 (2012-2013); Meld. St. 26 (2014-2015)) emphasize patient participation in the development of healthcare services: experiential knowledge is considered a crucial complement to professional knowledge and research to ensure that public service are high-quality.

The Health and Care Services Act (2011, § 3-10) grants representatives of patients and service users the right to be heard in municipal health service development. The health and social care services are responsible for establishing systems for gathering patients and service users´ experiences and points of view. The health and social care services must also facilitate collaboration with patient and volunteer organizations that fulfill similar tasks as the health and social care services. The patient or service user has the right to be involved in designing their care services (Patient and User Rights Act, 1999, § 3-1). The care services must, as much as possible, be conducted in collaboration with the service user or patient (The Health and Care Services Act, 2011, § 9-3).

The Quality Improvement Regulations (2016, § 6, 7, 8) further confirm the municipalities´ duty to evaluate and apply experiential knowledge when improving primary healthcare services. The duty to work systematically with quality improvement is asserted in section 6, the duty to apply experiential knowledge from patients, service users, and informal carers to improve the health and care services is pointed out in section 7, and the duty to evaluate the health and care services based on patients, service users, and informal carers´ experiences is underlined in section 8. Still, the municipalities can interpret how to obtain experiential knowledge and shape involvement to improve primary healthcare services.

All over Europe, patient organizations are increasingly involved in participatory activities (Gathen et al., 2023). The trend can be seen also in Norway. It makes the Federation of Organizations of Disabled People (FFO) concerned about the lack of a system to ensure patient participation (Elvestad, 2018). They and their 87 member organizations struggle to respond to the increasing demand for their representatives' involvement in public service development. FFO finds it a complicating factor that the Norwegian governing authorities recently cut the yearly earmarked funding of 64 patient organizations. The organizations must now apply for funding on an annual basis, competing for funds with other organizations. Following the cut, some organizations have laid people off, and some have shut down (Rønne, 2022). While primary healthcare is under pressure, it seems that patient organizations and patient representatives´ involvement in health service development are also under pressure.

2.2. An overview of research developments in the field of inquiry

This chapter addresses the state-of-the-art in this field. The multifaceted field of inquiry suggests that a systematic approach may help identify relevant primary studies and reviews. For the scoping review (Article 1), a senior academic librarian at the University of Oslo Library conducted searches of selected databases through mid-March 2019.The complete search strategy is published along with the scoping review (Sandvin Olsson et al., 2020). Several non-relevant reviews and primary studies were identified that still had relevance to the research process and were kept. The searches were re-run in May 2021 and June 2023 by senior academic librarians, yielding new useful reviews and studies to update the description of research within the field of inquiry. Appendix 2 contains the complete search strategy applied for the searches in 2021 and 2023.

To write this chapter, primary studies and reviews kept from the March 2019 searches were reviewed, as well as those identified in the May 2021 and June 2023 searches and the articles and book sections supplied through other sources. Relevant research literature highlighting discourses and issues surrounding patient participation in health service development was selected. However, when this literature was selected, no formal review methods were followed. Instead, primary studies and reviews were searched to elucidate how patient participation in developing health services is understood. As such, the purpose for reviewing primary studies and reviews for this thesis differed from and expanded upon the scoping review´s objective.

By applying the results from the searches from March 2019, May 2021, and June 2023, this chapter provides an overview of research developments concerning patient participation in health service development. The overview is based on identified reviews. However, several primary articles were also identified in the searches. These are incorporated throughout this thesis.

2.2.1. Overall research developments

Table 3 presents the total number of articles identified in the three searches and the number of those that used at least one of the keywords “review”, “primary health care”, “impact”, and “context”. Studies that inform this thesis are found in health service development, quality improvement, implementation science, organization and management, and other fields. They address the perspectives of healthcare professionals from various professional backgrounds and practice environments, including facilitators, senior leadership, and management. The patient-representative perspective is based on representatives from several patient or interest organizations representing various diagnoses, health challenges, and life situations. Finally, studies set in community, primary, and specialized healthcare related to somatic and mental health that address services for adults over 18 years of age are referred to.

Community health represents multiple sectors and disciplines´ collaborative efforts to engage and partner with a community. The goal is to enhance the health and well-being of all persons (Goodman et al., 2014), including those who find healthcare too expensive, experience physical healthcare facilities being out of reach, or do not trust traditional healthcare institutions (Heath, 2020).

Table 3. The number of retrieved titles from 2019, 2021, and 2023 searches and articles using the keywords “review”, “primary health care”, “impact”, and “context”, respectively.

The searches´ time-periods	Until mid-March 2019	From mid-March 2019 till mid-May 2021	From mid-May 2021 till mid-June 2023	Until mid-June 2023
# of retrieved titles	12 235	3032	1557	16 824
# of retrieved articles with “review” as a keyword	118 (1%)	73 (2%)	66 (4%)	257 (2%)
# of retrieved articles with “primary health care” as a keyword	805 (7%)	512 (17%)	330 (21%)	1647 (10%)
# of articles with “impact” as a keyword	741 (6%)	497 (16%)	398 (26%)	1636 (10%)
# of articles with “context” as a keyword	408 (3%)	316 (10%)	236 (15%)	960 (6%)

Table 3 indicates several potential relevant reviews among the retrieved titles from the March 2019 searches. To develop the Ph.D. project, we included 11 relevant reviews published in the last decade and the first review concerning the involvement of patients in the planning and development of healthcare published in 2002 by Crawford and colleagues (2002). Appendix 1 (refer to Table 1) represents an overview of the 12 reviews with information on each review´s type, findings, relevant conclusions, and calls for research. Two of the reviews addressed involvement in primary healthcare. Tierney and colleagues (2016) focused on implementing involvement and found a lack of routine regarding meaningful involvement in primary healthcare. They observed that the reasoning for practicing involvement in primary healthcare service development was mainly associated with political demands for co-governance and emancipatory ideas. Tierney and colleagues (2016) suggested that future research investigate stakeholders´ collaboration in specific projects. Bath and Wakerman (2015) investigated “the evidence” of community participation in primary healthcare. The authors found that community involvement had a modest but positive effect on health outcomes. However, in line with Mockford and colleagues (2012), Bath and Wakerman (2015) pointed out the challenge of distinguishing the impact of community involvement from contextual factors. These issues are also among the research focuses of current reviews.

Table 3 shows an increase in reviews between March 2019 and June 2023. This indicates more focus on summarizing and synthesizing knowledge about patient participation in developing health services in this period. The trend concurs with Usher and Denis´ (2022) findings in their meta-narrative review on improving healthcare systems through public and patient engagement. Among the 38 included reviews, 15 were published in 2018 or later (Usher & Denis, 2022). This may be partly due to the COVID-19 pandemic and its impact on research activity. However, the trend may also be a response to researchers trying to make sense of the multiple concepts and complexity that characterize the field of inquiry, reflected in that several reviews call for clearer concepts and terms (Halabi et al., 2020; Majid & Gagliardi, 2019; Usher & Denis, 2022).

While reviews provide valuable insights, they often conclude by highlighting uncertainties and lack of clarity related to the research focus. Appendix 3 offers an overview of the 13 reviews and one thematic synthesis identified in the 2021 and 2023 searches with relevance to this thesis. The type of review, its relevant findings, conclusions, and calls for research are included. The 13 reviews and the one thematic synthesis were published between 2019 and mid-June 2023.

2.2.2. Research developments with relevance to the overall research question

Table 3 implies that over the last four years, more research attention has been given to patient participation when developing primary healthcare services. Still, none of the reviews directly address involvement within a primary healthcare context. However, two reviews conducted by the same group of authors (Pedersen et al., 2021; Pedersen et al., 2022) concern patient participation in community health services.

The first of these reviews (Pedersen et al., 2021), explored public involvement approaches in the planning, developing, and implementing community health services. The authors found limited empirical research on the topic. Their findings correspond with current reviews underlining the need for knowledge about how patient participation may be applied to support implementation processes (Movsisyan et al., 2019). This emphasizes that implementing health services into practice to impact public healthcare and health outcomes is a complex endeavor (Bergerum et al., 2019; Wiles et al., 2022).

Table 3 also indicates increased recent attention on the impact of patient participation related to health service development. The trend is reflected in the reviews. Including this thesis´s scoping review, seven reviews (Bergerum et al., 2019; Ezaydi et al., 2023; Gathen et al., 2022; Modigh et al., 2021; Pedersen et al., 2022; Sagen et al., 2023; Sandvin Olsson et al., 2020) concerned impacts, outcomes, outputs, or added value related to involvement in health service development.

While there are calls for clarity concerning potential outcomes (Ezaydi et al., 2023; Sagen et al., 2023) of patient participation in health service development, there are also reports of several positive impacts from involvement. Modigh and colleagues (2021) found that the most commonly reported impact of patient and public involvement in healthcare concerns individual health outcomes. Ezaydi and colleagues (2023) showed that involving service users in co-production and design leads to more positive and significant service- and patient-level outcomes than less comprehensive involvement forms, such as service user consultation. They suggest that professionals prioritize clinical outcomes over service users´ perceptions of the service, whereas service users value the latter more. The authors thus argue that service user perception outcomes should be given equal importance to clinical outcomes (Ezaydi et al., 2023). Wiles and colleagues (2022) investigated engaging healthcare consumers, defined as “patients and potential patients, carers, and people who use healthcare services” (Wiles et al., 2022, p.4). Their findings indicate that healthcare consumer engagement improves health service interventions, patient care, and information materials and has several positive health policy, research, and service outcomes. For example, engaging healthcare consumers can help identify a broader range of healthcare priorities and impact perceptions of patient safety positively (Wiles et al., 2022). Nevertheless, consultative consumer engagement strategies are still most frequently employed in developing health services (Wiles et al., 2022).

Pedersen and colleagues (2022) further identified various degrees of added value at the service levels from public involvement in community health services. However, they also found that involvement led to unintended negative consequences related to participant recruitment, the involvement process, and facilitating the process. The authors (Pedersen et al., 2022) recommend addressing these negatives in development processes. They also call for involving groups of service users and training professionals to facilitate involvement, in line with Gathen and colleagues (2022). There are also reports of negative, harmful, or no impacts from patient participation in health service development, as seen from the perspective of patient representatives or service users. For example, speaking one's mind in the group led to fear of repercussions, lack of confidence, wariness of being the only representative present, and reluctance to be involved in similar processes in the future (Sandvin Olsson et al., 2020), disempowerment, and worsening of mental health (Gathen et al., 2022).

Few reviews have reported negative consequences concerning involvement in health service development from the healthcare professional perspective. However, Gathen and colleagues (2022) reported a worsening of the professional working environment due to accusations among professionals of unnecessary use of power toward persons with experiential knowledge. Biddle and colleagues (2021) pointed to professionals´ lack of interest concerning patient participation, leading to marginal and tokenistic involvement with minimal impact of service users or patient representatives on the development process. Our scoping review (Sandvin Olsson et al., 2020), reported that professionals realized that conducting participatory health service development requires time, resources, and facilitation competencies.

Perhaps in response to safeguarding against negative impact, several current reviews point to the need for establishing constructive approaches to involvement in health service development (Bergerum et al., 2019; Biddle et al., 2021; Cluley et al., 2022; Majid & Gagliardi, 2019; Pedersen et al., 2021). Along the same lines, there are calls for research about experiences with how patient engagement works on different levels within healthcare (Bergerum et al., 2019). There is a need to identify barriers (Gathen et al., 2022; Pedersen et al., 2021), as well as contextual factors that matter to patient participation in the development of health services (Bergerum et al., 2019; Gathen et al., 2022; Usher & Denis, 2022). These latter issues are also underlined in this thesis´s scoping review (Sandvin Olsson et al., 2020).

This chapter has described patient participation as a legal right. The research development concerning patient participation in health service development has also been addressed. This account provides an updated overview of the research focus and needs for knowledge within the field of inquiry. The overview also serves as a background to validate the research findings of this thesis. It seems safe to argue that several issues needing research a decade ago are still pertinent. It also seems safe to claim that this thesis´s research focus responds to several calls for research.

Next, the conceptual framework concerning patient participation in health service development that this thesis is built upon will be described.

3. Conceptual framework

This chapter aims to contextualize the concept of patient participation by addressing established theoretical perspectives. Reasonings behind the concept are presented first, before addressing its micro-, meso-, and macro-levels. Then, three models are introduced. These are regarded as useful analytical tools to explore perceptions of collaboration activated by patient participation as a way of developing primary healthcare services: the ladder of citizen participation (Arnstein, 1969), involvement as implied interest (White, 2000), and involvement as various approaches, purposes, and potential impact (Tritter, 2009). Last, the concept of impact is addressed. The chapter is rounded out with comments on the models´ implications for the thesis.

3.1. Reasonings of patient participation in a healthcare context

Patient participation can be a means to enhance the relationship between citizens and officials responsible for health service delivery and a means to improve services (Andreassen et al., 2014). This statement aligns with the understanding of patient participation that this thesis is built upon. The statement further reflects how patient participation in a healthcare context typically is grounded on two main reasonings: one democratic and one consumer-oriented (Tritter, 2009). This double-reasoning may complicate conducting participatory health service development. This point will be returned to in the Discussion.

An early rationale for patient participation is linked to ancient Greece and the development of democracy (Beresford, 2012). Today´s democratic reasoning originates from the African-American Civil Rights Movement and the democratization process in the 1960s. They led the fight for equal democratic rights for different groups, increased autonomy, and the right to decide concerning one's own life (Andreassen, 2005), fundamental values for patient participation of today. Furthermore, the patient, or a citizen, could convey their interests through patient organizations (Dent & Pahor, 2015). However, during the 1980s, patient participation became more mainstream (Cornwall, 2008) through the introduction of consumer-oriented reasoning. Deming's circle of improvement and other quality improvement tools (see Langley et al., 1992) were introduced in line with New Public

Management (NPM). Patient participation was seen as vital to control and improve services: it would make services more efficient and cost-effective and contribute to the services having the intended impact, as well as contribute to tackling paternalism within the health and social services (Tritter et al., 2009; Tritter, 2009). Patients became consumers responsible for their choices (Andreassen, 2014). The aim was to enhance patient autonomy through increased competition, service efficiency, and better management of healthcare expenditures. The latter aspect is often concealed in patient participation (Dent & Pahor, 2015).

In this way, the democratic and consumer-oriented rationales both focus on enabling patients and service users to impact the services they receive (Tritter, 2009). However, whether based on democratic or consumerist reasoning, it cannot be assumed that patient participation will always lead to better quality health services. This topic will be revisited in the Discussion. Next, the levels commonly alluded to concerning patient participation are addressed.

3.2. Levels of patient participation in a healthcare context

In this thesis, patient participation is understood as the shared objective of including the patient in the healthcare system (Halabi et al., 2020). This objective is relevant at three levels: the interaction between healthcare providers and patients during treatment (micro level), the organization of health services (meso level), and the relationship between society and its governing authorities (macro level) (Halabi et al., 2020).

These levels are also reflected in how the Norwegian Directorate of Health (2023) describes patient participation. The directorate refers to the three levels to describe how patients, service users, patient representatives, next of kin, or informal carers can impact the health services´ quality. To illustrate, the micro or individual level of patient participation may refer to doctors and nurses involving patients in making decisions regarding their health and treatment. The second level concerns this thesis´s research focus: patient participation on a meso, service, or collective level. This level may be described by healthcare professionals setting up a project to enhance the health services for patients with multiple sclerosis (MS) and inviting local representatives from the National MS Society[3] to contribute. The third level is patient participation on a macro, system, or policy level. It may be exemplified by the Norwegian Directorate of Health´s User Council[4], which contributes to prioritizing and developing strategies and implementing systematic patient participation within the directorate.

The second and third levels are meant to contribute to patients, service users, next of kin, or informal carers experiencing autonomy and shared decision-making on an individual level (Tritter & McCallum, 2006). However, how patients or service users are involved on an individual level, and patient representatives are involved in developing health services, depends on healthcare professionals´ ability and willingness to include them in the processes (Strøm & Fagermoen, 2014; Strøm et al., 2011; Tritter & McCallum, 2006). This issue will be addressed in the Discussion. However, first, a model illustrating varying degrees of patient participation is addressed.

3.3. Degrees of patient participation

Arnstein´s (1969) "A Ladder of Citizen Participation" represents the first description of different degrees of participation. It was published in 1969 and concerns citizen participation in urban housing developments in the USA. Anchored in democratic reasoning, Arnstein regards attaining power and having an impact on the process as the overall objective of citizen engagement.

Participation as praxis is often a contested process shaped by power relations and competing agendas (Cornwall, 2008). The understanding that healthcare professionals occupy powerful positions and patient representatives do not is a common perception regarding patient participation (see Nathan et al., 2014; Pearce, 2021). This thesis acknowledges that the relationship between professionals and representatives is characterized by asymmetry in power. To illustrate, representatives have agendas or motives concerning their involvement (Näslund et al., 2023, Sirris, 2020); institutional

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[3] See https://www.nationalmssociety.org/

[4] See https://www.helsedirektoratet.no/om-oss/organisasjon/rad-og-utvalg/helsedirektoratets-brukerrad

structures can limit the goal of sharing power and affect how power imbalances are created, upheld, or challenged within participatory contexts (Pearce, 2021). Furthermore, healthcare professionals are in a position to decide if patient representatives will be involved (Gathen et al., 2023; O'Shea et al., 2019), the degree of impact they will have in the process (Strøm & Fagermoen, 2014; Tritter & McCallum, 2006) as well as which representatives they will involve (Gathen et al., 2023; O'Shea et al., 2019). Professionals can resist representatives' involvement due to the power associated with the patient representative role (Moore & Zeeman, 2023). Also, professionals can grant some representatives a higher status than others if they contribute valuable knowledge (O'Shea et al., 2019) or agree with professionals´ opinions (Nathan et al., 2014). This thesis is thus built on the understanding that power imbalances exist between professionals and representatives. However, the thesis emphasizes the collaborative aspect of involvement rather than the asymmetrical power relations. This means that the discussion around the success or failure of patient participation in health service development is reframed to focus on relational dynamics between the parties involved in primary healthcare service development.

Arnstein (1969) underlines that participating in a process cannot be the same as having the power to affect the process and its results. She argues that without redistribution of power, participation is meaningless. Arnstein´s model thus raises awareness of what may be considered patient participation and what may not.

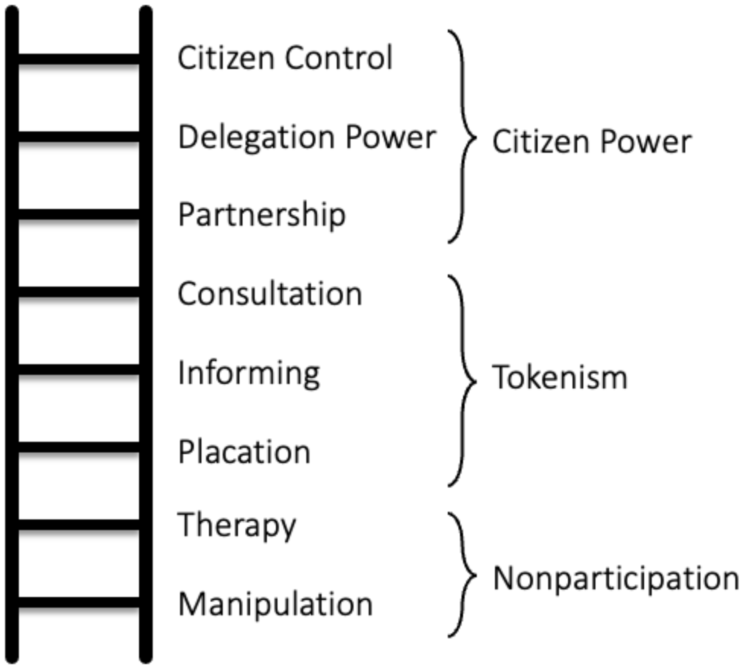


Figure 1. Adapted from Arnstein´s Ladder of Citizen Participation (Arnstein, 1969, p. 217).

The eight steps of Arnstein´s ladder (1969) refer to varying degrees of power to make decisions. The two lowest steps are called *manipulation* and *therapy*. These steps are substitutes for participation as the approaches form the citizens rather than empower them. Various therapies may not have included involvement in 1969. However, today, therapy is typically founded on involvement from the client, outdating Arnstein´s view of therapy.

The next three steps are *placation, consultation, and informing*. Placation suggests that patient representatives are invited to be involved merely because it is a requirement and not due to a genuine interest in exploring experiential knowledge. Some still think of this as patient participation (see Cornwall, 2008). In consultation, the participants´ claims and advice may be heard, but those in power decide the impact of the input. When patients inform healthcare professionals what they think of a health service, some professionals consider it patient participation. Also, when a project leader is tasked with improving healthcare professionals´ communication with informal carers and consults the latter about what they think is needed, some may also consider this patient participation. In the research literature, informing and consultation are also sometimes considered to represent patient participation (see, i.e., Elg & Gremyr, 2023). However, in Arnstein´s view, placation, informing, and consultation represent tokenism.

This thesis is thus also built on the assumption that in health service development, there may be a need to gather information from or consult service users, next of kin, or other relevant persons to develop health services suited to the public´s needs. Nevertheless, in the thesis, informing, consultation, and placation do not represent patient participation, in line with Arnstein (1969).

The top three steps, *partnership, delegated power,* and *citizen control*, are what Arnstein considers legitimate participation or citizen power. In the partnership lies the ability to negotiate and affect the result. In delegating power and citizen control, the participants have the right to lead and decide. Thus, only the top three steps demonstrate citizen power (Arnstein, 1969).

Arnstein´s (1969) model has been criticized. Tritter and McCallum (2006) argue that the model is normative and inflexible, and that there are other objectives and agendas for participating than attaining decision-making power. For example, healthcare professionals may see a need for incorporating experiential knowledge in different ways than through a partnership and in various phases of the health service development: successful patient participation requires differentiating roles and involvement categories in the process (Tritter & McCallum, 2006). Tritter and McCallum (2006) find that Arnstein´s model falls short in describing the complexity of patient participation in health service development.

However, Arnstein´s model (1969) may also be regarded as a continuum of degrees of participation, without hierarchical or normative references. This thesis´s research focus concerns the collaboration between healthcare professionals and patient representatives under the lead of a facilitator aiming to develop health services for the public´s good. Ideally, this collaboration is conducted as a partnership among those involved. However, a partnership is not always achieved, or the needed approach to gain experiential knowledge. Arnstein´s ladder thus represents a useful analytical tool for clarifying what patient participation is and is not, and as a background for discussing what impact patient participation may have in health service development. Aspects concerning what it takes for the collaboration to represent a partnership and what the consequences are of achieving it or not will be addressed in the Discussion.

The concept of impact will be returned to shortly. However, first, two frameworks that can contribute to untangling complexity and discussing nuances concerning involvement in the Discussion will be presented. White´s framework (2000) addressing interest in participation is the first one out.

3.4. Patient participation as implied interest

Tritter and McCallum (2006) argue that those participating in health service development may have different agendas for participating. Building on a similar notion, White (2000) proposes an analytical framework that describes four major forms of participation, which depend on the interests of the involved parties. The framework is displayed in Table 4 and addresses local participation and implementation efforts in development projects. It highlights the fact that participants usually have varying interests that also can change over time. The framework can help differentiate how those involved in participatory health service development use involvement as a means to achieve what is in their interest.

Table 4. Adapted from White´s Interests in participation (White, 2000, Table 1, p. 144)

Form	Top-Down	Bottom-Down	Function
Nominal	Legitimation	Inclusion	Display
Instrumental	Efficiency	Cost	Means
Representative	Sustainability	Leverage	Voice
Transformative	Empowerment	Empowerment	Means/End

Adapted to the context of this thesis, *nominal participation* may refer to a situation where healthcare professionals invite patient representatives to participate in health service development solely for the purpose of seeking legitimacy. The situation refers to what Arnstein (Arnstein, 1969) would consider tokenism. However, representatives are aware of this and participate in the interest of inclusion, which can bring status and compensation. In this respect, participation functions as a display. *Instrumental participation* may be exemplified by senior management´s invitation to local patient organizations to help organize and arrange the World Mental Health Day. Senior management´s interest is efficiency: a means to get the job done. However, in local patient organizations´ interest, participation is a cost: it takes substantial effort. Still, participation represents a means to create positive attention to their work and possible recruitment of more members – so they do it. *Representative participation* may be illustrated by a facilitator who seeks participation from representatives to create a self-management program for persons with fatigue symptoms. A patient participation goal may be to tailor the program to patient needs. Accordingly, the representatives´ interest is leverage: to apply their collective voice and make a meaningful impact on the program's development. Finally, *transformative participation* may refer to participation as a means of empowerment and a valuable means in its own right. For example, in a participatory healthcare service development, all involved gain valuable insights while collaborating to create a health service that serves the public's interests. With the various interests at play, White´s framework (2000) appears to be anchored in both democratic and consumer-oriented reasoning (see Andreassen, 2005; Tritter, 2009). Furthermore, what White (2000) refers to as representative and transformative participation seems to resemble Arnstein´s (1969) partnership.

Against this background, White´s (2000) framework can contribute to understanding why and how healthcare professionals and patient representatives engage in participatory health service development and will be revisited in the Discussion. However, below, a model by Tritter (2009) that can contribute to the debate of what patient participation is and is not will be introduced.

3.5. Patient participation as various approaches, purposes, and potential impact

Tritter (2009) has introduced his own model for patient and public involvement, categorizing different approaches based on their purpose and potential impact. The model is displayed in Figure 2. Without anchoring the model in underlying ideological reasoning, Tritter argues that various approaches to patient participation can be considered as involvement and that those in charge have the power to choose the appropriate type to apply. Tritter´s model (2009) distinguishes between the individual and collective levels of involvement. Patient participation is categorized as direct or indirect, reactive or proactive, resulting in eight types of involvement.

	Direct		Indirect	
Individual	Proactive	Reactive	Proactive	Reactive
Collective	Proactive	Reactive	Proactive	Reactive

Figure 2. Adapted from Tritter´s model of involvement (Tritter, 2009, Figure 2, p. 277).

In Tritter's model (2009), patient participation can take on different forms and serve various purposes. When patient representatives participate in decision-making, it is considered direct involvement. However, if healthcare professionals make decisions based on input from service users, it is indirect involvement. Proactive involvement occurs when patient representatives take the initiative to engage, while reactive involvement is when they respond to invitations from healthcare services to engage.

Tritter´s model (2009) positions patient representatives as proactive initiators when it comes to improving health services, which may be seen in relation to White´s (2000) model discussing the interest of those involved. Tritter (2009) puts the healthcare professionals in charge of deciding the approach to gain access to experiential knowledge, aiming for a qualitatively good result. Direct involvement may be understood as referring to Arnstein´s (1969) notion of partnership, whereas indirect involvement describes consultation or informing. Hence, indirect involvement does not qualify as patient participation in accordance with Arnstein (1969) or in the understanding that this thesis is built upon. Still, gathering information from service users to enhance health services may be a necessary approach to initiate changes to health services. Why it may be helpful not to portray this as patient participation will be addressed in the Discussion. The next chapter concerns how patient participation impact is understood in this thesis.

3.6. Patient participation impact

There is no established and agreed-upon definition of the term “impact” within the field of inquiry. This chapter clarifies how the concept of impact is understood in this thesis and why.

Arnstein (1969) points out that if involvement does not have an impact, it is meaningless. Arnstein claims a redistribution of power is necessary for citizens (patient representatives) to have an impact. White (2000) implies that those involved may have multiple agendas. This indicates that healthcare professionals and representatives may experience different forms of impact, including positive, negative, and no impact from involvement – depending on their respective agenda. Tritter´s (2009) model of individual and collective levels of involvement exemplifies different approaches to involvement. He suggests that those in charge must decide the type of involvement needed in the health service development. Tritter´s (2009) model appears to underscore that the ability of those involved to impact health service development depends on those in charge and their competencies and willingness to facilitate inclusion in the process (see Strøm & Fagermoen, 2014; Strøm et al., 2011; Tritter & McCallum, 2006). Accordingly, this thesis must apply a broad understanding of impact.

In the research literature, impact, effect, outcome, output, and meaning are often applied synonymously. According to Gulbrandsen and Sivertsen (2018), in a research context, short-term outputs are understood to lead to more long-term impact or outcomes, providing they work as intended. As such, impact is understood in a broad sense and represents more or less systematic and comprehensive attempts to quantify the total effects of research on various areas of society (Gulbrandsen & Sivertsen, 2018). The British Research Excellence Framework also defines impact related to research broadly:

> “An effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia” (UKRI, 2023).

Along the same lines, the Norwegian Research Council (2022) refers to impact as “expected societal effects”. Still, the word “effect” can give associations to an instrumental understanding of impact.

Prevailing definitions and models often view participatory processes as linear. This implies a donor-recipient model where impact occurs at the conclusion of a project following the incorporation and utilization of its results (Banks et al., 2017). The same notion is traceable in relation to patient participation (Gathen et al., 2023). For example, we defined impact of patient participation in health service development in Article 1, the scoping review (Sandvin Olsson et al., 2020) as “(…) *the effects of involving patients in the planning and development of health care*” (Crawford et al., 2002, p.1). However, in a participatory setting, pinpointing what brings forth changes, adjustments, or improvements can be challenging (Banks et al., 2017; Gathen, 2023). Furthermore, impact is intertwined with contextual factors (Bath & Wakerman, 2015; Bergerum et al., 2019; Mockford et al., 2012; Usher & Denis, 2022), and how contextual factors affect impact is also poorly understood (Rogers et al., 2020).

Using Crawford and colleagues´ (2002) definition of impact in the scoping review meant including a broad spectrum of impacts. Identified impact of patient participation included all types of “soft” changes (e.g., insights and attitude changes) based on the collaboration between healthcare professionals and patient representatives, as well as all types of “concrete” changes (e.g., changes in service delivery and provision) based on findings. This understanding of impact resembles Banks and colleagues´ (2017) concept of co-impact related to participatory action research. Co-impact entails three types of conceptually distinct impacts: participatory, collaborative, and collective impact. Co-impact represents “the generation of change as a result of individuals, groups and organisations working together” (Banks et al., 2017, p. 542). Furthermore, the co-creation enables the co-production of process-based impacts (Banks et al., 2017). Co-impact relates to the understanding of impact applied in this thesis´s research process.

The understanding of impact in this thesis is, therefore, inspired by Arnstein (1969), Tritter (2009), White (2000), and the concept of co-impact in participatory action research (Banks et al., 2017). Impact is regarded as any change, meaning, effect, output, outcome, or any perception of not having an impact. Additionally, impact is understood as any added value from patients, service users, patient representatives, and the public as potential patients, next of kin, or informal carers collaborating with healthcare professionals, including internal facilitators, in health service development and research.

3.7. The conceptual framework´s implication for the thesis

Above, the ladder of participation (Arnstein, 1969), involvement as implied interest (White, 2000), and involvement as various approaches, purposes, and potential impact (Tritter, 2009) have been presented. In this thesis, these three models are considered valuable analytical tools for exploring the perceptions of professionals, representatives, and facilitators regarding collaboration activated by patient participation as a way of working to develop health services. The models serve different but complementary purposes, allowing for a comprehensive exploration of various aspects of patient participation in health service development from the perspectives of those involved.

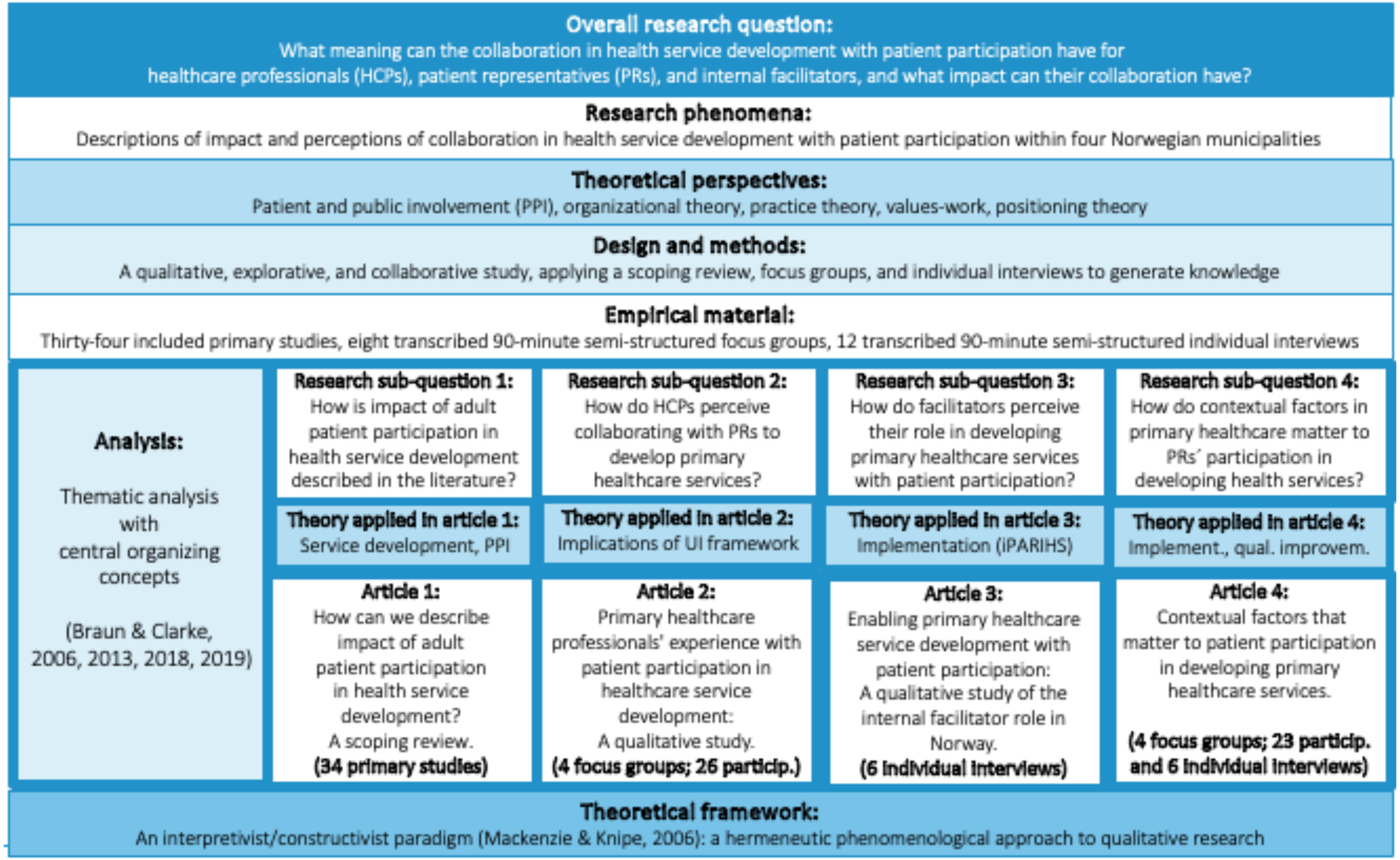
Arnstein´s ladder will be used to clarify the presence of different degrees of involvement of patient representatives and what may or may not be understood as patient participation. The model enables considering what may be tokenistic involvement, as it provides a background for discussing what impact patient representatives may have in health service development.

White's model (2000) will be utilized to delve deeper into the interests of the parties involved in the development of primary healthcare services. This model can help clarify how the parties view and utilize involvement as a tool to achieve their objectives, and how this can impact their collaboration. Tritter's model (2009) offers a broader perspective on involvement in health service development compared to Arnstein's model (1969). Tritter's model (2009) views involvement as a process and highlights the importance of experiential knowledge in various phases of health service development. The model will be applied to determine the type of service user information or involvement required to achieve the health service development's purpose.

This concludes this thesis´s conceptual framework and the understanding of patient participation in primary healthcare service development that this thesis is built upon. The next chapter addresses the thesis's design and methods.

4. Design and methods

This chapter describes this thesis´s research approach, methods applied, the empirical material, and the research process. My development as a researcher is also addressed. Figure 3 provides an overview of the thesis research design, methods, and empirical material.



Overall research question:
What meaning can the collaboration in health service development with patient participation have for healthcare professionals (HCPs), patient representatives (PRs), and internal facilitators, and what impact can their collaboration have?

Research phenomena:
Descriptions of impact and perceptions of collaboration in health service development with patient participation within four Norwegian municipalities

Theoretical perspectives:
Patient and public involvement (PPI), organizational theory, practice theory, values-work, positioning theory

Design and methods:
A qualitative, explorative, and collaborative study, applying a scoping review, focus groups, and individual interviews to generate knowledge

Empirical material:
Thirty-four included primary studies, eight transcribed 90-minute semi-structured focus groups, 12 transcribed 90-minute semi-structured individual interviews

Analysis:

Thematic analysis with central organizing concepts

(Braun & Clarke, 2006, 2013, 2018, 2019)

Research sub-question 1:
How is impact of adult patient participation in health service development described in the literature?

Theory applied in article 1:
Service development, PPI

Article 1:
How can we describe impact of adult patient participation in health service development?
A scoping review.
(34 primary studies)

Research sub-question 2:
How do HCPs perceive collaborating with PRs to develop primary healthcare services?

Theory applied in article 2:
Implications of UI framework

Article 2:
Primary healthcare professionals' experience with patient participation in healthcare service development:
A qualitative study.
(4 focus groups; 26 particip.)

Research sub-question 3:
How do facilitators perceive their role in developing primary healthcare services with patient participation?

Theory applied in article 3:
Implementation (iPARIHS)

Article 3:
Enabling primary healthcare service development with patient participation:
A qualitative study of the internal facilitator role in Norway.
(6 individual interviews)

Research sub-question 4:
How do contextual factors in primary healthcare matter to PRs´ participation in developing health services?

Theory applied in article 4:
Implement., qual. improvem.

Article 4:
Contextual factors that matter to patient participation in developing primary healthcare services.

(4 focus groups; 23 particip. and 6 individual interviews)

Theoretical framework:
An interpretivist/constructivist paradigm (Mackenzie & Knipe, 2006): a hermeneutic phenomenological approach to qualitative research

Figure 3. The thesis´s design, methods, empirical material, and articles concerning healthcare professionals (HCPs), patient representatives (PRs), and internal facilitators´ perspectives.

4.1. Applying a qualitative, explorative, and collaborative research design

The thesis applied a qualitative, explorative research design relying on the co-creation of knowledge. The research approach is considered appropriate to explore how participants perceive a research phenomenon (Thomassen, 2020; Braun & Clarke, 2013).

In order to get an overview of the state of the art in the research field and ensure contributing new knowledge, the first task was to conduct a scoping review. Aspects of its process are described below.

A mapping (The Norwegian National Advisory Unit on Learning and Mastery in Health, 2016) of primary healthcare service development with patient participation in Norway indicated limited experience with patient participation in health service development among healthcare professionals and patient representatives. Recruiting participants with relevant experience and generating data that adequately answered the research questions could be a challenge. After conferring with the research team, I decided to let the research process be empirically driven. Furthermore, data would first be generated by conducting focus group discussions (hereafter called focus groups, still representing discussions among the participants), then individual interviews. This meant conducting multimethod research. It also meant that potential participants knowledgeable about patient participation in health service development could be identified from the focus groups and asked to participate in individual interviews: data generated in focus groups could be complemented by data generated in individual interviews.

The research design´s final version is presented in Figure 3. Its first version was established early on in the research process and was adjusted in line with advancements, obstacles, and my development as a researcher. The latter entailed learning how to facilitate involvement in research in a way that was meaningful for the research process and those involved – which is addressed below.

4.2. Co-creating knowledge

This chapter addresses this thesis´s co-creation of knowledge, also called involvement in research. The first part describes how it was conducted. Then follows a reflection on its implications for the research process, including the assumptions and values that guided the involvement in research.

Co-creation of knowledge involves incorporating insights from those familiar with the context to develop applicable and trustworthy knowledge for the public and governing bodies (Grotz et al., 2020). The assumption is that they can contribute to incorporating more perspectives and creating fuller and more relevant knowledge than is possible without their input (Staniszewska et al., 2018). However, the co-creation of knowledge may also be described along a continuum between passive and engaged levels of involvement, for example, from passive consultation to collaboration to engaged, lay-controlled research (Shippee et al., 2015). As such, the involvement may be seen in relation to Arnstein´s ladder of participation (1969) (please refer to Chapter 3.3., Figure 1), illustrating how the involvement may range between low and high levels.

While underlining that there is no formula, the National Institute for Health and Care Research´s (NIHR) *Briefing notes for researchers – public involvement in NHS, health, and social care research* points to three different types of involvement in research (NIHR, 2023). “Consultation” is understood as asking members of the public for their opinions concerning a research topic and applying their input to inform the research process (NIHR, 2023, point 7.1.). “Collaboration” represents an ongoing partnership with members of the public where research decisions are shared (NIHR, 2023, point 7.2.). Last, “co-production” includes sharing power and responsibility from the start to the end of the project, including generating knowledge (NIHR, 2023, point 7.3.). The research process relied on all three of the above types of involvement.

4.2.1. Involvement in research in this thesis

Several individuals contributed to the co-creation of knowledge. Firstly, the focus and objective of the Ph.D. project were developed in a workshop with persons with experiential knowledge, primary healthcare professionals, and researchers (see Chapter 1.2. and Appendix 1). Secondly, a co-researcher with experiential knowledge was part of the research team throughout the research process. A co-researcher is a potential receiver of healthcare services who is a fully included research team member (Malterud & Elvbakken, 2020). As a person with experiential knowledge about living with a health challenge and its consequences, MH contributed her expertise to benefit the Ph.D. project just like the other members, but with a different lens: the patient perspective. As such, her role aligned with what the Canadian Institutes of Health Research (CIHR) calls a patient partner in research (CIHR, 2022). MH contributed her competence and perspective in the scoping review process, in our visits to each research site, conducted participatory observations of patient participation in health service development meetings with me, co-hosted the mixed advisory panel meetings with me, contributed to the analysis of the data, the writing up of the articles, and dissemination of findings.

Thirdly, a mixed advisory panel (hereafter called “the panel”) comprising three patient representatives and three healthcare professionals contributed insights and advice during the research process. They were selected based on criteria established in collaboration with the research team. The criteria entailed that the panel members must

- be composed of three members with experiential knowledge and three healthcare professionals
- be experienced in patient participation in health service development or involvement in research
- include men and women from geographically different places in Norway

The Norwegian Federation of Organizations of Disabled People (FFO) and my colleagues at the Norwegian National Advisory Unit on Learning and Mastery in Health contributed to making a list of relevant persons. All those we approached agreed to participate.

Co-creating knowledge well requires several persons with experiential knowledge (Grotz et al., 2020). Three patient representatives were engaged to be in the panel, anticipating that at least two of them would always be able to attend scheduled meetings. The goal was to ensure that no one had to express the patient perspective alone during a meeting, which can be overwhelming. Wanting to maintain a balance between representatives of the patient perspective and healthcare professionals on the panel, three professionals were included as members.

The panel´s mandate was to offer insights and advice during the research process. Thus, the patient representatives´ role was not to speak on behalf of other patients in the sense of representativeness. Instead, they were to contribute various patient perspectives, aligning with the patient representative role in the co-production of knowledge as described by Price and colleagues (2022). Accordingly, the professionals´ role was to provide input based on their professional backgrounds and work experience thereby offering a range of perspectives from their side of the table.

The name “mixed advisory panel” may give associations to a consultatory approach to involvement (see Biddle et al., 2021; Andreassen, 2018a). The involvement approach depended on what was needed to drive the research process forward. The panel was consulted regarding the content of the interview guides for the focus groups (see Appendices 4 and 5) and individual interviews (see Appendices 6 and 7). This meant that they gave their input to already established drafts of the guides. They contributed to adjustments and added questions. For example, the following questions were added: To what extent do healthcare professionals perceive that the patient representatives are representative of their group? What meaning do the patient representatives perceive that their involvement has in the health service development? These issues are addressed in Article 2 and Article 4, respectively, indicating the pertinence of consulting the panel in this phase of the research process.

However, collaboration, rather than consultation, may better describe how we worked together in the initial analysis of articles 2, 3, and 4, respectively. To facilitate analysis of each article, the panel received excerpts from the data transcripts a week ahead of the analysis meetings. They were asked to write down their immediate interpretations of what the excerpts “said something about”. The co-researcher, supervisor and I had selected data excerpts that we considered relevant to answer each article´s research question. At the meetings, we addressed everybody´s interpretations of the excepts and debated what they meant. Our discussion led to initial theme names. Grouping similar theme names, we made new themes and renamed some old ones. In this way, we established initial themes supported by illustrative quotations that we recognized as relevant for answering the research questions of each respective article.

As this background makes clear, involvement of different types of expertise at various stages substantially impacted the research process. Next, the values and assumptions that guided the involvement in research are addressed.

4.2.2. Assumptions and values concerning the involvement in research

Based on a narrative review, Gradinger and colleagues (2015) have identified a broad range of values related to involvement in research, organized into three overarching value systems: normative, substantive, and process. Normative values concern ethics and/or politics and encompasses values inherent in empowerment, change/action, accountability and transparency, and ethics. Substantive values, on the other hand, are those associated with consequences – the practical outcome – of involvement in research: effective, qualitatively good, relevant findings that are reliable and valid and recognizable to those the research is about. Last, process values concern how the involvement in research is carried out. Partnership and equality, respect, openness, and clarity are among the values comprising this values system. To ensure a positive impact for all involved in the research process, Gradinger and colleagues (2015) suggest that researchers debate and clarify the values they associate with involvement in research.

The research team, panel members, and I shared the assumptions that professional and experiential knowledge represented different and complementary knowledge types. Additionally, involvement in research would enhance the research's quality, relevance, and credibility and contribute to developing trustworthy and applicable knowledge, provided the involvement is well conducted. Our assumptions correspond with those described as impact of involvement in research by Grotz (2020), Staniszewska (2018), Brett (2014), Beresford (2003), and colleagues. The assumptions may be understood to express several values.

According to Gradinger and colleagues (2015), the view that involvement in research would contribute to enhancing the quality and relevance of the findings to those the research is about refers to substantive values. However, we also shared a concern for how the involvement in research was carried out. Rights to be involved and transparency concerning the roles of those involved in the research process were issues of importance to us. In line with Gradinger and colleagues (2015), normative values also played a part in the involvement in research. Last, our collaboration required mutual respect between all parties, and that everyone´s input was seen as mattering. This implies that process values guided the way we worked. Still, I had the final say in all decisions. Thus, the involvement in research appears not to be an equitable partnership. This last point and others concerning the co-creation of knowledge are addressed in the following section.

4.2.3. Implications of co-creating knowledge

The involvement in research required considerations of how and when to involve others while making it meaningful to them and to the research process. It was challenging.

How the co-researcher´s involvement specifically impacted the research process is referred to in the sections below when addressing the scoping review process, the data generation, and the analysis. However, overall, the co-researcher´s involvement ensured that the patient perspective was always present in the research process. Working together, the co-researcher and I were able to discuss our respective understandings and interpretations based on our different perspectives. My background as a physical therapist and facilitator of health service development allowed me to bring in a professional viewpoint, while the co-researcher asserted the patient perspective and used her experience from participation in health service development. This facilitated a productive exchange of ideas, contributing to a more comprehensive understanding of patient participation in health service development.

The panel impacted phases of the research process. The panel members´ contribution in the initial analysis resembled what Fangen (2010, p. 237) refers to as “communicative validation”: a process where those involved discuss contradictory interpretations concerning the phenomena of interest, debate the arguments, and contribute to developing an interpretation (Fangen, 2010). Additionally, having both healthcare professionals and patient representatives on the panel helped to generate knowledge that would be of relevance to both groups. However, It was my job to sift through the panel´s input and decide what to incorporate into the research process.

Price and colleagues (2022) suggest that emotional labor is needed to handle involvement in research: it involves tackling uncertainties, takes additional time, and requires a targeted focus on including the user perspective. It took time and energy to understand when the research process would benefit from involvement and how to facilitate the involvement to ensure the co-researcher and the panel´s input would impact the research process. For example, starting out, I assumed the panel would be involved more closely than what was achieved in practice. Several institutes offer guidance on how to conduct involvement in research, including the United Kingdom´s NIHR and INVOLVE, the Canadian Institute of Health Services and Research (CIHR), and the Patient Center Outcomes Research Institute (PCORI) in the United States. Nevertheless, co-creating knowledge appeared abstract and complex and was something I ultimately had to learn by doing.

Even if one is guided by good intentions, lacking competency to facilitate involvement well risks subjecting individuals to unintended negative consequences (Martin et al., 2018). None of those involved in these studies have implied that they had negative experiences during the involvement in the research process. However, members of the panel have indicated that they also expected to be more involved in the process. While involvement in research required constant attention to why, how, and when to involve others, I remain uncertain about how to facilitate it better within the scope and design of the Ph.D. project.

Price and colleagues (2022) also imply that in co-creating knowledge, academics must alter their research mindset and relinquish control over the research process. Receiving input helped nuance my understanding of patient participation in health service development. For example, the facilitator role appears to be more crucial after having conducted this research than before. However, the concept of power-sharing with those involved in the research process is difficult to grasp.

A hierarchy and differences in power were present throughout the research process: I had the final say in all decisions. Guided by the supervisors, it was my responsibility to lead the research process forward, facilitating involvement when I saw fit, and using or discarding the contributions. Thus, practicing equity in involvement during research in a Ph.D. project like mine appears difficult to realize. Perhaps equity is a utopian concept, as suggested by Bell and Pahl (2018). Stuhlfauth and colleagues (2020) suggest that researchers´ understanding of equity concerning involvement in research is constructed based on a discourse driven by their responsibility and duty to drive the research process forward. Their suggestion aligns with my experience.

Overall, involvement in research was a positive experience. It enabled the incorporation of multiple perspectives, which contributed to more relevant and trustworthy findings. Additionally, those involved offered a sense of community and support that made the research process meaningful to me. I warmly recommend involvement in research, provided that leadership support, time to do it well, and necessary funding are in place.

Concerning funding, the involvement of the co-researcher and the mixed advisory panel was made possible by the Dam Foundation and the Norwegian National Advisory Unit on Learning and Mastery in Health. The co-researcher had a 20% position for three years and a 10% position for the fourth year of the Ph.D. project, funded by NK LMH. The Dam Foundation covered her expenses incurred during the research process, for example, when visiting the research sites. The allocated resources were inadequate to cover the costs of the co-researcher's involvement in the individual interviews, which I conducted alone.

The panel´s representatives were compensated for the time they spent on the Ph.D. project with the funds provided by the Dam Foundation to cover expenses during the research process. They were paid in accordance with the Norwegian South-East Health Trust´s rates (Helse Sør-Øst, 2023). The workplaces of the panel´s professionals covered the time they spent on the Ph.D. project. All panel members´ travel expenses were compensated by the Ph.D. project´s expense funding. When the COVID-19 pandemic forced digital panel meetings, we met digitally when the research process called for it and did not have to consider travel expenses. According to the patient representatives, digital meetings also reduced the toll on their health.

Aiming for more transparency, this chapter has described how involvement was conducted in the research process, the assumptions and values that guided it, as well as its implications for the research process. Next follows an elaboration on how the data were generated.

4.3. Generating data

This thesis´s empirical material was created by using a scoping review, focus groups, and individual interviews and analyzing the data with Braun and Clarke´s thematic analysis (2006, 2013, 2019). This chapter describes the methods used and their implications for the generated data, the analysis, and the knowledge production. It is rounded off with methodological reflections. The scoping review process is addressed first.

4.3.1. Conducting a scoping review

The six-stage scoping review process based on Arksey and O´Malley´s framework (2005) and its enhancements (Daudt et al., 2013; Levac et al., 2010) is extensively described in Article 1, the scoping review. This section addresses why a scoping review was conducted, why only primary studies were included, and provides reflections on the process that were not specifically discussed in the article.[5]

To ensure that this thesis would add new knowledge, a review of the current state of research in the field of inquiry was conducted at the start of my Ph.D. project. Moreover, the findings would inform the further research process. There are different types of reviews that can be conducted depending on the purpose and research questions. Conducting a conventional systematic review was ruled out, as it primarily focuses on what works when there is conflicting evidence in clinical practice (Munn et al., 2018). An integrative review was also considered but found not suitable, as it summarizes empirical evidence and

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[5] The scoping review authors differ from the research team: a healthcare professional from the mixed advisory panel (KF) was involved, but one of the co-supervisors (TS) was not.

theoretical literature to develop theories for practice and policy (Whittemore & Knafl, 2005). Instead, exploratory reviews, including scoping reviews, proved promising, as they map the literature on complex phenomena by including studies from various methodologies and grey literature (Cooper et al., 2019). Conducting a scoping review in line with Arksey and O´Malley´s framework (2005) and its enhancements (Daudt et al., 2013; Levac et al., 2010) seemed most appropriate.

The scoping review can help to clarify definitions, terms, concepts, and boundaries of complex research phenomena (Khalil et al., 2016); identify gaps and evidence to inform practice, policymaking, and research (Daudt et al., 2013); map an emerging field based on various types and sources of evidence, as it allows the summarizing and synthesizing of data extracted from studies of different designs (Arksey & O'Malley, 2005; Peters, 2017). While a scoping review is not considered a qualitative research method, it incorporates descriptive and interpretive qualities, corresponding with this thesis´s research approach. Additionally, the co-supervisor (US) had methodological scoping review expertise and could provide guidance throughout the process, as recommended (Daudt et al., 2013; Levac et al., 2010). An inquiry to the University of Oslo Medical Library showed we also had the support of a senior academic librarian in establishing a good search strategy. Against this background, and with the research team´s support, I chose to conduct a scoping review.

Supported by the research team, only primary studies were included. This meant that the full potential of the scoping review was not employed and that its comprehensiveness could have been limited. Still, the decision enabled the application of the Mixed Method Appraisal Tool (Hong et al., 2018) to critically appraise the studies´ quality, as recommended by Daudt and colleagues (2013). The results from the MMAT are included in the scoping review´s appendices. Five studies were commented on, but none were discarded due to poor quality. The choice to include only primary studies ensured that the Ph.D. project´s further research process could be built on studies of good quality. Additionally, the findings would be more useful for others (Daudt et al., 2013).

I screened the titles using the research questions and the inclusion and exclusion criteria. It could have enhanced the review´s methodological quality if two researchers had done the initial screening. Recently, machine learning has been introduced as a tool to assist in the initial screening of studies (Page et al., 2021). Future reviews may benefit from machine learning in retrieving relevant studies and reducing the chance of erroneously excluding studies (Page et al., 2021).

As recommended (Levac et al., 2010), our team was multidisciplinary and inter-professional, including members with differing perspectives. This diversity enabled us to engage in discussions that helped facilitate the review process. The co-researcher and I collaborated closely concerning the inclusion of studies and data charting process, which helped us focus on the patient perspective. For example, during the data charting process, our different perspectives allowed us to identify different impacts. Since the scoping review involved navigating multiple terms, concepts, and fields of inquiry, our collective competencies were useful throughout the process and added rigor to the research process and its findings.

4.3.2. Choosing focus groups and individual interviews to develop data

In order to generate new knowledge about patient participation in health service development, it was necessary to explore the participants´ experiences, attitudes, beliefs, and meanings. After consulting with the research team, I opted to generate data through both focus groups and individual interviews. This decision was based on various assumptions and considerations.

Focus groups are characterized by group interaction concerning a topic the researcher decides (Halkier, 2016). They are ideal for exploring how a research phenomenon is perceived within a specific group, work culture, or environment (Halkier, 2016). An advantage of focus groups is that they can provide rich data about the participants' beliefs, perceptions, and experiences regarding the research phenomenon. Compared to individual interviews, focus groups offer the opportunity for participants to interact and engage in discussions with each other, which can result in more comprehensive accounts (Halkier, 2016).

However, we knew that finding participants with extensive experience in patient participation in primary healthcare service development could be challenging, as it is a rare practice in many municipalities (The Norwegian National Advisory Unit on Learning and Mastery in Health, 2016). Also, focus groups tend to favor consensus viewpoints over divergent comments, which can limit the representation of diverse perspectives in the data and in the subsequent analysis (Halkier, 2016). It means that the moderator must be ready to change the dynamic of the discussion and enable different stories to come forth in the discussion.

The data obtained from such discussions is context-specific and can be understood to reflect the participants´ collective beliefs and attitudes rather than their individual thoughts and emotions (Hollander, 2004). Thus, relying solely on data from focus groups may lead to incomplete or skewed answers to research questions. Nonetheless, the focus groups were likely to include participants with diverse and unique experiences, whom we could interview individually to obtain more in-depth and nuanced data.

In focus groups, the data are produced based on conversations centered around the researcher´s questions – in a situation set up by the researcher in the interest of exploring the meaning of the participants´ experiences. This is also the case for the individual interview. The qualitative research interview is a purposeful and structured conversation that enables the interviewee to expand upon and clarify topics of research interest (Brinkmann & Kvale, 2018). It provides an opportunity to explore selected participants' perspectives, opinions, and experiences, allowing the researcher to interpret their accounts of the research phenomenon in greater detail (Brinkmann & Kvale, 2018).

4.3.3. Selecting municipalities

Only Norwegian municipalities that had experience in practicing participatory health service development and met the inclusion criteria participated in the Ph.D. project. The reasons were twofold. Firstly, it ensured that participants from the selected municipalities would have relevant experiences. Secondly, exploring involvement in contexts that had experience in conducting participatory health service development could help uncover issues that municipalities with less focus on involving patient representatives to develop health services could also encounter.

After consulting with the research team, we developed a set of criteria to select municipalities for the Ph.D. project. The municipalities had to

- have practiced patient participation in health service development for several, some, or only a few years,
- have a larger, mid-sized, or smaller population,
- represent different parts of Norway.

We anticipated that selecting municipalities based on these criteria would ensure participants with relevant experience, contributing to rich descriptions of involvement in developing primary healthcare services and their impact.

In Norway, municipal Healthy Life and Coping Centers aim to promote health, prevent non-communicable diseases, and support efforts to live a healthier lifestyle or better cope with health challenges (the Norwegian Health Directorate, 2016, 2015). The centers' activities are developed with patient participation (the Norwegian Health Directorate, 2016, 2015). Healthcare professionals in the centers lead participatory primary healthcare service development. These facilitators have a network of colleague professionals and patient representatives they can rely on to help develop primary healthcare services. Municipal Healthy Life and Coping Centers thus represented an arena for recruiting participants with the necessary experience.

My colleagues at the Norwegian National Advisory Unit for Learning and Mastery in Health helped identify ten municipalities with a Healthy Life and Coping Center assumed to fit the criteria. Using the criteria and aiming for variety among the municipalities, we made a list of ten potential municipalities to ask to participate. Aiming for variation and adhering to the inclusion criteria, we made a prioritized list of municipalities to ask to participate. Selecting the municipalities began by contacting the leader of the Healthy Life and Coping Center in each municipality via phone. I explained the purpose of my project and asked if they would be interested and able to participate. Fortunately, all four leaders who were contacted showed enthusiasm and willingness to participate. Then, the administrative offices of each municipality were contacted to formally request their participation in the research. All the municipalities that were approached agreed to take part and assigned a contact person for me.

The four contacts were familiar with conducting patient participation when developing healthcare services and had a network of healthcare professionals and patient representatives. The participating municipalities vary in population size, how long they have practiced patient participation in primary healthcare service development, and geographical location. This ensured diversity in the sample group and allowed for a more comprehensive investigation. The selected municipalities are not described in detail to protect their and the participants´ identities.

4.3.4. Purposively sampling participants

Prior to generating data, the co-researcher and I visited the research sites. We wanted to establish a relationship with the contacts and safeguard the selection of participants. The participants should be willing to be involved and should represent relevant experiences that could contribute to generating data that reflected the diversity in their experiences, beliefs, and attitudes (see Etikan et al., 2016; Malterud et al., 2016). We also wanted to acquire a sense of the participants´ context and familiarize ourselves with the culture and people, to generate ideas about what would be interesting to explore.

After establishing rapport with the contacts, they were asked to suggest potential participants with minimal, medium, and extensive experience, aiming to generate data based on many perspectives. Two of the contacts informed me that they knew of a few representatives with extensive experience from involvement in primary healthcare service. They also knew of several who had been involved only once or twice in primary healthcare development. Based on their networks at the Healthy Life and Coping Centers, each contact made a list of potential participants. At each site, the contact, the co-researcher, and I discussed whom to approach about participating in the focus groups, aiming for diverse experiences among those who were available.

The contacts, however, were experienced in facilitating patient participation in health service development. They also knew the potential participants – though some better than others. The contacts´ assistance was helpful in several ways. Firstly, it enabled recruiting participants quickly: all those approached by the contacts agreed to participate. Secondly, it was possible to put participants with diverse experiences together in the focus groups. Still, the purposive sampling also illustrated how `patient participation´ may be interpreted differently, even among us working in the same field. It underlined the importance of sitting down and exploring research phenomena to ensure that those involved in the research process are on the same page.

The contact further identified ongoing healthcare service development meetings and arranged for the co-researcher and me to “sit in” and conduct participatory observations. The aim was to get a better feel for the sites´ practice of patient participation – and as such, prepare for the focus group interviews. However, we also used the experience from the participatory observations to develop the interview guides, which are addressed below. The contacts further arranged for suitable locations for conducting the focus groups and individual interviews.

4.3.5. The participants´ demographics

The participants in this Ph.D. project come from four municipalities located in different parts of Norway, representing large, mid-sized, and small municipalities. The degree to which the participants had practiced patient participation to develop health services varied. All were affiliated with a municipal Healthy Life and Coping Center. The participants include 55 unique individuals from 11 professional backgrounds and 15 patient organizations.

A total of 26 healthcare professionals participated in the focus groups: 24 women and two men. The focus groups comprised five, six, seven, and eight participants. The participants´ professions included: nine nurses, five physical therapists, three occupational therapists, three psychologists, two healthcare administrative managers, one deacon, one nurse trained in learning disabilities, one teacher, and one theologist. They occupied different administrative and clinical positions within somatic and mental healthcare services. Their age range was 30-64, with a mean age of 49.

The 23 patient representatives participating in the four focus groups included 17 women and six men. The different focus groups had four, four, six, and nine participants representing conditions such as autism spectrum disorders, cancer, dementia, hearing impairment, heart and lung disease, osteoporosis, metabolic challenges, stroke, and rheumatoid arthritis. One belonged to a next-of-kin organization, whereas nine did not represent any patient organization. Their age range was 35-80, with a mean age of 61.

From the focus groups, four patient representatives were recruited to participate in individual interviews. Two more were recruited by the contacts. All those approached agreed to participate. The six representatives participating in individual interviews comprised four women and two men. Their degree of experience with involvement in health service development differed: three had been patient representatives for over 12 years, two for around two years, and one had only been involved a couple of times. Four represented patient organizations concerning autism, hearing impairment, mental health, and osteoporosis, respectively. Their age range was 39-75, with a mean age of 56.

Last, the contacts recruited six female healthcare professionals who acted as facilitators for health service development with patient participation in their respective municipalities. All those approached agreed to participate in individual interviews. They had different degrees of facilitation experience. One had over ten years of experience, two had between six and eight years, and three had two years. All six had initiated and led primary healthcare service development with patient participation more than four times. Their professional backgrounds included nursing, occupational therapy, psychology, and physical therapy. Their professional roles and responsibilities varied: one was a healthcare division manager, two were service-level leaders, and three were service-level coordinators. Three of them were asked to participate in an individual interview after participating in a focus group. Their age range was 39-62, with a mean age of 50.

4.3.6. Visiting the research sites and developing the interview guides

An ethnographical visit to the first research site generated insights that were used to develop the interview guides. The co-researcher and I visited each research site. Prior to these visits, we talked to each other about our expectations of what would meet us at the sites and what experiences we might gain, and discussed our preconceived notions about the research site. It functioned as a preparation for identifying what would be interesting to explore when visiting, and later, through focus groups and individual interviews, as suggested by Fangen (2010) and Hammersley (2006). To become familiar with the research sites, the people, and the culture, we also conducted participatory observations in a health service development meeting at each site. The primary purpose of attending these meetings was to experience first-hand how patient participation was practiced. We assumed it would contribute to acquiring a sense of the participants´ context and the culture of each site. We found it helped establish ideas about what to follow up on in the focus groups and the individual interviews.

In the health service development meetings, a facilitator led the collaboration between healthcare professionals and patient representatives to develop a type of health service or activity: the improvement of a 6-day self-management program, the planning of a day of activities and health information for the municipality´s senior citizens; the planning of the municipal program for the World Mental Health Day; establishing the center´s activities for the public and designated patient groups for the coming year. In these meetings, we explored the interaction among those participating to learn more about the context and what would be interesting aspects to inquire about in the focus groups and the individual interviews.

We took field notes during our visits. In line with Fangen´s (2010) recommendations, they consisted of observation notes (what happened, without too much interpretation), theoretical notes (attempts to create meaning from one or several observational notes), and, last methodological notes (reminders or instructions to self, reflexive notes, experiences or emotional impressions). Based on the scoping review findings, the visit, and the participatory observation of a health service development meeting at the first research site and discussions with the co-researcher, I developed drafts for the focus group interview guides for healthcare professionals and patient representatives, respectively. The guides for the individual interviews with the professionals and the representatives were developed at a later stage. They built on the data from the scoping review, the visits to the four sites, the four focus groups with healthcare professionals, and the four focus groups with patient representatives.

All draft guides were scrutinized by the co-researcher and mixed advisory panel, then the rest of the research team, and adjusted based on their input. The co-researcher and I conducted a test focus group, and the co-supervisor (US) and I ran a test individual interview. These led to further adjustments of the guides to ensure clarity. Also, the feedback from the co-researcher and the co-supervisor contributed to my development as a moderator and interviewer. In accordance with the empirically driven research process, the guides were slightly altered from one focus group or individual interview to the next to ensure the research questions could be answered adequately. However, all four guides´ main questions remained the same during the data generation. The guides are presented in Appendices 4, 5, 6, and 7. Nevertheless, generating data by applying two different methods had implications for the data, the analysis, and the knowledge production.

4.3.7. Conducting focus groups and individual interviews

The participants´ experiences and opinions regarding patient participation in health service development were explored through focus groups and individual interviews.

Focus groups

The focus groups were conducted from October 2018 to September 2019. I moderated the focus groups, and the co-researcher was a co-host. The participants filled out a demographic information form (see Appendices 8 and 9) and a written consent form (see Appendix 10) at the start of the focus groups. When they were done, they were handed a form about the right to withdraw from the research project at any time (see Appendix 11).

The participants were encouraged to speak freely and share their views and experiences in response to the interview guide's topics – and in line with what they felt comfortable sharing. Each focus group was opened by asking every participant about their favorite candy, aiming to establish a relaxed and pleasant atmosphere. It worked well. Also, to get focus group discussions started, the co-researcher and I would comment on our differing views based on our respective perspectives.

During two focus groups with patient representatives, it was especially challenging to keep the participants' discussions centered around patient participation in health service development and not patients´ participation in their own treatment. Likewise, focus groups of healthcare professionals also had to be reminded that the topic was patient participation in health service development. In one focus group with professionals, it was especially demanding to get the discussion going: the participants seemed hesitant to express their views and share their experiences. I explained that I would ask each participant about their experience with patient participation, beginning with a participant that we had spoken to earlier during our visit to the research site. The participant started telling her experiences, and it opened up the discussion. Upon reflection, it appeared that patient-representative participants were more willing to share their views than healthcare-professional participants. We attributed it to the patient representative role of contributing experiential knowledge. Also, we reflected that professionals may be more apprehensive about expressing their views and beliefs in a group of participants with multiple professional backgrounds. However, in general, the focus group participants willingly shared diverging, challenging, and positive experiences regarding involvement, although some individuals expressed their opinions more frequently than others. It meant that as a moderator, I sometimes had to change the dynamic of the discussion and enable different participants to speak during the sessions. In these situations, asking the co-researcher if there was something we needed to explore enabled redirecting the discussion to its desired focus.

Following each focus group, the co-researcher and I discussed the participants, the setting, what was said, and our interpretations of it. We identified participants who we considered especially knowledgeable and would ask to participate in individual interviews. In total, we recruited five patient representatives, and four professionals to participate in individual interviews. The next day I listened to the audiotape of the focus group and summed up the impressions, the interpretations, and the discussion between the co-researcher and myself. I also tried to think of what was not said.

The focus groups generated knowledge about the healthcare professionals and patient representatives´ experiences of the positive and challenging sides to patient participation in health service development, as well as some about its impact. However, to better understand the positive and challenging aspects of patient participation, its meaning to professionals and representatives, the collaboration involved, and the context of patient participation, further in-depth exploration was required.

Individual interviews

The individual interviews were conducted from April to September 2019 by me. The participants filled out a demographic information form (see Appendices 8 and 9) and a written consent form (see Appendix 10) at the start of the individual interview. The participants were encouraged to speak freely, share their views, and elaborate on their experiences in response to the interview guide's topics and issues addressed in the focus groups – in accordance with what they felt comfortable sharing. After each individual interview, I noted interview reflections. The next day I listened to the audiotape of the interview and summed up my impressions and interpretations of the participant, the setting, what was said, and what was not said. Then my notes and the generated data were discussed with the co-researcher and the main supervisor.

During one interview, the interviewee was struggling and I suggested that it was okay to stop the interview if needed. The interviewee asked for a break. They explained they had received bad news just before the interview, which made it hard to concentrate. After the break, I adjusted my approach and slowed down the pace of the interview. Afterward, when inquiring how the interview had been, the interviewee said it was okay but tiring. It was interesting to see how this setting generated much less transcribed text and applicable data when compared with the other interviews. It illustrated that interviewing persons who have difficulties staying focused demands sensitivity to their challenges and time to allow for breaks.

Mik-Meyer (2020) argues that researchers must be sensitive to the participants´ preferences concerning participation in research. As the data generation relied on both focus groups and individual interviews, it was easy to accommodate one of the participants´ wishes to participate in an individual interview rather than in a focus group. Using both focus groups and individual interviews further enabled the exploration of participants´ perceptions on a collective level to be complemented with data from the individual interviews. Issues that came up in the focus groups could be explored more in-depth with the interviewees in the individual interviews, and vice versa. This way, the data generation was empirically driven, building on the knowledge created in the previous focus groups and individual interviews.

Transcribing the data

To decide on the form of the transcripts, I looked to Braun and Clarke (2013). They regard the transcripts as representations: altered versions of the actual focus group or individual interview experience. Thus, they argue for including not only what is said by whom, but also incorporating verbal utterances from all speakers. The goal is to provide a clear account of what is expressed.

An external resource helped transcribe the focus group and the individual interview data. Beforehand, the transcriber signed a confidentiality agreement. We discussed what a verbatim transcription meant and how to include utterances (øh, eh, ah), marking pauses (…), as well as laughter, long pauses, and strong emphasis while transcribing. Upon receiving the transcripts, I listened to the audiotaped sessions while simultaneously reading the transcripts. I adjusted when discovering errors or mishearing in the transcriber´s version.

The choice to use a professional transcriber was pragmatic: conducting a scoping review and ensuring meaningful involvement in the research process were recognized as time-consuming activities that challenged the Ph.D. project´s time frame. If I had transcribed the data, however, I might have started the analysis earlier and acquired a deeper knowledge of the data.

Stopping the generation of data

The research team and I debated whether to continue or to close the data generation. Applying the concept of information power as defined by Malterud and colleagues (2016), we discussed whether the data could adequately answer the research questions or need to be complemented. We almost stopped after having generated data with participants in three municipalities. However, we decided the generated data could benefit from further exploring the collective patient representative and healthcare professional perspectives. Upon reviewing all the data transcripts after generating the data in the fourth municipality, we were satisfied we could adequately answer the research questions and stopped the process.

4.4. The empirical data

This thesis´s empirical data constitute the 34 included primary studies of the scoping review and transcribed data from eight semi-structured focus groups of circa 90 minutes each and 12 semi-structured individual interviews of circa 90 minutes each. The audiotaped data represent approximately 12 hours of focus group data and 18 hours of individual interview data. The focus groups and individual interviews were transcribed verbatim. The transcripts were anonymized. The transcribed data are around 800 pages (Calibri text size 12 with 1.5 line spacing). This thesis´s data transcripts have not been publicly released to protect the anonymity of the participants. There are few municipal Healthy Life and Coping Centers in Norway, and the number of patient representatives affiliated with each Center is limited. Based on the content of the transcripts, the research sites and those working there or affiliated with the sites may be identified.

As focus groups and individual interviews represent different approaches to exploring the participants´ experience and meaning-making, Lambert and Loiselle (2008) assert the need to attend to each method´s type of data separately when combining focus groups and individual interviews. In this thesis, the data from the focus groups and individual interviews have been handled as two separate data sets: explored and analyzed parallel to one another.

The Ph.D. project was initially designed to consist of three articles. However, during the exploration and analysis of the data, it became clear that the facilitator role needed to be investigated further. Therefore, the empirical material was applied in a total of four articles (see Figure 3).

4.5. Conducting the thematic analysis

Different types of thematic analysis exist that are often poorly defined (Braun & Clarke, 2012). Accordingly, thematic analysis has been criticized as an “anything goes” approach to analyzing qualitative data (Braun & Clarke, 2006, p. 78). Responding to the criticism, Braun and Clarke have developed a six-step thematic analysis, quality guidelines, and an assessment tool (Braun & Clarke, 2021) for evaluating and reviewing thematic analysis research. Thematic analysis enables the researcher to systematize and arrange patterns of meaning or experience across data sets (Braun & Clarke, 2013).

Supported by the research team, I chose to apply Braun and Clarke´s reflexive thematic analysis to analyze this thesis's empirical data. The stages of analysis involved – after having transcribed the data – (1) familiarization with the data; (2) generating codes; (3) generating themes; (4) reviewing themes; (5) defining and naming themes; and (6) writing up the article (Braun & Clarke, 2013, pp. 202-203). However, the authors underline that the stages do not represent a recipe to follow. Instead, the researcher must actively engage in the stages, entering in and out of them during the analysis (Braun & Clarke, 2013).

The data sets from the focus groups and individual interviews were analyzed separately and in different periods of time. It was a highly iterative process – and it took trying, failing, and guidance to get the hang of it.

The focus group data were analyzed first – without a sorting tool. Reading and marking issues of interest in the transcripts and collecting quotations that seemed to illustrate discussions and points. However, maintaining an overview was a struggle. Well-acquainted with my data, I started applying the sorting tool NVivo (QSR International, 2020). It was very helpful: it provided an easy way to keep track of the text excerpts and related codes; it also enabled making “a code book” that helped present the coded data at different stages in the thematic analysis to the research team and the mixed advisory panel.

Using NVivo to sort the data, the first healthcare professional focus group´s data underwent open coding. Then, the remaining healthcare professional focus groups and the patient representative focus groups were coded based on established codes. However, original codes were altered and collated, and new ones were created during the coding process. The individual interview data transcripts underwent coding in the same manner.

The data were first organized in relation to codes describing approaches to, characteristics of, context, or impact of patient participation in healthcare service development. Then, I started seeing different issues, more in line with what the data told something about. I reorganized the data from the standpoints of those who commented: facilitators, healthcare professionals, and patient representatives. Then, the codes were collated under various subthemes and themes.

When the two data sets were adequately coded, code books were developed in NVivo. Using them, the co-researcher, the main supervisor, and I reviewed the codes and the data excerpts belonging to the codes: we discussed, renamed, and collated codes until we were clear about what they meant. The process nuanced the interpretation of the data. After that, we looked for shared meaning patterns across the focus groups and then across the individual interviews.

Building on our work, I generated central organizing concepts: the initial themes for the focus group and individual interview data, respectively. An example of an initial theme, its initial subthemes, codes, and original data excerpts is provided in Table 5. The process required constantly going back and forth between the four first stages of the thematic analysis.

Table 5. Example of an initial theme, its initial subthemes, codes, and original data (translated) concerning the facilitator role and patient representatives (from Article 3).

Initial theme	Initial subthemes	Codes	Original data
Establishing a network of competent representatives	Locating potential representatives to involve	Locate representatives who they can collaborate with	*We need to know them first. (..) We have experience with contacting patient organizations. (..) Then we´re at the mercy of the person they send, and we don't know if this person is someone who can speak on behalf of many, or is this person someone who can´t see beyond their own suffering. (Facilitator B)*
	Ensuring representatives are competent collaborators	Select suitable representatives to involve	*To be a patient representative is not like being a member of a social club. It´s good that it is nice to participate, but it is a job. (Facilitator A)*
			It is all about how they behave. The language they use and their attitudes toward those they will be meeting with. It´s also about humility, which, of course, goes for all involved. (Facilitator A)
		Try to build representatives´ participation competence	*It´s important that they have their own experience, but at the same time, that they know they represent the experience of many. However, they can slip in and out of that perspective, depending on the issue addressed or their current health situation. That´s just the way it is. (Facilitator D)*
	Mediating between representatives and administrators	Mediate between administrators and representatives	*I go down to my municipal director and ask why he hasn´t responded to the e-mail from the patient organization. (..) He says he´s sorry and explains that it has been so busy with the reorganization. Then, I report this back to the PR, making sure that they understand that the lack of response has nothing to do with them. (Facilitator F)*

Keeping separate files for the focus group and individual interview data in NVivo (QSR International, 2020) showed that the individual interview data complemented the focus group data. For example, the healthcare professional and patient representative focus group data did not include many descriptions of the context of primary healthcare service development. However, the data from the individual interviews provided better descriptions.

At this point, the mixed advisory panel scrutinized the initial themes with the co-researcher and me, debating their content and wording, collating, altering or coming up with new names for the themes – now representing the initial findings. Then, further analysis and interpretation were undertaken by the research team. When they were presented with the initial themes, we discussed the themes´ meaning, content, and wording, collated some, arranged the initial themes into themes and subthemes, and slightly altered the names of the themes and subthemes.

During the analysis, I read literature concerning patient participation, patient and public involvement, professional practice, values-work, and organizational theory. It opened the empirical data up to analyses and to understand what the material or text said and then more in line with “what it talks about”.

Writing the article´s findings, presenting the text to the research team, and getting their feedback, led to further alterations in the way the themes were presented. The process did not cease until the articles´ final manuscripts were in place. The process enabled a rich analysis built on multiple perspectives representing the findings of Articles 2, 3, 4, and this thesis. The analysis was completed upon the finalization of this thesis.

4.6. Relying on a hermeneutic phenomenological research approach

The empirically driven and collaborative approach to creating knowledge was not straightforward. For example, it took time to establish which understanding of the world and view of knowledge should inform the overall research process. Therefore, Articles 2, 3, and 4 were positioned within the broad interpretivist/constructivist paradigm (Mackenzie & Knipe, 2006). However, during the research process, it became clear which framework within the interpretivist/constructivist paradigm inspired the research process, namely a hermeneutic phenomenological approach.

This chapter first describes the interpretivist/constructivist paradigm. Then, underpinning assumptions of a hermeneutic phenomenological framework and their implications for the research process are addressed.

4.6.1. Positioning the articles in the interpretivist/constructivist paradigm

In the article titled “Research dilemmas: paradigms, methods and methodology”, Mackenzie and Knipe (2006) aim to ease novice researchers´ confusion about what type of study to undertake and what research paradigm would be appropriate to apply. Addressing the role of theoretical paradigms across qualitative, quantitative, and mixed-method research, they clarify how research paradigms and methodology work together to form a study.

A research paradigm informs a study's overall research process or methodology (Mackenzie & Knipe, 2006). Mackenzie and Knipe (2006) present four broad paradigms that shape the research process: Postpositivist, interpretivist/constructivist, transformative, and pragmatic. According to the authors (Mackenzie & Knipe, 2006, p. 6, Table 1), the interpretivist/constructivist paradigm encompasses several more specific theoretical frameworks, such as phenomenological, hermeneutic, interpretivist, and constructive, all originating from the phenomenology of Edmund Husserl (1859-1938) and the hermeneutics of Willhelm Dilthey (1833-1911) and fellow German philosophers. Furthermore, studies positioned within the interpretivist/constructivist paradigm 1) aim to understand "the world of human experience" through the views of the participants, 2) see knowledge creation as a social process, 3) take an inductive approach to develop patterns of meaning, 4) explore participants´ perspectives through qualitative methods, for example, interviews, and 5) recognize that the researcher´s background and experience matter to the research process (Mackenzie & Knipe, 2006, pp. 4-7).

The qualities describing studies positioned in an interpretivist/constructivist paradigm corresponded with the understanding of the world and view of knowledge that I used in the Ph.D. project, as well as the applied research approach and methods. While it may be argued that the paradigm is so broad that it means little to position one´s research in it, its broadness represented a possibility to indicate the type of theoretical framework on which this thesis relied from the start. Articles 2, 3, and 4 were thus positioned within the interpretivist/constructivist paradigm described by Mackenzie and Knipe (2006).

Attending Ph.D. courses, Muni-Health-Care seminars, researcher network meetings, and engaging in academic discussions about ontological and epistemological underpinnings in the Ph.D. project I developed as a researcher. In the process, the relevance of letting the thesis´s research approach be inspired by hermeneutic phenomenology became clear.

4.6.2. Applying a hermeneutic phenomenological research approach

According to van Manen (2016), hermeneutic phenomenology is a human science that studies persons situated within a historical, cultural, and social world. The approach is anchored in the traditional philosophical disciplines of hermeneutics and phenomenology (van Manen, 2016). The underpinning assumptions of a phenomenological perspective are described before the hermeneutic phenomenological perspective is addressed.

Applying a phenomenological perspective on doing research means to question and explore the world in which we live as human beings (van Manen, 2016). While Edmund Husserl (1859-1938) is considered its founder, the contributions of many philosophers have come to represent several branches of phenomenological thought (Thomassen, 2020). Martin Heidegger (1889-1976), Jean-Paul Sartre (1905-1980), Maurice Merleau-Ponty (1908-1961), and Emmanuel Levinas (1906-1995) have all been influential (Zahavi, 2019), as well as Hans-Georg Gadamer (1900-2002) (Laverty, 2003).

Husserl (1970) focuses on the relationship between the knower and what can be known about the world: the situated meaning of being a human in the world. According to van Manen (2016), to know the world is to be in the world in a specific way. Husserl (1970) introduces the concept of intentionality, which highlights the deep connection between humans and the world around us. Intentionality refers to the active direction of our attention and consciousness toward something outside of ourselves (Zahavi, 2019). This interwovenness characterizes all our experiences, as we can only understand the object of our attention in relation to the world we live in. In this way, our experiences are shaped by the environment and context in which we exist (Thomassen, 2020). Thus, when using a phenomenological research approach to explore phenomena of interest, we must start by understanding how persons experience the world we live in, or “the lifeworld” (Zahavi, 2019, p. 51). By studying a phenomenon, including those aspects of it that we take for granted or consider common sense, we can uncover its unique qualities or essence. These are things that cannot be replaced (van Manen, 2016).

As a researcher, I want to understand the significance or essence of patient participation in primary healthcare service development. According to Husserl (1970) in order to understand this phenomenon, I must suspend my preconceived ideas and seize the immanent notion of the phenomenon in itself. However, philosophers have challenged this notion of “bracketing” in further developments based on Husserl´s phenomenology.

Hermeneutic phenomenology represents a development of Husserl´s phenomenology by Heidegger and Gadamer (Laverty, 2003). Heidegger's approach is more centered on the subject's lifeworld and the nature of reality (van Manen, 2017). However, Heidegger (1962) rejects Husserl's notion of bracketing. He argues that consciousness cannot be separated from the world, but instead, it forms our lived experience, which is shaped by our background, history, and the cultural, social, and historical context in which we live. He states that understanding a phenomenon requires interpretation, and therefore, the term “hermeneutic”, which comes from the Greek verb “to interpret”, is added to phenomenology (Heidegger, 1962).

Gadamer is considered the most prominent hermeneutic theoretician (Thomassen, 2006). He focuses on how understanding is achieved, building on Heidegger's idea that preunderstanding is always present and affects how we interpret the world. Gadamer (1998) suggests that language and understanding are intertwined and that we understand the world through interpreting language in an ever-evolving process. He argues that understanding is a hermeneutic process representing a fusion between the reader and the text and that it involves a back-and-forth movement between parts and the whole of our experience until we develop meaning.

This thesis follows a hermeneutic phenomenological research approach that originated from Husserl's (1970) phenomenology and was further developed by Heidegger (1962) and Gadamer (1998). Its implications for the research process are addressed in the following section.

4.6.3. Implications of applying a hermeneutic phenomenological research approach

As I developed as a researcher, I came to understand the relevance of anchoring the thesis on a hermeneutic phenomenological research approach and its implications for the research process. It means recognizing that my preconceptions about patient participation in health service development are always present and affect how I understand the phenomenon and my being in the world. It requires an awareness of what affects my interpretation, though being fully aware is considered impossible. It means engaging in questioning my assumptions and beliefs about patient participation in health service development, articulating them, and using them creatively in the research process. Furthermore, it means making transparent my experiences concerning the phenomenon of interest and describing the research process thoroughly. It also entails acknowledging that language is the primary way to explore meaning, corresponding with exploring the experiences of those involved with collaborative health service development through focus groups and individual interviews. Additionally, by analyzing in this way, those involved in the research process and I can engage in a hermeneutic circle of knowledge co-creation – analyzing the data transcription process by drawing upon our pre-existing knowledge and the historical, cultural, and social context in which we are situated. In doing so, we can gain a deeper understanding of patient participation in health service development and answer the thesis research question.

4.7. Reflections concerning the developed data and findings

This chapter addresses issues that mattered to the data and findings that were developed.

The four contacts in the municipalities were experienced in facilitating patient participation in health service development. They had collaborated with most of the potential participants within their networks. The contacts´ knowledge of potential participants´ competencies mattered when deciding who was invited to participate in the Ph.D. project. For example, the contacts reflected on which participants would be likely to work well together and stimulate discussion in the focus groups. Additionally, the contacts approached the potential participants to ask if they would be willing to be involved in the Ph.D. project and whether they would allow me to contact them to set it up. The reputation of the contacts in their respective municipalities and their relationships with potential participants likely affected the recruitment process. All those approached by the contacts agreed to participate, making the recruitment process easy. However, it also meant the participants were competent in collaborating and shared an understanding that patient participation in health service development was primarily a positive thing. This raises the question of whether those involved may have been “too similar” to contribute to developing data that illuminates the complexity of patient participation in health service development. Still, those involved appeared to represent a diversity of experiences from three different perspectives: healthcare professionals, patient representatives, and internal facilitators. This contributed to rich descriptions of the research phenomenon from a collective point of view, based on the focus groups, as well as individual points of view from the interview data.

Upon establishing the research team and the mixed advisory table, those involved engaged in discussions to clarify attitudes, beliefs, and assumptions concerning patient participation in health service development. The purpose was to actively apply these in the research process. These discussions showed that all involved shared a positive attitude toward patient participation in health service development and were eager to enhance its implementation within primary healthcare. Nevertheless, through our discussions, we discovered variations in our interpretation of the data. For example, upon analyzing the data with the mixed advisory panel, we found that the healthcare professionals mainly reflected on the data from a position of responsibility for the collaboration and its outcome, while the patient representatives primarily shed light on the patient view and voice in the process. This added depth and nuance to our understanding of how the data could be interpreted and helped establish the initial themes, representing the findings.

Preparing to visit the first research site, the co-researcher and I read Fangen´s (2010) book about conducting participatory observation. We engaged in thorough self-reflection to identify our preconceived notions concerning patient participation and each research site. The exercise illustrated how we were drawn toward different aspects of the research situation. The co-researcher paid attention to notes and messages for patients, service users, or informal carers at the first site, while I was more interested in the interior design and layout of the meeting rooms. We found it illustrated how our different experiences and backgrounds, with the co-researcher having participated in collaborative health service development and me being a physical therapist and facilitator of collaborative meetings, complemented each other. This helped us gain a better understanding of our different roles and how we could work together to benefit the research process. It also meant that the patient representative perspective was actively addressed in all discussions during the different phases of the research process, affecting the developed data, the analysis, and the findings.

In one municipality, we conducted a participatory observation of a collaborative health service development meeting before we had had a chance to familiarize ourselves with the research site. When discussing our experience afterward, we realized that we in general perceived conducting participatory observations as awkward. Those present appeared self-conscious, though mostly in the beginning. Also, the facilitators would often ask me a question related to the NK LMH or patient participation, which I interpreted as an attempt to ease the tension created by our presence. However, this particular participatory observation session was still more complex than the others we had conducted. To me, this situation highlighted the ethical considerations concerning research, as our presence and that of the co-researcher had an impact on the people around us.

During the first focus group, the co-researcher and I were so focused on getting everything right that we forgot to consider how the participants would feel. We noticed that many of them seemed nervous when they arrived. We learned from this experience and made sure to create a warm and welcoming atmosphere in the remaining focus groups. One of us would greet the participants at the entrance and engage in small talk on the way to the focus group room. The other would assist them in filling out the required forms regarding their demographics and informed consent. When we asked the participants in these subsequent focus groups about their experience, they mentioned that our warm and friendly greeting made them feel comfortable and appreciated. They felt it was safe to share their experiences. This showed us that it is important to take the time to create a welcoming and safe environment to develop rich data.

The generated data represented the participants´ interpreted accounts of their perceptions, attitudes, and meanings about patient participation in health service development. Furthermore, the data represented my interpretation of the participants´ interpreted accounts. This understanding helped creating a distance to the field of inquiry in which I had worked for several years. My attention was turned toward that which I did not immediately see or hear when visiting the research sites. Doing so opened the data to new interpretations of the participants´ accounts while recognizing that the findings always involve the researchers´ interpretations. Accordingly, the findings of this thesis represent how things are understood in relation to the historical, cultural, and social context in which the data and findings were generated.

4.8. Reflexivity

Qualitative research is understood as a subjective process. This chapter addresses how I mattered to the research process. The aim of engaging in reflexivity is to generate research that questions its interpretations and knowledge creation to produce qualitatively good research (Pillow, 2003).

Reflexivity may be divided into functional and personal reflexivity. Functional reflexivity concerns critical reflection on how the methods and processes applied may matter to the research (Braun & Clarke, 2013). I have already described how applying a collaborative research approach, conducting a scoping review, using focus groups and individual interviews to generate data, and analyzing data with Braun and Clarke´s (2006, 2013, 2019; Clarke & Braun, 2018) thematic analysis have mattered to the research process. Therefore, this chapter focuses on personal reflexivity: acknowledging one´s identity as a researcher and how one's presence and embodiment matter to the research (Braun & Clarke, 2013).

The Ph.D. project emanated from Norwegian National Advisory Unit on Learning and Mastery in Health at Oslo University Hospital. The NK LMH´s objective is to improve the quality of patient education and self-management programs in hospitals and primary healthcare through patient participation. The NK LMH had long wanted to conduct research concerning patient participation in health service development: it was an expressed need in the field. The Norwegian Federation of Organisations of Disabled People[6] (FFO) is a collaborative partner of NK LMH. They also expressed a need for this research.

The NK LMH is placed within a healthcare context, and I consider myself a healthcare professional. My educational background encompasses a bachelor's degree in science of psychology from the University of Washington[7], USA, a bachelor of arts degree in physical therapy at what is now called the Western Norway University of Applied Sciences[8], a master's in health sciences from the University of Oslo, and last, my researcher education from VID Specialized University´s Ph.D. program in Diaconia, Values, and Professional Practice[9].

When taking on the work of writing a Ph.D. application concerning patient participation in health service development on behalf of the NK LMH, I had already worked there for several years. I had both led and been involved in health service development with patient participation on many occasions. My motive for conducting the Ph.D. project was thus affected by priorities, politics, and interests within and in the context surrounding NK LMH. Additionally, the Dam Foundation[10] funded research projects focusing on patient participation, as well as studies set within primary healthcare. However, I was also motivated by my struggle with the idea of equity, power imbalances, and when and whom to involve in health service development. I had experienced that involvement conducted for the wrong reasons led to negative impacts. I was critical of notions that patient participation "was always a good thing" and "should always be conducted". Simultaneously, I experienced many positive impacts when healthcare professionals collaborated with patient representatives. It sparked my interest in improving the practice. I wanted to explore those issues that were problematic or difficult to grasp and considered such research necessary to strengthen patient participation in health service development.

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[6] See www.ffo.no
[7] See https://www.washington.edu/
[8] See https://www.hvl.no/en/
[9] See https://www.vid.no/en/units/centre-of-diaconia-and-professional-practice/
[10] See https://dam.no/

In order to develop the idea and focus of the project, my colleagues and I established a workshop. Those involved were people who, if the project received funding, agreed to function as the research team (except co-supervisor TS, who joined later in the process). They were people I knew well: a former colleague (AS) and two current colleagues (US, MH). After facilitating the workshop, I authored the Ph.D. project application, including the research questions, with support from the research team and became a Ph.D. student. I chose the mixed advisory panel members based on discussions with the research team and colleagues. I made the final decision on all matters related to the Ph.D. project. My role as a researcher thus affected this thesis from start to finish.

My extensive knowledge and experience in the field of inquiry affected my start as a Ph.D. student: it was difficult for me *not* to understand patient participation in health service development based on my experience. Skjervheim (2001) proposes that being closely related to a research topic may cover aspects and features that are of importance. To conduct research in the field that I had worked in for several years required me to “take a step back” to be able to see patient participation in health service development through a new lens. It meant stopping to attend weekly team meetings at work and letting go of my role as a special advisor. I kept a reflexive log, engaged in discussions with the supervisors and the co-researcher about what the researcher role meant, and simultaneously explored my taken-for-granted views concerning patient participation. I tried to look behind that which I already knew and to explore new issues. Discussions with the co-researcher, who had mixed experience from participating in health service development, were helpful. Fangen´s (2010) book on participatory observation was also useful. Addressing these topics when attending Ph.D. courses, Muni-Health-Care researcher school seminars and meetings with my Ph.D. student group further contributed to new ways of seeing patient participation in health service development. Against this background, my understanding of the researcher role evolved, and I developed a distance to the field of inquiry and an ability to see other issues than before.

Nevertheless, my connection to the NK LMH and the field of inquiry played a part during the visits to the research sites. For example, prior to conducting participatory observations at each research site, the facilitator of the respective health service development meeting and I talked about the roles of the co-researcher and myself in the meeting. I explained that the purpose was to sit in to learn how they collaborated, not to participate in the meeting. Two facilitators expressed concern that maybe they were not doing patient participation “the right way”. Their comments illustrated the normativity associated with patient participation within the field of inquiry: there is a right way to do it. Furthermore, I was often associated with the position to say whether they were doing it right or not. It made sense: NK LMH has long predicated a way of working[11] concerning patient participation in health service development. Additionally, many expressed high expectations about my work: I would produce knowledge that would make senior leadership prioritize patient participation in health service development. It felt daunting. The visit to the first research site prompted useful discussions with the co-researcher and main supervisor: I realized I could apply my pre-understanding and experience from working in the field to ask questions concerning issues that I knew were difficult yet not much debated – to create new knowledge.

The episodes underlined the importance of establishing a researcher role independent of NK LMH interests, despite the project originating from there and me being employed there as a Ph.D. student. The experience led to talks with my leader at NK LMH, who supported this stance. The Muni-Health-Care researcher school, the VID specialized university´s researcher network, User Participation in Health and Welfare services (UPHEW), and my Ph.D. student group provided important academic environments for discussions and learning during the work on this thesis, and in my development as a researcher. Building on previous knowledge and understanding, creating a distance to the research matter through critical reflection, discussions, and theory, I obtained new perspectives that contributed to developing new knowledge in collaboration with the research team and the mixed advisory panel.

4.9. Ethical considerations

This thesis represents health services research. The Oslo University Hospital, represented by the Norwegian National Advisory Unit on Learning and Mastery in Health, is responsible for

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[11] The way of working may be read in Norwegian here: https://mestring.no/wp-content/uploads/2012/12/Standard_metode_2011.pdf

controlling the Ph.D. project´s data. The Ph.D. project was thus approved by the Oslo University Hospital Data Protection Officer (reference number 18/05851, see Appendix 12).

In line with The Personal Data Act (in Norwegian: personopplysningsloven), the Data Protection Officers of the municipalities ordered the issuing of a Data Treatment Agreement (in Norwegian: Databehandleravtale) between the Data Controller in each municipality and the Norwegian National Advisory Unit on Learning and Mastery in Health. A Data Treatment Agreement in Norwegian is presented in Appendix 13. It is anonymized to protect the identity of the participants. I assert that all procedures contributing to this work comply with the Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects of 1964, as revised in 2013 (World Medical Association, 2022), and the Oslo University Hospital's guidelines for research (Carlsen et al., 2021).

When approached about participation, the participants were informed about the Ph.D. project, that participation was voluntary, and what it would mean to them. When consenting to participate in this Ph.D. project, the participants were informed in writing about the Ph.D. project objective, the method for generating data, and that the data would be non-identifiable when published. The participants were also informed of the option to withdraw from the Ph.D. project at any time. This information was repeated verbally at the start of the focus group and individual interviews before written consent was obtained. At this time, I also informed the participants in the focus groups that it was a courtesy to keep what was talked about to themselves. However, I reminded them to only disclose information they were comfortable with sharing. The forms with written consent were stored in a locked archive in a locked room at the NK LMH. The interview data were treated confidentially. All transcripts containing identifying information were de-identified. The key applied to anonymize the participants was stored in the locked archive in the locked room at NK LMH. The transcripts and the recordings were stored on Oslo University Hospital's research server.

During the focus groups, the patient-representative participants sometimes shared experiences concerning their health situation and care in the focus groups. It was not the focus of the research, and it made my moderator role more complex. This was my responsibility to avoid harming the participants. However, it was difficult to determine what would be least harmful: to interrupt them or to let them share their experiences and risk them feeling vulnerable in the group afterward. In these cases, the participants were allowed to speak freely before I redirected the discussion when I found a natural opportunity. Doing so, I acknowledged that their experiences sounded difficult and thanked them for sharing. Afterward, I asked the respective participants how they were doing. They responded they were OK. Upon receiving the transcripts, I removed the sections concerning their private accounts of their health situation. Still, I recognize the patient representatives´ experiences were what motivated them to become involved in the Ph.D. project. Excluding the pertinent paragraphs about this from the transcripts was done to protect their identities, not to disregard their experiences.

During the focus groups, I made ensure to ask everybody about their opinions and views. Ahead of the focus groups, we planned that when needing to reflect on what we must talk more about, I could ask the co-researcher what she thought we should address further. Also, she could suggest we return to a topic that needed more exploring. When conducting the individual interviews alone, it was sometimes hard to redirect an interviewee. It helped having conducted a practice individual interview and receiving feedback from the co-supervisor (US): the individual interview guide was used actively to redirect the conversation by referring to its focus and questions.

Despite planning well, a totally unforeseen situation came up: a patient representative who was not invited showed up to participate in a focus group. Although we made room for that person, the situation served to problematize who was included to generate knowledge, why, and its consequences. Participants with diverse experience in developing health services were selected and approached about participating in the focus groups. This meant that some were not included. However, I had not considered how it could be interpreted within the patient representative network that some were asked to participate and others were not. Patient representatives´ engagement is based on sharing personal experiences concerning their or next of kin´s health challenges. Being invited to share your experience in research may be understood as some having more valuable experience than others. It underlined caution and clarity about why some participants were included while others were not. After this incident, I asked the contacts to emphasize to their networks that, in our opinion, everybody had valuable experience to share. However, the focus groups were put together with the intention of probing *differences* in experiences concerning patient participation in health service development.

4.10. Quality criteria

While the criteria validity, reliability, and generalizability have long been associated with the quality of quantitative research, these criteria have also been given meaning within qualitative research in recent decades (Braun & Clarke, 2013). Discussing the quality of this thesis research, the criteria validity, reliability, and generalizability are used as they are understood by Kvale (2011).

4.10.1. Validity

Validity in qualitative research concerns the degree to which the research shows what it claims to show and the quality of the knowledge that is generated. In Kvale´s (2011) terms, validity concerns the quality of the researcher´s craftmanship throughout the research process. It involves continuously checking, questioning, and theorizing the findings´ interpretations to make sure the knowledge claims hold ground (Kvale, 2011).

This thesis´s research questions, research design, analysis, and findings have been repeatedly scrutinized based on multiple perspectives throughout the research process – due to the thesis´s collaborative approach to knowledge creation. Involving the research team and the mixed advisory panel in the research process may be understood as having enhanced the research´s communicative validity: testing the findings´ validity by discussing them with relevant partners (Kvale, 2011). In addition, the Ph.D. project, its design and methods, and findings were presented in several fora, for example, in the seminars of the Muni-Health-Care researcher school, the research network UPHEW, my Ph.D. student group, in NK LMH-seminars, and conferences. Last, this thesis´s findings are validated against findings in extant research literature.

In Articles 2, 3, and 4, the participants address several negative issues concerning patient participation in health service development. For example, in Article 4, several patient representatives reported not being heard or included in the health service development team by the healthcare professionals. Some of these participants were quoted several times, while others were not. This raises the question of whether the critical views in the data were prioritized over more complex issues or whether the participants had similar negative experiences with patient participation in health service development. However, during the focus groups and the individual interviews, both challenges and positive aspects of patient participation were discussed. Against this background, the generated data allowed us to address the difficulties faced by those involved and to nuance our understanding of what was challenging. However, it should be noted that focusing on the challenges of patient participation may be viewed as a limitation of the thesis' findings.

4.10.2. Reliability

The reliability of qualitative research concerns the trustworthiness and dependability of the findings. The criterium relates to transparency: the researcher must describe in adequate detail issues concerning the chosen research questions and methods, the applied analysis, and the creation of the findings and conclusions for the reader to evaluate the reliability of the findings (Kvale, 2011). Braun and Clarke (2013) assert that researchers must also practice reflexivity about how their preunderstanding and experience have been used in and matter to the research process.

I have persistently used my preunderstanding and experience during all phases of the research process. My role as a researcher has affected the whole of the research process and the findings.

To strengthen the findings' trustworthiness, the co-researcher and I familiarized ourselves with the research sites. We identified what would be significant to explore through the focus groups and, based on the focus group data, what to follow up on in individual interviews. I kept a reflexive journal during the whole of the research process, and the co-researcher kept one during the data generation phase. We recorded and debated our preconceptions, researcher roles, respective interpretations, and the findings concerning the focus group data and the individual interview data. Aiming for investigator triangulation, the co-researcher, the main supervisor, and I discussed the codes until we were clear about what they meant. The mixed advisory panel was involved in the initial analysis phase, and the research team in further analysis.

It may be understood as a weakness to the research findings´ validity that I did not transcribe the focus groups and individual interviews myself: this meant that I did not engage with the data in the transcription phase. Still, when receiving the transcripts, I listened to the audiotapes while simultaneously reading the transcripts. It made me remember situations in the focus groups and previous discussions and interpretations that the co-researcher and I had made. It was a fruitful way to enter the main analytical phase. Nevertheless, I do not know if transcribing the audiotapes myself would have contributed to the analysis.

As described, the co-researcher played a crucial role in the initial analysis of the focus group data: we engaged in discussions after the focus groups about what happened, what was said and how, and how we interpreted it. I conducted the individual interviews alone, as the resources did not allow for the co-researcher´s involvement. This may be considered a weakness of the data generation. From the interviewees' perspective, however, this may have seemed less stressful than having to relate to two interviewers. After each individual interview, I wrote down my immediate impressions of the interviewee, how the interview progressed, what was said and how, and my interpretations. Some days later, my impressions were presented to the co-researcher and the main supervisor, and we discussed their meaning.

4.10.3. Generalizability

The criteria of generalizability concerning qualitative research may be understood as transferability: the extent to which findings may be relevant and useful in relation to other groups of people or contexts (Kvale, 2011).

Presenting this thesis´s findings in fora connected to the field of inquiry within Norway, there have often come reactions of recognition from those present. This has not been a surprise, as those involved in the research have contributed to generating relevant findings. However, the findings have also been recognizable to a Scandinavian as well as an international audience. I interpreted these reactions as indicating that many had experiences similar to those described in this thesis within their respective contexts. Still, I agree with Kvale (2011) that it is the receiver who must assess to what degree research findings may be useful in their context or situation. Thus, my job as a researcher concerns providing detailed descriptions of the research context and arguing the findings´ transferability to other contexts. This way, the reader may be able to make an informed evaluation of the transferability of the findings to their context. It necessitates transparency in the research process. Therefore, the Ph.D. project's research context, sampling strategy, the participants' characteristics, the way the data generation and analysis were conducted, and how the findings were created are carefully described. The steps of the scoping review process have been followed in line with Arksey and O´Malley´s (2005) framework and its enhancements by Levac (2010), Daudt (2013), and their colleagues. I have further strived to adhere to Braun and Clarke's (2021) guidelines for assessing the quality of thematic analysis research and have followed the steps in reflexive thematic analysis (Braun & Clarke, 2019).

Having elaborated on several issues concerning this thesis´s design and methods, the next chapter aims to summarize the findings of the articles comprising this thesis.

5. Summary of findings

This chapter presents the main findings of the four articles comprising this thesis and serves as the basis for the Discussion in Chapter 6.

Article 1 explores how impact of adult patient participation is described in the research literature. Article 2 discusses the experiences of healthcare professionals collaborating with patient representatives. Article 3 focuses on the perception of facilitators regarding their role in developing primary healthcare services with patient participation. Last, Article 4 investigates the experiences of patient representatives concerning the contextual factors that affect their involvement in the development of primary healthcare services.

5.1. Article 1

Article 1 is titled "How can we describe impact of adult patient participation in health service development? A scoping review". It was published in *Patient Education and Counseling*. The article explored the following questions based on 34 included primary studies:

- What characteristics of the studies, the study participants, and the service development with patient participation are described?
- What purposes for and approaches to patient participation are reported?
- What impacts associated with patient participation in health-service development are described?

The included studies were published between 1998 and March 2019 and come from Western countries. Most have a qualitative design, and most rely on several methods to generate data. A third of the studies are set within primary healthcare. An essentially equal number of studies focus on services related to chronic and mental illnesses. Few studies report the characteristics of study participants. The eight studies that do show a total of 2591 participants between 18 and 67 years old, and 59% women. Around a third of the studies state their purpose for involvement. These were interpreted to belong to one of four categories: develop health services, develop strategies for patient participation, evaluate a health service development intervention, or evaluate patient participation as part of a health service development intervention.

The studies show a great variety in how they conducted patient participation. The most common approaches include participation in a working group, a panel or advisory board, a workshop or focus group interview, and healthcare professionals' consultation. The studies report using various types of involvement in different phases of the same health service development. A third of the studies report involving patients or representatives as partners in processes and thus offer advice on conducting successful participatory health service development. The most frequently listed success criteria are to ensure leader support, clarify roles and expectations, include patient representatives in the team, and establish mutual respect among the participants.

The findings show that the studies describe impact of patient participation in health service development in a broad way. The identified impact was interpreted to belong to two main themes with three subthemes each. Firstly, professionals and representatives´ collaboration impacts how they collaborate (9 types of impact). The collaboration also affects the professionals (13 types of impact) and the representatives (17 types of impact) in several respects. Secondly, patient participation affects the organization´s culture and service delivery (17 types of impact), service users (4 types of impact), and healthcare providers (5 types of impact).

Positive patient participation impact was reported most frequently across the six subthemes. For example, collaboration enhances collaborative skills and balances power differences among those involved. The parties gain valuable insights and understand better the other party´s situation. The patient representatives feel empowered and expand their social network. Healthcare professionals increase their motivation for change based on experiential input and realize a need for knowledge about involvement to do it well. Negative impact was identified only from representatives´ collaboration with professionals. For example, when representatives face professionals´ tokenistic attitudes or behavior, they have limited to no ability to affect the process. Also, patient representatives fear repercussions when criticizing services. They report a lack of confidence when involved and express a need for education and support. Accordingly, some are reluctant to participate in similar processes in the future. Some patient representatives report letting those in charge control the process and decide its result.

Healthcare professionals did not overtly express any negative impact of patient participation. They reported that their negative expectations turned more favorable during productive collaboration. For example, some professionals reported realizing that previous involvement could be characterized as tokenistic and seeing a need to change their behavior. Also, patient representatives´ ability to represent their group was no longer a concern. The most often reported change due to participatory health service development was an increase in the general practice of involvement in the organization. However, having participated in challenging processes, the professionals saw the need for competent facilitators to lead the process. They also acknowledged that involvement demanded time and resources.

Participatory health service development positively impacted the service users, the healthcare providers, and the organization. Service users reported experiencing better access to more relevant services, less waiting time, and enhanced patient satisfaction. Four studies indicated patient participation improved service users' health outcomes. Still, two studies found no impact on patient satisfaction from involvement. Concerning implications for healthcare providers, patient participation aligns their way of working with patient representatives´ suggestions. Providers report increasing involvement in their daily work routine. However, some report not knowing how to practice involvement, suggesting a need for knowledge about patient participation and support in practicing it.

Concerning impact of patient participation on the organization´s culture and service delivery, the most often reported impact represents easily mended or fixed issues, for example, improving the wording in patient information pamphlets. Also, participatory health service development commonly produces new ideas and improvement possibilities. Patient participation is further associated with changes in prioritizing, enhanced health service efficiency, fewer hospital admissions, and reduced costs—additionally, more organizational transparency and better accreditation measures. Last, while participatory health service development contributes to more involvement within the healthcare organization, the findings show it also contributes to spreading patient participation to the healthcare organization´s partner organizations.

This article expands previous knowledge concerning impact of patient participation in health service development. This is the first review that provides a comprehensive overview of the broader impacts of patient participation in health service development. The article emphasizes the importance of identifying and understanding impact based on the collaboration between healthcare professionals and patient representatives, along with the impacts on service users, healthcare providers, and the organization's culture and service delivery. Furthermore, the article lists types of patient participation impact that can guide future projects, identify their purpose, and help determine desired outcomes of involvement in health service development. Lastly, based on the recommendations provided in the included studies, the article outlines success criteria for conducting participatory health service development.

5.2. Article 2

Article 2 is titled "Primary healthcare professionals´ experience with patient participation in healthcare service development: A qualitative study". It was published in *PEC Innovation*. The article is based on four focus groups with a total of 26 participants. It elucidates professionals´ perspective on collaboration with patient representatives to develop primary healthcare services.

The findings are presented as four themes, describing how professionals find that it is to collaborate with patient representatives. The professionals:

- Value a complementary interprofessional relationship
- Navigate between a position of authority and collaboration
- Reconcile the need for patient participation with its challenges
- Prioritize collective representation to ensure a more evidence-informed result

The first theme suggests that the professionals see the involvement as a complementary inter-professional relationship, which they value. Working together with representatives is perceived as meaningful and reassuring. They gain insights about the patient situation that they apply in their professional lives. Furthermore, professionals find that representatives' input enhances the health service´s relevance to service users. Thus, they see representatives as "equal colleagues" with experiential knowledge that adds to the collective knowledge field. However, the feeling of equity is disturbed by their perceived authority over representatives, including a notion that professional knowledge is more important than experiential knowledge. The second theme thus indicates that professionals navigate between positions of authority and collaboration when developing health services with representatives. Professionals sense their authority sometimes makes the representatives not speak up. Therefore, they behave in a gentle, attentive, and agreeable way. Sometimes, they refrain from stating their opinions. Professionals new to patient participation struggle to make representatives understand their point of view.

The third theme implies that professionals face challenges in collaboration that they try to reconcile with the value of having representatives in their team. When they overrule representatives´ incorrect input, they feel bad. They describe getting impatient when discussing issues they perceive as unimportant, while representatives need to discuss the matter. However, they find it particularly challenging when representatives share their private experiences in meetings. Then, apart from taking up a lot of meeting time, the professionals wonder how to interrupt the representatives and move the meeting along without hurting the representatives´ feelings. Often, they do not know how and do nothing. They underline having enough time set aside to collaborate with representatives would likely improve the overall experience.

The fourth and last theme suggests that healthcare professionals are skeptical of the meaning, content, and origin of representatives' input. They also find their own knowledge more important than experiential knowledge. Professionals struggle to balance what they assume may be representatives´ personal experience with their collective representation. They have difficulties identifying what parts of the representatives´ input to apply and ensuring they produce a result that they and their colleagues can endorse. However, some patient representative input does not correspond with professional standards. Then, professionals translate or adjust the input to fit their professional context and standards or disregard it.

Andreassen´s (2018a) framework concerning the implications of various involvement types informs the article´s discussion. The findings show how participatory primary healthcare service development in practice repositions and diversifies professionals´ traditional functions. The findings indicate that while professionals appreciate collaborating with representatives and receiving their input, they sometimes confuse them as “equal colleagues”. It appears this may further complicate the professionals´ relationship and collaboration with the representatives, because when collaborating, the professionals experience not being equals to the representatives.

The professionals´ collaboration with representatives requires handling complex relationships and emotions. The findings imply that addressing the challenges and celebrating the differences between professionals and representatives may ease tension in the relationship. Acknowledging the complementarity of their knowledge types and underscoring the benefits of including multiple perspectives in health service development may support a less complex collaboration.

This article adds to the existing research by shedding light on how professionals are challenged by collaborating with representatives, which has previously received little attention. The article offers valuable insights that can be used to facilitate constructive and productive participatory health service development.

5.3. Article 3

Article 3 is titled “Enabling primary healthcare service development with patient participation: A qualitative study of the internal facilitator role in Norway”. It was published in *Primary Healthcare Research and Development*. The article sheds light on the facilitators´ extensive work to prepare for participatory primary healthcare service development.

The facilitator role is explored based on six semi-structured individual interviews. The findings represent three themes, each with two subthemes, describing how facilitators experience their role in conducting health service development with patient participation in their municipalities. The facilitators:

- Establish a network of patient representatives
    - Locate, select, and train suitable representatives
    - Establish good relations to ensure representatives´ future participation
- Encourage healthcare professionals to engage with patient participation
    - Promote patient participation
    - Locate and engage healthcare professionals
- Call upon senior managers and supervisors to take responsibility
    - Tackle barriers to patient participation
    - Counter senior managers and supervisors´ hesitancy toward patient participation

Developing health services with patient participation aims to provide high-quality health services that cater to the public's needs (Andreassen, 2018b; Tritter, 2009). Facilitation is explored by addressing the IPARIHS framework's (Harvey & Kitson, 2015a) concepts of innovation, recipients, and context. Here, innovation pertains to patient participation in developing health services. The recipients are individuals affected by the implementation of patient participation in the development of health services, such as supervisors and senior managers on the organizational level and professionals and representatives involved in health service development. Primary healthcare in Norway serves as the implementation context.

The first theme suggests that facilitators must establish a network of patient representatives before conducting health service development with patient participation. Representatives are a scarce resource in most municipalities. Thus, the subthemes indicate the facilitators must locate, select, and train suitable representatives who can be involved. Then, they must establish good relations between senior managers and representatives to ensure future involvement. Facilitators searched for representatives who could take on a meta-patient-perspective, share ideas, respectfully discuss issues, and appear aware of who they represent. Some facilitators interviewed potential representatives to locate the right person. However, the facilitators´ senior managers and supervisors often failed to show their support to the patient organizations and make the representatives feel appreciated and respected. It negatively affected the facilitators´ relationship with the patient organizations and their representatives.

The second theme implies that to enable primary healthcare service development, the facilitators must encourage colleague healthcare professionals to engage with patient participation. The subthemes indicate it includes promoting patient participation in primary healthcare. Teaming up with patient representatives, they emphasize the positive impact of their collaboration. The facilitators must locate and engage professionals willing to participate on top of their other responsibilities, as supervisors do not always let them take time away from their regular duties. The facilitators look for professionals who appear confident in their role and dare to discuss and question the representatives´ input respectfully.

The third theme shows that the facilitators call upon senior managers and supervisors to take responsibility for implementing patient participation in primary healthcare. The subthemes suggest that this comprises tackling several barriers. The facilitators emphasized that not having a budget affected the degree to which they involved representatives. They had to counter senior managers and supervisors´ hesitancy toward participatory health service development. The facilitators expected their superiors to implement patient participation actively. However, only one facilitator had superiors who shouldered this responsibility. Instead, some senior managers did not respond to patient organizations´ offer to contribute to enhancing health services, others displayed tokenistic behavior. Accordingly, the facilitators feared representatives would avoid future participation in their municipality. Due to the superiors´ lack of adequate involvement knowledge, the facilitators must show them its usefulness to gain support and resources for practicing it. One facilitator observed that the role included a continuous responsibility to sustain the support of patient representatives, healthcare professionals, supervisors, and senior managers.

The IPARIHS framework, the integrated Promoting Action on Research Implementation in Health Services (Kitson & Harvey, 2016), informs the article´s discussion. This framework was chosen as it considers the importance of facilitation, the local, organizational, and broader health system context, and the recipients of the innovation as essential components to successfully implementing innovations. The discussion addresses how the successful implementation of an innovation (in this case patient participation in health service development) requires those contributing to understand the innovation well. In general, this appears not to be the case in primary healthcare. Furthermore, the characteristics of the recipients (senior managers, superiors, healthcare professionals, and patient representatives) can hinder or facilitate the implementation. Last, the context in which an innovation is to be implemented plays a crucial role. While only municipalities that are known to practice patient participation in health service development well are included in this study, short of one municipality, the facilitators experience a lack of patient participation knowledge and support.

The findings indicate the facilitator role requires continuous work on multiple organizational levels. Senior managers and supervisors seem not to grasp patient participation and how to support it fully. Facilitators, supervisors, and senior managers must be responsible for implementing patient participation. Our findings also show that to conduct participatory primary healthcare service development, facilitators must maintain a panel of persons with experiential knowledge, engage healthcare professionals, and ensure senior management´s understanding and support.

This article expands the field of inquiry by contributing knowledge about what it takes for facilitators to comply with laws and regulations concerning the involvement of patient representatives in primary healthcare service development. It underlines that the responsibility for implementing patient participation in primary healthcare service development must be shared between facilitators, supervisors, and senior managers.

5.4. Article 4

Article 4, titled “Contextual Factors that Matter to Patient Participation in Developing Primary Healthcare Services" is submitted to a journal. It explores patient representatives´ experience with involvement in primary healthcare service development to identify contextual factors that affect their participation.

The article´s empirical material constitutes two sets that are analyzed separately: one set is based on four semi-structured focus groups with a total of 23 participants, and the other is based on six semi-structured individual interviews. The findings are presented as two overarching themes illuminating contextual factors within primary healthcare that can hinder patient participation in health service development in Norway. Patient representatives find that primary healthcare:

- Lacks an overall plan for practicing patient participation and that this limits involvement
- Lacks an organizational patient participation culture and that this complicates involvement

The first theme indicates the absence of a comprehensive plan for patient participation in primary healthcare. This has several implications for patient representatives. It affects the focus on patient participation in primary healthcare, including healthcare professionals´ understanding of whom to involve, when, and how to involve them. It is also understood to affect resource allocation.

Municipalities have a legal obligation to involve patient representatives in developing health services. However, there is a lack of systems, routines, and knowledge that support this involvement. Representatives are sometimes invited to participate only because it is required, but their involvement typically leads nowhere, limiting their ability to impact the process. Also, the representatives perceive that healthcare professionals are unaware of their potential contribution to the process and the outcome. Often, representatives are invited after the process has already begun; this means that the patient perspective is not considered from the beginning. Moreover, professionals have been found to arrive late and unprepared to meetings, reducing the possibility of representatives impacting processes positively.

The patient representatives often experience that their involvement is cut short or they are excluded from processes due to a lack of funding to compensate for their participation. They also highlight that the absence of a plan for patient participation affects the selection of participants, as the same group of representatives are usually invited repeatedly. Including a more diverse group of service users is being called for, although it is acknowledged that it will require more time and resources. The argument is that this will enable health services to be better suited to the needs of the public. However, the lack of an overall plan for practicing involvement is understood to reduce the degree to which representatives are allowed to participate in primary healthcare service development.

The second theme suggests that while some healthcare professionals conduct patient participation competently, primary healthcare lacks a culture that supports patient participation in developing health services. This affects the patient representatives´ involvement in various ways. The findings imply that representatives expect to be treated respectfully and included in the team. The representatives stated that while they do not necessarily expect to get their way, they expect to be treated equally, and expect their input to be discussed. However, professionals often do not seem to appreciate their contributions or include them as team members in the processes. This makes involvement complex and arduous for the representatives. For example, representatives describe that it can be challenging to fight for recognition or be the one representative promoting the patient perspective in a meeting with four professionals – who overrule their input. In an effort to fit in, representatives often use professional jargon and substantiate their input by referencing white papers or research to impact the processes.

Patient representatives´ participation is only valuable if they can impact the process and its outcome. Thus, representatives find they need to have certain skills, such as the ability to prioritize which issues to address and which ones to leave aside and the capacity to provide objective and factual experiential knowledge on behalf of their patient group. However, it makes involvement difficult, time-consuming, and sometimes too costly to representatives´ health. Thus, they carefully evaluate the pros and cons before getting involved. The findings suggest more representatives would be able to participate if professionals would accommodate their involvement.

The article´s discussion draws attention to how overarching contextual factors in primary healthcare may affect patient participation in health service development. Involvement in primary healthcare appears to pose several challenges to the patient representatives, take much time, and sometimes prove too costly to their health. It makes some representatives consider involvement not worth prioritizing. Leadership plays a crucial role in implementing patient participation in healthcare. However, the municipalities´ leadership seems to have limited knowledge and understanding of what involvement entails. Limited focus on and knowledge about patient participation in organizations can lead to false appearances of inclusion and unintended tokenism. If those involved in health service development are not fully committed to the process, it will likely diminish the representatives´ ability to achieve meaningful involvement. This contrasts with the idea of involvement as an empowering, democratizing, and value-based approach.

This article highlights an untapped potential of patient participation in developing healthcare services that cater to the public´s needs in Norway. It expands the current knowledge base by providing insights about contextual factors within primary healthcare that matter to patient participation. It also describes the implications – aiming to help others avoid the pitfalls.

The four articles´ findings point to several issues that must be discussed to answer this thesis´s overall research question. The next chapter provides this thesis´s Discussion and Conclusion.

6. Discussion and conclusion

This thesis explores patient participation in developing primary healthcare services in Norway from three perspectives: healthcare professionals, patient representatives, and internal facilitators. The thesis focuses on the collaboration among these parties and its impact.

Aiming to contribute to strengthening the practice of involvement, this chapter will answer the thesis´s overall research question:

> What meaning can the collaboration in health service development with patient participation have for healthcare professionals, patient representatives, and internal facilitators, and what impact can their collaboration have?

In this Discussion, the articles´ findings will be combined and interpreted to illuminate relational and contextual aspects that matter for participatory health service development and its impact. In line with previous studies´ findings (Majid & Gagliardi, 2019; Martin et al., 2018; McCarron et al., 2019), the following discussion is founded on the view that when professionals and representatives collaborate in a partnership, everyone is empowered to impact the process and its result, which may in turn lead to several positive outcomes. While the discussion is also founded on the understanding that the professionals´ and representatives´ relationship comprises asymmetry in power (see Nathan et al., 2014; Pearce, 2021), the main focus lies on how they work together to develop primary healthcare services. Against this backdrop, the following three chapters aim to contribute to answering the overall research question:

- Complexity and tension in the collaboration
- Contextual factors that can hinder patient participation
- Realizing the potential positive impact of the collaboration

These three chapters contain references to this thesis´s Articles 1, 2, 3, and 4. Article 1 is the scoping review on how impact of patient participation is described in the research literature (Sandvin Olsson et al., 2020). Article 2 explores healthcare professionals´ perspective on collaboration with patient representatives (Sandvin Olsson et al., 2022). Article 3 describes the facilitators´ perception of their role in enabling involvement in health service development (Sandvin Olsson et al., 2023a). Last, Article 4 explores how patient representatives perceive the primary healthcare context for involvement (Sandvin Olsson et al., 2023b).

6.1. Complexity and tension in the collaboration

Combining the findings from Articles 2, 3, and 4, this chapter focuses on what meaning healthcare professionals and patient representatives ascribe to their collaboration to develop health services. The following sections aim to elucidate central issues and challenges that may arise from their collaboration. The first concerns uncertainties associated with patient participation from the viewpoints of professionals and representatives. The second involves the need for different types of knowledge in health service development.

6.1.1. Uncertainties about involvement

The findings imply that repositioning professionals and representatives as colleagues can raise several issues that may prevent or disrupt achieving a partnership and its potential positive impact.

Professionals are critical in enabling involvement in the health service development (O'Shea et al., 2019; Ocloo & Matthews, 2016). In the findings, professionals express uncertainty about “how to do involvement”. This suggests that patient participation is a complicated task for the professionals, which may contribute to tension in the collaboration. According to Arnstein (1969), a partnership means a shift in power between those in charge and those involved – and the possibility for all to impact the process and its result. Article 2 shows that the professionals find working with representatives to resemble a complementary interprofessional relationship, implying that those involved are equal colleagues. However, their perception of having the authority that their professional background gives them over representatives disrupts the feeling of equality.

Whether the health service development may be considered a partnership depends on professionals´ capacity to include the representatives and exchange and apply professional and experiential knowledge (Boström et al., 2017; Rycroft-Malone et al., 2015; Strøm & Fagermoen, 2014). Limited knowledge about patient participation can lead to false appearances of inclusion (Ocloo & Matthews, 2016) and unintended negative consequences (Gathen et al., 2022; Martin et al., 2018). It implies that uncertainties about what patient participation is and entails can lead to tension and difficulties in the collaboration between professionals and representatives.

In line with our findings, Andreassen (2018a) understands participatory health service development to place those involved in positions other than what they are used to from clinical practice. Professionals practice involvement in different ways than they do in regular clinical practice, for example, when explaining and obtaining consent from patients (Strøm & Fagermoen, 2014). Instead, health service development requires engaging in dialogue and collaboration, practicing a different form of involvement. Professionals struggle with this transition. They express becoming careful about what they say and how, and about asserting their views during collaboration. They also fear overruling representatives' input may hurt their feelings, as also suggested by Førland and Ringsberg (2011). The findings further show that professionals struggle with adjusting to the representatives´ pace, which they find is slower than their own in the collaboration. They feel impatient, especially when discussing issues they consider unnecessary to discuss. Collaborating to develop health services demands a different type of professionalism from professionals than their traditional healthcare provider role. This may be understood to create uncertainty about “how to do it”.

From the representatives´ perspective, they expect to be involved in dialogue and discussion with the professionals. They do not expect to necessarily get their way but to discuss their input equally with other members' input. However, instead of collaborating productively with professionals, representatives describe often fighting for recognition and to be heard or not overruled. It creates uncertainty about whether they will be able to impact the process – and notions that the involvement may be a waste of their time.

White´s analytical framework (2000) may elucidate partly what is at stake for professionals and representatives when they collaborate. Based on the framework, professionals may be inclined to see involvement in an instrumental sense: a means for efficiently enhancing health services. Article 3 indicates that professionals are pressed for time and often must participate in improving health services on top of their other tasks. Article 4 shows representatives perceive they have more time to prepare for meetings and follow up on issues than professionals. These findings may be interpreted as professionals sometimes perceive participatory health service development as a waste of time – unless the collaboration is efficient. Using White´s framework (2000), representatives, on the other hand, may be understood as seeking representative participation: involvement in the interest of gaining leverage by contributing experiential knowledge, or "voice", to impact the process and its result. Alternatively, the representatives can aim for transformative participation, which means that they participate in the interest of personal empowerment that benefits others involved and contributes to a health service suited to the public's needs. Correspondingly, representatives only find involvement meaningful if they can impact the process and its result, as indicated in previous studies (Majid & Gagliardi, 2019; Martin et al., 2018; McCarron et al., 2019).

This section has elucidated asymmetrical power relations between professionals and representatives in practice. It has also illuminated that diverging interests may complicate the collaboration between the parties involved in participatory health service development. The professionals maintain power over representatives when aspiring to work in partnership, and this power complicates professionals´ collaboration with representatives. This suggests that repositioning professionals and representatives as colleagues can lead to issues that may hinder achieving a partnership and its potential positive impact. The next section explores what it means to the collaboration that professionals and representatives possess different types of knowledge.

6.1.2. Differing needs for different types of knowledge

The findings suggest that participatory health service development concerns different needs for different types of knowledge for the parties involved, an issue that appears to complicate collaboration among professionals and representatives.

In the development of health services, experiential and professional knowledge are meant to be incorporated, contributing to forming a new or improved health service that fits the needs of the service users (Andreassen, 2018b; Tritter et al., 2009). However, our findings imply professionals regard their knowledge as more important than the representatives´ knowledge. Representatives may be understood as supporting this view: professional knowledge is considered a safeguard in health service development, as their experiential knowledge alone is insufficient. This suggests that how the parties´ knowledge is regarded and handled in health service development may be a source of tension in their collaboration.

Professional knowledge can be understood to encompass scientific and clinical expertise. Professionals´ knowledge draws on theoretical, scientific, and clinical knowledge and skills, which are partly tacit (Polanyi, 1958; Strøm, 2010). This suggests that professional knowledge encompasses both scientific and experience-based practice knowledge. The representatives´ experiential knowledge, however, relies on elements such as emotions, actions, and cognition, representing subjective knowledge that cannot be easily verified (Strøm, 2010). Article 2 shows that professionals express skepticism toward the meaning, content, and origin of the input representatives provide. Previous studies have observed the same (Bergerum et al., 2020; Forbat et al., 2009; Renedo et al., 2018). Professionals further believe that representatives´ input should reflect the experiences of multiple individuals to be used in the development of health services.

Professionals seem to partly handle their skepticism of experiential knowledge by trying to ensure that the representatives´ input is representative of several individuals: a complex task.
The findings further show that professionals struggle to determine which parts of the representatives´ input meet their professional standards. Thus, professionals tend to review, interpret, and modify the information representatives provide to align it with their understanding and context. Andreassen identifies the professionals involved in health service development with patient participation as “recipients, interpreters and translators of feedback” (Andreassen, 2018a, p. 10). This thesis´s findings show that the professionals perform all these functions in participatory health service development. It seems

contradictory that professionals must acquire experiential input only to change it to fit their purpose and standards.

Professionals´ handling of representatives´ input may be interpreted as negativity and a disregard toward experiential knowledge. However, our findings suggest professionals find themselves in a tight spot: it is not a clear-cut task to put representatives´ input to use. It entails interweaving “knowledge based on lived/embodied illness experiences and scientific biomedical knowledge” (Renedo et al., 2018, p. 791). This difficult situation may be interpreted as activating a need to acquire experiential knowledge through diverse approaches.

According to Tritter´s model of involvement (2009), when healthcare professionals include patient representatives as working group members, this implies that representatives are to participate in decision-making. In Tritter´s terminology, this represents direct, reactive involvement on a collective level, or what Arnstein (1969) calls a partnership. However, professionals may also choose to consult a group of service users to gain their input on enhancing the health service. This approach suggests that the service users have no say in the process. In Tritter´s (2009) wording, this is indirect, reactive participation on a collective level, corresponding to the consultation and informing steps of Arnstein´s ladder of participation (1969). Consulting may represent a good alternative to professionals seeking experiential knowledge. However, Arnstein (1969) considers this approach to exemplify tokenism, as those being consulted have no decisional power in the process or concerning its result.

Tritter´s model (2009) also positions representatives as potential proactive initiators – underlining that they can initiate change and health service improvement. However, the findings imply that representatives face several requirements and must navigate a complex relationship to impact participatory health service development. Representatives often perceive that professionals do not fully value their contributions. They find that professionals often ask for their participation in processes merely due to legal obligations. White (2000) calls this type of involvement nominal participation. Arnstein (1969) regards it as tokenism: professionals´ interest in involvement concerns fulfilling requirements or complying with laws rather than genuine interest in improving the health services by incorporating experiential knowledge. From the view of representatives, such involvement is meaningless, as it typically leads to nothing. Previous studies indicate that while experiential and professional knowledge are often presented as equally important to the process (Strøm & Fagermoen, 2012), professionals seem primarily interested in experiential knowledge that they consider relevant to their work (Renedo et al., 2018). The findings show that representatives call for greater awareness among professionals concerning the complementarity of their type of knowledge and professionals´ knowledge and expertise when creating health services that comply with the public´s interests.

This section has shed light on how regard for experiential and professional knowledge types can challenge the relational dynamics of professionals and representatives´ collaboration. It seems both parties may benefit from knowledge about the other party´s situation and difficulties, motivations and expectations for involvement, and how to contribute to making participatory health service development successful. The next chapter explores and discusses how contextual barriers may affect the quality of the involvement and their collaboration.

6.2. Contextual factors that can hinder patient participation

Combining the findings from Articles 2, 3, and 4, this chapter addresses contextual factors that can affect patient participation in primary healthcare service development. The aim is to address what may hinder involvement in primary healthcare – as perceived by healthcare professionals, internal facilitators, and patient representatives. Next, two key barriers and their implications will be discussed from the viewpoints of facilitators and representatives, addressing other potential obstacles along the way. These include a lack of a culture and support for patient participation and a need for knowledge and skills among those involved in participatory health service development.

6.2.1. Lack of involvement culture and support reduces patient participation

The findings imply that the organizational culture and support for patient participation in primary healthcare service development could be better. Organizational culture and support represent important contextual factors for implementing innovations (Nilsen & Bernhardsson, 2019). The term “context” is understood as pre-existing, dynamic, and emergent micro, meso, and macro-level factors of an implementation process that are closely interconnected to an organization´s culture, leadership, and resource availability (Rogers et al., 2020). The term “culture” is understood as values and inarticulated know-how that guide the actions of those within an organization (see Flyvbjerg, 2006).

Implementing participatory health service development into primary healthcare appears to be a lonely job for the facilitators. The findings show that they call for senior managers to shoulder the responsibility of being role models and active implementors of involvement. Instead, while facilitators think that no senior manager is likely to deny the importance of patient participation, they find that how they support its incorporation into practice differs greatly. Our findings concur with studies implying that senior managers often offer mere verbal support for health service development without providing the necessary resources and support (see Hespe et al., 2022; Murray et al., 2022).

Previous research has identified that the availability of representatives is a contextual factor that matters to patient participation in health service development (Ayton et al., 2017; Bombard et al., 2018; Murphy et al., 2021). Moreover, the findings imply that facilitators´ recruitment and involvement of eligible representatives is a contextual factor that may facilitate or hamper the implementation of patient participation. The findings show that before facilitators can conduct participatory health service development, they must invest considerable effort in establishing and maintaining a network of suitable representatives they can call on to be involved. Norway has too few representatives (Elvestad, 2018) to meet the increasing demand for involvement in participatory activities (Gathen et al., 2023). To the facilitators, this means that their municipality must represent an environment in which representatives want to contribute.

Article 4 indicates that representatives perceive primary healthcare as lacking an overall working plan for patient participation – with systems, routines, and knowledge that support involvement. Additionally, they find primary healthcare lacks a culture supporting involvement. For example, representatives are often invited after processes have begun, and healthcare professionals do not always seem open to including them. The facilitators´ experience confirms the representatives´ perception. The facilitators face hesitancy among senior managers and supervisors concerning involvement, who also seem not to understand the importance of establishing a network of representatives for future involvement. Thus, facilitators find little support from leadership in keeping good relations with patient organizations and their representatives. For example, when patient organizations send suggestions or queries concerning how they can contribute to better health services and senior management does not respond, this creates difficulties and tension in the facilitators´ relationship with representatives. Facilitators worry it leads to no representatives wanting to be involved.

Article 3 supports the idea that the relationship between facilitators and leadership is largely neglected. The lack of leadership support and understanding for practicing patient participation makes facilitators consider quitting their job. It represents a contextual barrier to implementing patient participation as a way of working to develop health services. The relationship between leadership and facilitators needs more focus to ensure successful implementation processes (van der Zijpp et al., 2016). The lack of support also comprises the extent to which leadership allocates funding for participatory activities.

Studies have identified that the availability of resources represents a contextual factor that matters for patient participation (Ayton et al., 2017; Bombard et al., 2018; Murphy et al., 2021). Articles 3 and 4 concur and indicate that if senior management allocates no funding for participatory activities, it negatively affects facilitators´ and representatives´ practices of patient participation in several ways.

Facilitators who do not have a budget for involving patients in developing health services describe facing the challenge of minimizing costs. Some say they respond by avoiding organizing meetings that would include representatives. Some say they invite fewer representatives in processes than they would have preferred, and think that they therefore miss out on experiential input important for improving health services. Also, facilitators report they involve representatives in parts of processes only instead of in the whole process, which would be too costly. Facilitators' descriptions of how they limit patient participation to save costs confirm representatives´ experience of being less involved in health service development when funding is scarce.

Facilitators describe trying to find ways to acquire resources to conduct participatory health service development. For example, they ask for support from their superiors and spend time applying for project funding. However, it seems that, in their busyness, they often fail to inform the representatives about their struggles. Their silence toward representatives can be interpreted as a disregard for the representatives´ situation. However, the findings indicate that facilitators often do not know to what extent they can involve the representatives due to funding constraints – and work hard to find solutions. Nevertheless, the situation warrants that facilitators and healthcare professionals take pains to communicate as clearly as possible the degree and extent of involvement that the representatives may expect. These findings imply facilitating participatory health service development is a complex task, concurring with previous studies (Renedo et al., 2018; Rycroft-Malone et al., 2016; Staniszewska et al., 2012)

This section has illuminated that for patient participation to be a way of working to develop primary healthcare services, it is necessary to establish a supportive context and organizational infrastructure that facilitates meaningful involvement. The section below discusses the importance of knowledge and skills regarding facilitation and patient participation.

6.2.2. Lack of knowledge and skills risk unforeseen consequences from the collaboration

The findings indicate that primary healthcare senior managers, supervisors, and professionals could benefit from knowledge about patient participation and what it means to those involved. This suggests that representatives need knowledge and skills to handle situations caused by limited knowledge about involvement in primary healthcare.

To be a facilitator requires several skills, including ensuring that everyone involved works well together towards the common goal of improvement (Kitson & Harvey, 2016) while using team-focused strategies to support change (Harvey & Kitson, 2015b). Still, healthcare professionals who lack experience in facilitation and work in under-resourced environments are frequently assigned to facilitate the development of health services (Bergstrom et al., 2020; Walunas et al., 2021).

Knowledge about patient participation and training about how to include representatives in developing health services are considered key contextual factors to participatory health service development (Ayton et al., 2017; Bombard et al., 2018; Murphy et al., 2021). However, in the findings, representatives comment that facilitators or healthcare professionals seldom inquire about how to facilitate representatives´ involvement or consider their convenience when scheduling meetings. Some representatives say they must decline participation, believing it will be too costly for their health. At the same time, representatives often avoid discussing their health issues and accommodation needs with healthcare professionals. They prefer to be seen as partners rather than patients, to increase their chances of impacting the process. Skilled facilitators may know this and avoid asking representatives about their health challenges. Nevertheless, these findings suggest it is important for healthcare professionals on all levels in the municipality to understand representatives´ situation and involvement motivation. In this way, they can support and help recruit and maintain a network of representatives to be involved in health service development.

Representatives describe often having taken on the role as they cannot have a regular job due to a disability or health challenge. Enhancing service-user experiences and giving back motivates their involvement. In turn, representatives experience wellness and positive shifts in identity, providing the collaboration works well, as also suggested by Neech and colleagues (2018). However, the findings imply that the perceptions of meaningful and constructive processes for representatives differ from those of facilitators and healthcare professionals. To representatives, it is important to be involved in health service development from the start, as underlined also by Majid and Gagliardi (2019). This allows them to contribute to shaping the ideas, focus, process, and outcomes of the development of health services. Furthermore, it enables the discussion of the phases where their contributions would be necessary and those where they would be less critical. To professionals, on the other hand, constructive processes may be interpreted as those producing a health service that they and their colleagues can endorse and which is conducted efficiently.

Representatives report they often find themselves involved in not-so-meaningful health service development. For example, representatives who have been involved from the start of a process and expect to be involved in the rest may instead find professionals do not call them back. In response, representatives spend time and energy worrying it is due to having done a poor job. They see being active in only a limited part as demoralizing. Furthermore, when kept out of large parts of a process, they do not always agree with its outcome. However, having their names included in the report indicates they support it. Also, the reports may fail to accurately depict the extent of the representatives' involvement, leading to a false impression that they participated in the entire process. This does not sit well with them. Therefore, they ask for clarity concerning the scope of their involvement in processes.

Patient representatives´ experiences may be understood to resemble what Gathen and colleagues (2022) warn about. Not being fully included in processes can be interpreted as tokenism. Representatives´ experiences appear to illustrate unintended consequences of patient participation, as pointed out by Martin and colleagues (2018).

The findings also show that patient representatives often struggle to be fully included in the health service development team. Their struggle may be seen in relation to facilitators who say they try to engage only representatives who are knowledgeable and competent collaborators and know their role in the working group and health service development. This suggests that if professionals do not consider the representatives to fulfill these criteria, representatives may be less likely to be included in the team. It further illustrates issues that can hinder patient participation. However, the findings suggest that professionals are not the only ones needing skills and training to be involved in participatory health service development. Representatives consider collaboration with professionals to require several skills to pull it off well – underlining that participation is “not for all” and contradicting the idea of involvement as a democratic right.

To avoid tokenistic involvement or having no impact on the process, representatives tailor their contribution to be acceptable to professionals (Martin et al., 2018; Renedo & Marston, 2011). Patient representatives underline the necessary skills include being able to prioritize which issues to address, limit their focus to one or two topics during each meeting, and present their points in a way that is not confrontational. They must also offer experiential knowledge factually, reflecting the views of the group they represent rather than their own. Hence, representatives must corroborate their opinions with others or gather examples and cases from their network. However, despite efforts to adapt the input to what representatives assume the professionals expect and desire, professionals often fail to recognize them as team members.

Dent and Pahor (2015) find that the success or failure of patient participation policies depends on whether the process empowers or disempowers those involved. Our findings imply that merely learning to facilitate participatory health service development by doing may not be the most efficient or cost-effective way to acquire the necessary skills, nor may it necessarily empower those involved. Instead, not knowing how to facilitate involvement may lead to negative consequences (see Armstrong et al., 2013; Carter & Martin, 2018) and distrust in the relationship between citizens and those in charge of delivering healthcare services (see Andreassen et al., 2014). Thus, the findings imply that achieving a successful collaborative health service development that empowers those involved and leads to a good result requires a competent facilitator. Otherwise, not having skilled facilitators appears to be a potential contextual barrier to implementing patient participation in an organization.

This section has elucidated how contextual factors can impede the actual practice of patient participation and ultimately reduce the relevance and sustainability of health services. Knowledge and reflection about what patient participation is and what it means to those involved may benefit senior managers, supervisors, healthcare professionals, and facilitators in primary healthcare. Additionally, the facilitators leading the process may benefit from learning about team-focused strategies to support change and patient participation practices.

Still, identifying what brings forth changes, adjustments, or improvements in a participatory setting can be challenging (Banks et al., 2017; Gathen, 2023). The following chapter will discuss how to realize positive impact of patient participation and avoid negative impact in processes.

6.3. Realizing potential impact of the collaboration

Combining the four articles' findings, this chapter discusses what meaning those involved may ascribe to positive and negative impact of participatory primary healthcare service development. The following section discusses the potential benefits and drawbacks of collaborating to develop health services. Then, laws and regulations concerning involvement are discussed before addressing various possible approaches to obtaining experiential knowledge.

6.3.1. Benefits and drawbacks of collaboration

The findings imply that grasping the potential of developing health services in a partnership between healthcare professionals and patient representatives requires a broad understanding of its impact. However, a partnership may not always be achieved, and involvement may not always lead to benefits (Gathen et al., 2022; Sandvin Olsson et al., 2020; Martin et al., 2018; Ocloo & Matthews, 2016). Therefore, grasping the potential of patient participation also requires understanding its possible drawbacks.

Consultative strategies are the most frequently reported approach employed in developing health services (Wiles et al., 2022). Nevertheless, a comprehensive review (Ezaydi et al., 2023) indicates that co-production leads to more positive and significant service- and service-user-level outcomes than less comprehensive involvement forms, such as service-user consultation. In co-production, service users´ experience is recognized equally with the knowledge of healthcare professionals. It comprises power-sharing among all involved, allowing for mutual impact on the process and its result (Ezaydi et al., 2023). As such, co-production aligns with Arnstein´s (1969) and this thesis´s understanding of a partnership. Achieving a partnership between professionals and representatives thus has the potential to create health services that meet the public's needs. Furthermore, our findings imply that developing health services in a partnership can add a broad spectrum of positive impacts.

The findings show that professionals and representatives appreciate working together when a partnership is achieved. Professionals say they gain insights that help them professionally, making participatory health service development meaningful. Additionally, involvement reassures them that the health services will be relevant for the service users. Representatives say involvement is meaningful, motivating, and worthwhile when they are recognized for their experiential knowledge and enabled to impact the process and its result. The scoping review findings can help further concretize process-based impacts that may be achieved from a partnership (Sandvin Olsson et al., 2020, Table 3, p. 1456). The most reported impacts on participating patient representatives were enhanced collaboration competencies, empowerment, and a sense of belonging to a network or a community. Healthcare professionals who participated enhanced their understanding of service users´ needs and collaboration competencies and realized the need for a competent facilitator to lead the process. Their collaboration's most frequently reported impact included an integrated patient perspective, enhanced mutual understanding, and balanced power differences. Consistent with previous studies (Majid & Gagliardi, 2019; Martin et al., 2018; McCarron et al., 2019), our findings thus support that a partnership leads to process-based positive impact on those participating, including the way that they collaborate.

However, the scoping review may also contribute to concretizing more traditional findings-based impacts (Sandvin Olsson et al., 2020, Table 4, p. 1457). The most reported impacts on service users were enhanced access to health services, reduced waiting time, more relevant services, and enhanced service satisfaction. The healthcare providers changed how they worked in response to the service users´ input, leading to more patient-centered care and patient participation. The organization improved communication and information to service users, conducted small-scale improvements, changed to a more participatory working culture, and increased service efficiency. These types of impact align with what is called collaborative impact (see Banks et al., 2017).

Banks and colleagues (2017) also underline the pertinence of broadly defining the impact of involvement. They suggest using the term “co-impact”, which includes participatory and collective impact (Banks et al., 2017). Participatory impact refers to process-based thinking, emotions, and practice changes due to involvement (Banks et al., 2017). These align with the aforementioned process-based findings in the scoping review – on the parties involved and their collaboration. Collaborative impact, on the other hand, relates to the more traditional findings-based understanding of impact: impact of participatory research by individuals and organizations that “change practice and policy, and influence attitudes and culture” (Banks et al., 2017, p. 543). These align with the scoping reviews´ identified impact on service users, healthcare providers, and the organization.

Defining impact of patient participation as co-impact, including process-based and collaborative impact (Banks et al., 2017), it is interesting to note that negative impacts are reported only from the perspective of representatives. Furthermore, that negative impact (Gathen et al., 2022; Ocloo & Matthews, 2016; Sandvin Olsson et al., 2020), unintended consequences (Martin et al., 2018), and the perception of having no impact (Gathen et al., 2022), all represent process-based impact. To illustrate, in our scoping review, the negative impact most commonly reported by representatives include that their contribution means nothing, the feeling of uncertainty and need for support and education to do a good job, and the fear of repercussions from professionals due to their criticism of the current health services.

Since the first review of patient participation was made by Crawford and colleagues in 2002, there have been advancements in the field. The four articles of this thesis imply there is still a need to enhance the practice of involving representatives in the development of health services and release its positive impact. This is also suggested by other researchers (Bergerum et al., 2019; Biddle et al., 2021; Cluley et al., 2022; Majid & Gagliardi, 2019; Pedersen et al., 2021).

This section has highlighted the need to look beyond traditional findings-based impact and incorporate process-based impact of patient participation to understand its potential benefits and drawbacks. If professionals at all levels within the municipality are familiar with patient participation, negative impact may be avoided. However, recognizing the potential of involvement may also enable making more informed decisions about how to enhance health services for the public. Still, primary healthcare professionals must comply with laws and regulations concerning patient participation, which is addressed next.

6.3.2. Laws and regulations concerning patient participation

The findings suggest that Norwegian municipalities have room for interpretation concerning how to obtain and apply experiential knowledge to improve health services.

The municipalities are responsible for ensuring that local democracy works well and that the welfare services are of good quality and efficient (Sirris, 2020). Involving citizens and service users is regarded as a democratic right and as essential to developing a strong relationship between the public and the officials responsible for implementing public policies. Involvement is believed to promote a healthy democracy and a more united society (Andreassen, 2018b). It can make decisions seem more fair and help service providers respond better to the public´s needs (Andreassen et al., 2014). However, studies show considerable confusion about patient participation and what it means (Halabi et al., 2020; Majid & Gagliardi, 2019; Usher & Denis, 2022). It is reasonable to assume that if those responsible for improving municipal welfare services are uncertain about patient participation, they are less likely to choose involvement as a means to enhance health services. Furthermore, the development of health services is likely to be poorly conducted. This indicates that to realize the potential of patient participation in health service development, there needs to be less confusion about patient participation and more incentives “to do it”.

Norwegian laws and regulations are meant to ensure involvement as a way of working to improve the services within primary healthcare. The Health and Care Services Act (2011, § 3-10) grants patient representatives the right to be heard in health service development. It also confirms the healthcare professionals´ duty to facilitate the involvement of patient organizations. However, no regulations specify how this will be done in practice while complying with the laws. The Quality Improvement Regulation (2016, § 6, 7, 8) confirms the municipalities´ duty to work systematically with quality improvement; apply experiential knowledge from patients, service users, and informal carers to enhance the health and care services; and evaluate the health and care services based on patients´, service users´, and informal carers´ experiences. Still, the interpretation of how to gain experiential knowledge and enhance health services is left to the discretion of the municipalities.

Several positive implications of well-conducted participatory health service development have been addressed above. However, obtaining feedback from service users or next of kin to improve health services may also be a constructive way to initiate changes. Depending on the purpose of obtaining feedback, it seems pertinent to discuss whether to apply consultatory approaches when developing health services or to go for a participatory approach – regardless of laws and regulations.

While some facilitators and professionals are competent in conducting involvement, patient representatives describe often being invited to participate because it is the law and not out of genuine interest in their experiential knowledge. Representatives describe that in such situations, their involvement has little meaning and is unlikely to affect the outcome. It also undermines their contributions, belittles their role in the process, and discourages future participation. These findings suggest that municipalities may need clearer regulations regarding what it means to comply with laws concerning involvement in health service development. The findings also imply that a skilled facilitator is crucial for constructive health service development with patient participation.

This section has illuminated the possibility for municipalities to choose the best approach to enhance the health services, rather than “tick off on the involvement box” due to laws or regulations (see Tritter, 2009, p. 276). This suggests that having a skilled facilitator to guide the development of health services may be advantageous in selecting the best approach to improve them.

6.3.3. Fruitful approaches to working together

The findings imply that there are different approaches to working together to enhance healthcare services. Taking into account the purpose, contextual factors, desired impact, and available resources of the health service development may guide the best course of action.

The scoping review showed that healthcare professionals typically use several approaches to obtain service users or representatives´ experiential knowledge to apply in health service development (Sandvin Olsson et al., 2020). These findings are confirmed by Wiles and colleagues (2022). These approaches include recruiting representatives to health service development teams, facilitating representatives´ participation in workshops, or conducting service user consultations. The scoping review further indicates that different approaches may be used simultaneously or in various phases of the same health service development. Still, consultatory approaches are the most common (Wiles et al., 2022). It may reflect that those in charge of processes rely on familiar methods or choose approaches that do not require as many resources as more holistic approaches, e.g., co-creation of health services. However, it may also reflect that informed choices have been made regarding the most appropriate approach, given the time, resources, and competencies at hand.

The findings imply that facilitators are put in a difficult position when tasked with developing health services with patient participation: they are to comply with policies and laws concerning involvement but have limited to no resources to spend. Simultaneously, they face demands from their leadership to deliver high-quality health services at a rapid pace (Siantz et al., 2021; Walunas et al., 2021). Facilitators describe being frustrated over their leaders´ unfamiliarity with patient participation, including the resources and time it takes and its potential benefits. Additionally, representatives report that little or no focus on patient participation reduces the degree to which they are involved. They also underline that the same small pool of representatives is repeatedly asked to be involved. Representatives therefore call for systems to support the involvement of diverse groups and contribute to better, equitable primary healthcare services. They recognize that this will require time and resources and emphasize the need for leadership support in implementing a working overall plan for patient participation.

Given these circumstances, it seems necessary to consider whether conducting health service development using consultative approaches may be a better and more ethically and morally sound solution. Firstly, inviting representatives to be part of health service development teams but letting them have limited or no impact in the process represents tokenism and should have no part in health service development. Still, consulting service users about their experiences may be fruitful in a service development phase. Also, it cannot be considered tokenism if those being consulted are clear that gathering their experiences is the sole purpose, and it is the professionals´ job to apply their input as they see fit. Secondly, consulting implies no partnership with an exchange of power among those involved. In this thesis, it does not pass as patient participation. Thus, this thesis´s concept of patient participation contrasts with Tritter´s (2009) understanding that consultation is a form of patient participation. Also, consultation is less likely than a partnership to contribute to a broad range of positive process-based impact (Ezaydi et al., 2023). It thus seems important to distinguish between the possibilities that patient participation as a partnership represents, compared to consulting service users to gain experiential knowledge to improve health services. Distinguishing the two may help clarify some of the confusion about patient participation and its implications (see Halabi et al., 2020; Majid & Gagliardi, 2019; Usher & Denis, 2022). However, the findings imply that there are more issues to consider.

Apart from representing a potential to improve health service quality, patient participation is grounded in democratic and consumerist reasoning (Tritter et al., 2009). It gains its authenticity from the democratic representation of interests and the responsibility of healthcare providers to receive input from service users (Martin, 2008). Patient participation is thought to help reduce inequality in health by strengthening the possibilities for all, but especially vulnerable groups in the population, to voice their needs and impact the form and content of local healthcare services (Andreassen et al., 2014; Gathen et al., 2022). This implies that when choosing whether to use patient participation or consultative approaches to improve the municipality´s health services, it also seems crucial to consider how these approaches can impact local democracy and the quality of welfare services. It also seems pertinent to consider if the democratic argument may be overshadowed by consumerist thoughts – and that local democracy and health service quality may benefit from it being placed in the foreground.

Considering the effort, resources, and time required from the individuals involved for a successful process, it appears ethically and morally sound to review the health service development´s purpose and what contextual factors are at play. Moreover, the team should consider the desired impact, what approaches may be fruitful to reach this impact, and the potential approaches´ possibilities for negative impact. Last, the team must consider whether a partnership is the most favorable approach.

This chapter has shed light on that several factors can be considered for a health service development team to choose the most fruitful way to work together to improve health services. Making an informed decision includes knowing the potential impacts of the chosen approach, how it corresponds with laws and regulations, as well as the purpose, context, desired impact, and available resources of the health service development.

6.4. Conclusion

This thesis has aimed to explore patient participation in primary healthcare service development and its impact. To expand current knowledge and contribute to strengthening patient participation, this thesis has sought to move beyond the traditional dualistic notion of power between healthcare professionals and patient representatives. Recognizing that their relationship is asymmetric in power, the thesis delves into the meaning that those involved ascribe to the collaborative dynamics that arise. Based on the perspectives of professionals, representatives, facilitators, and extant research literature, the following overall research question has been addressed:

> What meaning can the collaboration in health service development with patient participation have for healthcare professionals, patient representatives, and internal facilitators, and what impact can their collaboration have?

While international and Norwegian policies call for including the patient voice in health service development, this thesis has shed light on how collaborative processes to improve health services are challenging on several levels to those involved. The findings show that relational dynamics and contextual barriers put professionals, representatives, and facilitators in a tight spot at the interface between policy ideals and the actual practice of involvement. The thesis adds to the current knowledge base a more nuanced and profound understanding of difficulties, uncertainties, and contextual barriers that professionals, representatives, and facilitators must overcome to collaborate constructively to develop health services that suit the public´s needs.

The thesis findings imply that professionals, representatives, and facilitators ascribe complexity and tension to their collaboration. Facilitators and representatives also appear to have a complicated and strained relationship with leadership regarding involvement. The findings suggest that repositioning professionals and representatives as colleagues can raise several issues that may prevent or disrupt achieving a partnership and its potential positive impact. For example, professionals express uncertainty about "how to do involvement", including how to incorporate input from the representatives. On the other hand, representatives are uncertain if they will be able to impact the process and its result. The parties´ different needs for different types of knowledge seem to complicate collaboration.

The findings elucidate several contextual barriers with implications for facilitators´ involvement practice, how healthcare professionals can be involved, and how representatives tackle participation in health service development. It appears that knowledge about patient participation, what it can contribute, and what challenges it may represent, is limited among primary healthcare senior managers, supervisors, and professionals. There is also a lack of allocated resources for participatory activities. Ultimately this reduces the degree to which representatives are involved. Instead of representing a deliberately and chosen way of working on a policy level, involvement seems to happen primarily due to the dedication and effort of individual facilitators, professionals, and representatives. Nevertheless, the findings show that when a partnership is achieved among the health service development team members, all involved appreciate collaborating. Furthermore, their collaboration can positively impact those involved, the practice of patient participation in the organization, the service users, healthcare providers, and the organization's provision and delivery of health services. The findings thus imply there is great potential for gaining value from professionals and representatives collaborating in a partnership under the lead of a skilled facilitator. Norwegian municipalities have room for interpretation concerning how to obtain and apply experiential knowledge to improve health services. The findings suggest that there are different approaches to working together to enhance healthcare services. Taking into account the purpose, contextual factors, desired impact, and available resources of the health service development may guide the best course of action.

Aiming for the transferability of findings to other contexts, this thesis has explored patient participation in Norwegian municipalities that are known to practice involvement in the development of health services. Despite this, the findings indicate that Norwegian municipalities are largely unprepared to work with patient representatives to improve health services. While some facilitators and professionals possess the necessary skills to facilitate involvement, patient representatives report that their experiential knowledge is often not genuinely sought after when they are invited to participate. This thesis questions the practice of conducting patient participation to “tick off the involvement box”. Linked to democratic and consumer reasoning of patient participation, laws and regulations state that patient representatives have the right to be involved, and healthcare professionals must facilitate their involvement. The findings underline a need for a discussion at the policy and local levels regarding prioritizing and implementing patient participation — furthermore, discussions about what ethical and moral reasoning ought to guide involvement in health service development. Pertinent questions to be addressed may be what culture and infrastructure are needed to practice involvement and why. Other questions include: What approaches to gaining experiential knowledge are considered inside the scope of the law? How may senior managers, supervisors, and healthcare professionals avoid exposing patient representatives to unintended negative consequences or tokenism? It also seems pertinent to consider if a transparently consultative approach can mean preventing unintended consequences and tokenism, less harm to those involved, and securing future involvement in developing health services.

Last, this thesis suggests that Norwegian municipalities may benefit from prioritizing and committing to more involvement. This entails establishing a conducive context and organizational infrastructure that supports patient participation and ensures its impact. This way, local health service improvement efforts can lead to process- and collaborative impact, affecting relations among primary healthcare providers and service users and offering better healthcare services for the public´s good.

6.5. Implications for practice and research

This thesis provides valuable knowledge concerning patient participation in primary healthcare service development and holds several implications for practice and research. Reflecting that the field of inquiry is multidisciplinary and complex, the relevance of the thesis´s findings spans health service development, quality improvement, implementation science, co-production, social innovation, organizational development, and management. The findings are considered relevant to patient representatives, healthcare professionals, facilitators, supervisors, senior managers within primary and specialized care, and staff in educational institutions. The thesis´s findings are also perceived as useful to researchers interested in patient participation in health service development, quality improvement, implementation science, and the co-creation of knowledge concerning health and welfare services.

Regarding practice implications, this thesis presents useful knowledge for healthcare professionals, patient representatives, and internal facilitators concerning involvement in health service development. By providing the perspectives of the three parties, the thesis offers knowledge and insights that can enhance participatory processes. Uncertainties and difficulties of each party are elucidated, and discussing these in health service development teams can contribute to clarifying potential misconceptions or misunderstandings among those involved.

This thesis demonstrates limited knowledge among senior managers, supervisors, and healthcare professionals about involving patient representatives in improving health services. To avoid negative impact and unintended consequences from involvement, it could be beneficial for municipalities to include training on patient participation for their employees. The training could include topics such as how to practice involvement, what resources are required, potential benefits and drawbacks, and how professional and experiential knowledge complement each other. It seems essential to make senior managers, supervisors, and professionals, as well as patient representatives, aware of the complexity involved in collaboration between professionals and representatives. This can help all parties contribute to constructive processes. Therefore, such training could be available to employees at all levels of the organization.

In light of this thesis´s findings, facilitators learning about team-focused strategies that support change, and knowledge about patient participation, could make the difference between a good and a poor health service development process and result. Examples of team-focused strategies include conducting frequent meetings, enabling team members to get to know each other, and facilitating team discussions about how to establish a culture of mutual respect, common language, and trust (see Harvey & Kitson, 2015b). To further contribute to raising awareness concerning constructive collaboration to develop health services, the mixed advisory panel has contributed to developing topics that representatives and professionals can discuss when aiming for constructive collaboration. These are presented in Table 6 below and Table 1 in Article 2 (Sandvin Olsson et al., 2022, p. 6). Our findings also suggest that having a clear guideline for compensating patient representatives´ involvement may help reduce tensions between senior managers and facilitators and between facilitators and representatives.

This thesis also contributes knowledge about the types of impact that patient participation in health service development can lead to. The scoping review identified a wide range of impacts related to the process of collaborating (participatory impact), which is less commonly reported than the more traditional findings-based impact (collaborative impact). Additionally, the scoping review´s Table 3 (Sandvin Olsson et al., 2020, p. 1456) lists impact on representatives, professionals, and the organization´s involvement practice, while Table 4 (Sandvin Olsson et al., 2020, p. 1457) lists impact of patient participation on the design and delivery of health services related to patients, healthcare providers, and the healthcare organization. These tables could serve as a point of departure when planning health service development with patient participation and help identify the desired impact of a project. The findings suggest that an important first step could be establishing what experiential and professional knowledge is required to achieve the desired impact. Subsequently, discussions of the best suitable approach to obtain the necessary input – within the given timeframe and project scope. In cases where patient partnership is deemed appropriate to develop health services, Table 7 of the thesis´s scoping review (Sandvin Olsson et al., 2020, p. 1462) could prove a helpful tool. It comprises recommendations about how to conduct participatory health service development based on the findings of the studies included in the scoping review.

Concerning implications for research, this thesis indicates that there is a need to explore the perspectives of primary healthcare senior managers and supervisors concerning patient participation in health service development. Future studies should investigate what implementing involvement as a way of working to develop health services would mean to their position and function. In addition, future research should explore innovative ways to conduct patient participation in developing health services. Technological advancements during the pandemic have led to increased digital skills. Technological possibilities concerning involvement that could enhance possibilities for participation among diverse groups of service users need exploring.

The role of context in participatory health service development, including what context means concerning various approaches to patient participation, also needs further research. Identifying impact without describing its context makes it difficult to know whether it relates to patient participation or other factors. Studying context can help establish a reporting system for the identified impact of involvement in health service development, improvement, and implementation of innovations – further contributing to understanding the possibilities and drawbacks of involvement.

Table 6. Discussion topics concerning service-level patient participation for patient representatives and healthcare professionals.

Constructive collaboration	Representatives describe how collaborating with professionals to develop health services can be rewarding and energizing. - How can representatives contribute to constructive collaboration? - How can professionals be made aware of the importance that constructive collaboration plays for user representatives? - How can professionals use the spinoffs from collaborating with representatives?
Tokenism	Representatives experience that professionals sometimes involve them because they are obliged to, not because they are interested in hearing the user perspective. - How can professionals become more aware of the user voice as a resource? - How can representatives avoid tokenistic involvement? - What are suggestions for improving this?
Expectations and roles	Representatives find that professionals sometimes cannot describe their expectations concerning the representatives´ involvement in health service development. - How can expectations concerning the user role be clarified? - What are the professionals´ role in the collaboration? - What are suggestions for improving this?
Organizational readiness for user involvement	Representatives describe that senior management and professionals have limited understanding of what involvement is and entails. - How can different degrees of organizational readiness for involvement affect representatives´ involvement? - How can limited understanding affect professionals´ practice of involvement? - What are suggestions for improving this?
Complementary knowledge	Representatives sometimes feel that professionals do not value their experiential knowledge. - How can this play a part their collaboration? - How can representatives´ knowledge complement professionals´ knowledge? - What are suggestions for improving this?

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Appendices

Appendix 1. Involvement in the development of the Ph.D. project

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Appendix 1. Involvement in the development of the Ph.D. project

The Ph.D. project initiative sprung out of the Norwegian National Advisory Unit on Learning and Mastery in Health (in Norwegian: Nasjonal kompetansetjeneste for læring og mestring innen helse, NK LMH), situated at the Oslo University Hospital, in Norway. The NK LMH's main objective is to improve the quality of patient education and self-management programs in hospitals and municipal health and care services. Patient participation is practiced systematically in the NK LMH's service development and research projects.

A diverse group developed the Ph.D. project's research idea and focus. They were hand-picked in collaboration with my colleague, Kari Hvinden, and the main supervisor, Anita Strøm, to ensure varied perspectives, types of knowledge, and expertise concerning the development of primary healthcare services with patient participation. We had also established that Una Stenberg, a senior researcher at NK LMH, was to co-supervise in the Ph.D. project and that Mette Haaland-Øverby, a person with experiential knowledge at NK LMH, was to be the co-researcher of the Ph.D. project.

Those involved in the workshop, their titles, and affiliations at the time of the workshop:

- Gry Grøvik (occupational therapist, Lørenskog municipality),
- Mette Haaland-Øverby (person with experiential knowledge, NK LMH),
- Kari Hvinden (special advisor/public health nurse, NK LMH),
- Ingeborg Kristiansen (practice development nurse, Stange municipality),

- Anita Strøm (associate professor at VID Specialized University, nurse),
- Karl Fredrik Westerman (person with experiential knowledge, NK LMH) and
- Arnfinn Årnes (advisor/person with experiential knowledge, FFO[1]).

Una Stenberg (researcher, social worker, NK LMH) was invited but could not attend. She contributed input before the workshop concerning what the Ph.D. project should focus on. Her input was included in the process.

The group collaborating to develop the Ph.D. project's focus included one person (AÅ) from FFO, an advisor with experiential knowledge. Furthermore, two healthcare professionals, an occupational therapist (GG) and a nurse (IK), are from primary healthcare. They had expressed an interest in health service development with patient participation in seminars at the Norwegian National Advisory Unit on Learning and Mastery in Health. Also, three colleagues contributed: two based on their experiential knowledge (MH-Ø, KFW) and expertise contributing to the patient perspective in health service development and research; and one (KH) with extensive knowledge of health service development with patient participation in the municipalities and hospitals, process leadership, and project development. I facilitated the process.

Before the workshop, the members were informed about white papers underlining involvement in primary healthcare service development (The Coordination Reform, The Primary Healthcare

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[1] FFO is the Norwegian Federation of Organisations of Disabled People. Please refer to: https://ffo.no.

Services of Tomorrow, Care 2020/Omsorg 2020). They were also informed about the Dam Foundation’s call for research concerning involvement in primary healthcare services.

A three-hour workshop was conducted on March 31, 2016. Before starting, those involved ate lunch together. This enabled a relaxed atmosphere in the workshop, as everybody had already been introduced and had talked a bit with the others.

In the workshop, everybody first shared their experience concerning health service development with patient participation. While they all regarded involvement as applicable to develop services suited to the public’s needs, they had experienced several challenges: power imbalances, healthcare professionals’ lack of competencies to ensure constructive collaboration, and issues concerning the representativity of input from patient representatives.

Having shared their experience, the members were asked to respond to the following questions about involvement in primary health service development on Post-it notes:

- What works well? (Pink notes)
- Why does it work? (Yellow notes)
- What is hard? (Orange notes)
- Why is it hard? (Green notes)

Afterward, all notes of the same color were reviewed and discussed in turn in the plenum and grouped on the meeting room’s walls. Then, we collectively named the categories of notes grouped. The process yielded around 30 issues addressing involvement in primary healthcare service development.

After a break, the members were given ten heart stickers each to “like” those issues most interesting and pertinent to explore. The process left four central points (with several sub-issues) in need of research, presented in the group’s prioritized order:

I. How to make involvement work well in primary healthcare.
II. What competency is needed from patient representatives for primary healthcare service development?
III. What is the primary healthcare culture concerning democracy and patient participation in health service development?
IV. Development of a system for documenting meso-level patient participation in primary healthcare.

The group discarded the fourth issue: it was seen as a health service development project, not research. At this point in the process, I presented to the group an overview of current reviews’ calls for research (see Table 1).

Table 1. Reviews' findings, conclusions, and calls for research that contributed to this thesis' research focus.

#	Year	Authors & DOI	Type of review	Title	Findings/conclusions/calls for research with relevance for this thesis
1	2002	Crawford et al.	Systematic review	Systematic review of involving patients in the planning and development of health care	- Identified total lack of an evidence base regarding the effects of patient and public involvement.
2	2012	Mockford et al.	Systematic review	The impact of patient and public involvement on UK NHS health care: a systematic review	- Found a need for establishing clear concepts, adequate reporting, and valid tools for measuring the impact and costs of PPI. - Identified a need for considering the involvement context when defining impact of patient and public involvement.
3	2014	Tierney et al.	Critical interpretive synthesis	A critical analysis of the implementation of service user involvement in primary care research and health service development using normalization process theory	- Found a lack of routine concerning meaningful involvement in primary healthcare. - Reasoning for involvement in primary healthcare service development was mostly associated with political demands of co-governance and emancipatory ideas. - Suggest future research must investigate stakeholders' collaboration in specific projects. - Call for primary healthcare researchers to provide their working definitions of the term "service user involvement".
4	2015	Conklin et al. 2015	Scoping Review	What is the evidence base for public involvement in healthcare policy?: results of a systematic scoping review	- Found unclear concepts concerning PPI. Identifies inadequate reporting of the evidence of public involvement. - Found sparse evidence of the effect of involving lay persons in public involvement processes. - Identified research needs concerning roles and motivations for public involvement in healthcare policy. - Identified the need for research concerning public involvement's contextual influences and impact.
5	2015	Bath & Wakerman	Literature review	Impact of community participation in primary health: what is the evidence?	- Identified a small, significant effect of community involvement to be associated with improved health outcomes. - Commented on the difficulties in separating the impact of involvement

					from other potentially influencing factors. • Call for developing a pragmatic mechanism for assessing and monitoring community participation within primary healthcare.
6	2015	Macinerney et al.	Qualitative systematic review	Patients' involvement in improvement initiatives: a qualitative systematic review	• Identified scarce proof of successful involvement in quality improvement. • Applied the terms "soft" and "hard" outcomes from patient involvement. • Identified barriers to patient participation and difficulties in implementing involvement. • Found that involvement resulted in innovation and surprising outcomes. • Call for studies that address patient participation in quality improvement within healthcare.
7	2015	Groene & Sunol	Literature review	Patient involvement in quality management: rationale and current status	• Found that involvement in hospital quality improvement was low. • Call for qualitative research to explore the context in which PPI is implemented.
8	2016	Ocloo & Matthews	Narrative review	From tokenism to empowerment: progressing patient and public involvement in healthcare improvement	• Identified that healthcare professionals are uncertain about why and how to do involvement. • Call for reducing tokenism through broader and more democratic inclusion models.
9	2016	Semrau et al.	Systematic review	Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: systematic review	• Found few studies concerning their focus. • Reported involvement in health policy and strategy development and the training of healthcare professionals. • Call for research concerning rigorous evaluation of involvement and the complexity of its impact.
10	2017	Bench et al.	Scoping review	The nature and extent of service user involvement in critical care research and quality improvement: A scoping review of the literature	• Identified positive PPI experience. • Identified positive impact of PPI on service design and improvement efforts. • Found challenges of recruitment of service users with diverse backgrounds. • Found power hierarchies. • Identified a lack of evidence base for best practice PPI within critical care. • Call for research concerning PPI in critical care.

11	2017	Boström et al.	Narrative literature review	Cultural Change of Applying User Involvement for Improving Healthcare Quality: A Review of the Impact on Attitudes, Values, and Assumptions among Healthcare Professionals and Users	• Found limited impact of involvement on healthcare professionals and users' attitudes, assumptions, and values. • Identified a need for comparative research about the change in organizational culture before and after involvement initiatives to improve health services.
12	2018	Bombard et al.	Systematic review	Engaging patients to improve quality of care: a systematic review	• Found low-level engagement was typically associated with developing educational materials, tools, policy, and planning documents. • Found that high levels of engagement in the form of co-production were typically associated with service development to enhance care or structural outcomes like enhanced care process, service delivery, and governance. • Identified a need to adopt effective involvement strategies that identify the involvement context facilitating the outcomes. • Call for research concerning patients' involvement experiences and how various types of impact may enhance the quality of care.
12	2018	Liang et al.	Scoping review	Patient engagement in hospital health service planning and improvement: a scoping review	• Identified barriers among providers, including lack of skill and negative beliefs concerning patient engagement. • Call for research demonstrating the impact of engaging patients in health service improvement.

Against this background, the group landed on the following statement concerning the Ph.D. project's idea and objective:

> *This Ph.D. project will explore municipal arenas where health service development with patient participation is practiced and describe how it is practiced. The objective is to*

> *contribute new knowledge that informs constructive collaboration in primary healthcare service development with patient participation.*

The group assumed that the Ph.D. project would lead to new knowledge about how to facilitate collaboration well in primary healthcare service development with patient participation. Furthermore, that this knowledge would contribute to strengthening involvement within primary healthcare service development.

The workshop helped clarify the research idea and objective. When asked about their impression of the development process, the group's feedback was positive. Based on the workshop, and the identified reviews' calls for research, I developed the Ph.D. project application that this thesis' research is founded on. The development of the application was supported by those who took the roles as the main supervisor (Anita Strøm), the co-supervisor (Una Stenberg), and the co-researcher (Mette Haaland-Øverby) of the Ph.D. project.

The workshop enabled several actors to take an active interest in the Ph.D. project: several of those who were involved in the Ph.D. project's development wanted to be involved with the Ph.D. project's research team, mixed advisory panel, or help recruit participants. The Norwegian Federation of Organisations of Disabled People (FFO) supported the application. Øivind Skotland, a patient representative for FFO, applied for the Ph.D. project's funding from the Dam Foundation on my behalf, representing NK LMH. The Dam Foundation provided the grant (reference number 18/05851) that made the Ph.D. project possible.

Appendix 2. Documentation of literature searches in May 2021 and June 2023

Initial searches were done in March 2019 by Mikaela Aamodt, Senior Librarian at the Medical Library, University of Oslo. The original searches are included in the scoping review article (Sandvin Olsson et al., 2020).

To identify relevant published and unpublished reports, systematic literature searches were conducted using medical subject headings (MeSH) and free-text search terms for "patient participation" and "health service development". The following databases were searched from inception to present: MEDLINE (Ovid), Embase (Ovid), PsycInfo (Ovid), Cochrane Library (all), and SveMed+.

The complete searches were run again on 14 May 2021 by Academic Librarian Hilde Strømme. All hits from the new searches were imported into an EndNote library containing the references from the 2019 search. Duplicates were removed. The numbers in this documentation reflect the hits from the searches performed in May 2021, i.e., the total number of hits from the inception of the databases until mid-May 2021. The searches yielded 3032 new primary studies since the initial searches conducted in March 2019.

The complete searches were run again on 13 June 2023 by Senior LibrarianTarjei Fiskå Werner. Please note that the database SweMed+ was not searched, as this database no longer exists. All hits from the new searches were imported into an EndNote library containing the references from the 2019 and 2021 searches. Duplicates were removed. The numbers in this documentation reflect the hits from the searches performed in June 2023, i.e., the total number of hits from the inception of the databases until mid-June 2023. The searches yielded 1557 new primary studies since the searches were conducted in May 2021.

The following databases were searched in May 2021:

Database	Number of retrieved references
Medline (Ovid):	11513
Embase (Ovid):	2835
PsycInfo (Ovid):	963
Cochrane Library:	607
SveMed+	831
Number of references before deduplication:	16749
Number of references after deduplication:	14018

Ovid MEDLINE(R) ALL <1946 to May 14, 2021>

1	Patient Participation/	27014
2	((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) adj (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*)).ti.	7799
3	or/1-2	33030
4	Delivery of Health Care/	95936
5	Quality of Health Care/	74632
6	*Health Services Administration/	3376
7	Health Planning/	21791
8	Health Services/	25441
9	*Community Health Nursing/	15678
10	Mental Health Services/	35242
11	Community Mental Health Services/	18745
12	*Health Services for Persons with Disabilities/	110
13	*Health Services for the Aged/	13970
14	*Urban Health Services/	2031
15	*Rural Health Services/	9700
16	Rehabilitation Centers/	8361
17	*Hospital Units/	5632
18	Health Policy/	68515
19	Health Care Reform/	32915
20	*National Health Programs/	20446
21	*primary health care/	52873
22	Community Health Services/	32192

23	Quality Improvement/	27418
24	Organizational Innovation/	24878
25	(health* or care or hospital or rehabilitat*).ti.	1475046
26	or/4-25	1725155
27	3 and 26	11513

Embase Classic+Embase <1947 to 2021 May 14>

1	((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) adj (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*)).ti.	10120
2	(health* or care or hospital or rehabilitat*).ti.	1835204
3	1 and 2	2835

APA PsycInfo <1806 to May Week 2 2021>

1	((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) adj (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*)).ti.	3438
2	(health* or care or hospital or rehabilitat*).ti.	307839
3	1 and 2	963

The Cochrane Library

Number of hits: 1 Cochrane Review, 1 Cochrane Protocol, 605 Trials

(((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) near (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*))):ti AND ((health* or care or hospital or rehabilitat*)):ti (Word variations have been searched)

SveMed+

1	exp:"Community Participation"	948
2	exp:"Quality Improvement"	116
3	exp:"Organizational Innovation"	319
4	exp:"Delivery of Health Care"	21785
5	exp:"Quality of Health Care"	57037
6	exp:"Health Services Administration"	42148
7	exp:"Health Planning"	4236

8	exp:"Health Services"	34776
9	exp:"Community Health Nursing"	372
10	exp:"Mental Health Services"	2193
11	exp:"Community Mental Health Services"	484
12	exp:"Health Services for Persons with Disabilities"	2
13	exp:"Health Services for the Aged"	700
14	exp:"Urban Health Services"	21
15	exp:"Rural Health Services"	108
16	exp:"Rehabilitation Centers"	403
17	exp:"Hospital Units"	1441
18	exp:"Health Policy"	3050
19	exp:"Health Care Reform"	484
20	exp:"National Health Programs"	279
21	exp:"Primary Health Care"	4122
22	exp:"Community Health Services"	6058
23	exp:"National Health Programs"	279
24	%232 OR %233 OR %234 OR %235 OR %236 OR %237 OR %238 OR %239 OR %2310 OR %2311 OR %2312 OR %2313 OR %2314 OR %2315 OR %2316 OR %2317 OR %2318 OR %2319 OR %2320 OR %2321 OR %2322 OR %2323	85713
27	%231 AND %2324 Limits: doctype:"artikel"	831

The following databases were searched in June 2023:

Database	Number of retrieved references
Medline (Ovid):	1438
Embase (Ovid):	976
PsycInfo (Ovid):	230
Cochrane Library:	109
Number of references before deduplication:	2753
Number of references after deduplication:	1557

OVID Medline
1 Patient Participation/ 29379
2 ((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) adj (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*)).ti. 10091
3 1 or 2 37145
4 "Delivery of Health Care"/ 116461
5 "Quality of Health Care"/ 77442
6 *Health Services Administration/ 3407
7 Health Planning/ 21966
8 Health Services/ 27603
9 *Community Health Nursing/ 15775
10 Mental Health Services/ 38403
11 Community Mental Health Services/ 19037
12 *Health Services for Persons with Disabilities/ 115
13 *Health Services for the Aged/ 14105
14 *Urban Health Services/ 2053
15 *Rural Health Services/ 10442
16 Rehabilitation Centers/ 8644
17 *Hospital Units/ 5674
18 Health Policy/ 72097
19 Health Care Reform/ 33438
20 *National Health Programs/ 20786
21 *Primary Health Care/ 55434
22 Community Health Services/ 33087
23 Quality Improvement/ 32463
24 Organizational Innovation/ 25328
25 (health* or care or hospital or rehabilitat*).ti. 1698462
26 or/4-25 1961658
27 3 and 26 12875
28 limit 27 to yr="2021 -Current" 1438

Embase

1 ((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) adj (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*)).ti. 13245
2 (health* or care or hospital or rehabilitat*).ti. 2153425
3 1 and 2 3739
4 limit 3 to yr="2021 -Current" 976

APA PsycInfo
1 ((patient or user or carer or caregive* or public or client or lay or stakeholder or representative) adj (participat* or involve* or collaborat* or engag* or evaluat* or consult* or perspectiv* or view* or express*)).ti. 4064
2 (health* or care or hospital or rehabilitat*).ti. 348666
3 1 and 2 1173
4 limit 3 to yr="2021 -Current" 230

Cochrane Library
#1 ((((patient OR user OR carer OR caregive* OR public OR client OR lay OR stakeholder OR representative) NEAR (participat* OR involve* OR collaborat* OR engag* OR evaluat* OR consult* OR perspectiv* OR view* OR express*)))):ti 2359
#2 (((health* OR care OR hospital OR rehabilitat*))):ti 160183
#3 #1 AND #2 566
Reviews: 0
Cochrane Protocols: 0
Trials: 109

Appendix 3. Overview of reviews identified from literary searches in 2021 and 2023

Table 1. Current reviews and a thematic synthesis on patient participation in health service development, including relevant findings, conclusions, and calls for research.

#	Year	Authors and DOI	Type of review	Title	Findings, conclusions, and calls for research
1	2019	Bergerum et al.	Realist literature review	How might patient involvement in healthcare quality improvement efforts work—A realist literature review	• Presented a program theory and guidance for active involvement in improvement efforts. • Found that active patient involvement can be a tool (resource) if tailored for interaction and partnership (reasoning), that leads to behavior change (outcome) concerning quality improvement within healthcare. • Underlined the importance of context, co-design, resources, and reasoning. • Call for research concerning how involvement is experienced by the involved and how it works on different levels within healthcare.
2	2019	Majid & Gagliardi	Qualitative systematic review	Clarifying the degrees, modes, and muddles of “meaningful” patient engagement in health services planning and designing	• Offer nuances in the meanings of terms often applied synonymously to patient engagement (collaboration/cooperation/co-production, active involvement, partnership, and consumer/peer leadership). • Call for research to explore what meaning patients put on the different terms within engagement frameworks.
3	2019	Movsisyan et al.	Systematic review	Adapting evidence-informed complex population health interventions for new contexts: a systematic review of guidance	• Call for an exploration of the roles of key stakeholders and management of potential conflicts in efforts to adapt and implement population interventions.
4	2020	Halabi et al.	Scoping review	“Patient participation” and related concepts: A scoping review on their dimensional composition	• Identified dimensions associated with patient participation. • Identified similarities and differences in concepts related to patient participation. Propose that "patient participation" be used as a generic concept describing the healthcare system's overall aim to involve

					the patient, whether on a micro-, meso-, or macro-level.
5	2020	Sandvin Olsson et. al *	Scoping review	How can we describe impact of adult patient participation in health-service development? A scoping review	• Reported diverse approaches to patient participation. • Identified impacts from collaborative health service development on the involved healthcare professionals and patient representatives, and the collaboration itself, • Identified impact from patient participation in health service development on the service users, the organization's staff, and the organization itself. • Call for research on impact of the collaboration between healthcare professionals and patient representatives and the role of context.
6	2020	Biddle et al.	Systematic review	Attitudes and approaches to patient and public involvement across Europe: A systematic review	• Patient and public involvement (PPI) is unevenly implemented across Europe, influenced by infrastructure, guidance, and support availability. • Identified seeming convergence of how PPI is conceptualized across Europe. • Where interest and commitment are lacking, PPI is less likely to develop. • Call for research about attitudes and approaches to PPI in Europe.
7	2021	Modigh et al.	Meta Scoping review	The impact of patient and public involvement in health research versus healthcare: A scoping review of reviews	• More reviews containing information about PPI impact have been published in healthcare than in health research since 2000. • The most commonly reported impacts of PPI in healthcare were individual health outcomes/clinical outcomes. • Identified uncertainty about the strength of PPI, especially concerning collective involvement in policymaking and service improvement initiatives at hospitals or the like.
8	2021	Pedersen et al.	Scoping review	Public involvement in the planning, development, and implementation of community health services: A scoping review of public involvement methods	• Identified scarcity of empirical research on public involvement in the implementation of health services. • Call for research exploring public involvement in health service implementation.
9	2022	Wiles et al.	Systematic review	Consumer engagement in health care policy, research and	• Identified that consultative consumer engagement strategies were most frequent in the development of health service interventions.

				services: A systematic review and meta-analysis of methods and effects	- Found evidence that consumer engagement enhanced the results in the development and delivery of care of pregnant women and reduced neonatal mortality. - Found evidence that involving consumers in patient information development resulted in more relevant, readable, and understandable material for patients and can improve knowledge. - Found some evidence that consumer engagement may have a complementary role in identifying a broader range of health care priorities that are complementary to those from professionals. - Found some evidence that consumer engagement in monitoring and evaluating health services may impact perceptions of patient safety and quality of life. - Found growing evidence from randomized controlled trials of the effects of consumer engagement on the relevance and positive outcomes of health policy, research, and services.
10	2022	Cluley et al.	Scoping review	Mapping the role of patient and public involvement during the different stages of healthcare innovation: A scoping review	- Identified that PPI is most used in the early stages of innovation. - Found that PPI risk being described as a tick-box exercise. - Identified the need for systems and support to guide PPI in healthcare innovation to ensure its accessibility and inclusivity in the innovation journey. - Call for the use of PPI across the whole innovation journey to support the adoption and diffusion of innovation.
11	2022	Gathen et al.	Scoping review	User participation among people in vulnerable situations at service level. A scoping review exploring impact for individual stakeholders and services	- Argue for a circular understanding of impact. - Identified the following individual-level impacts of user participation: ○ personal empowerment among users, ○ disempowerment among users, ○ enhanced knowledge among healthcare professionals. - Identified several organizational-level impacts of user participation, including changes in attitudes, knowledge, culture, professional practice, interventions, increased number of employees, organizational development, and policy changes.

					• Underline the importance of facilitating user participation to avoid causing harm to participants. • Call for research on the challenges and possible negative effects of user participation.
12	2022	Pedersen et al.	Thematic synthesis	The added value and unintended negative consequences of public involvement processes in the planning, development and implementation of community health services: Results from a thematic synthesis	• Identified several levels of added value at the individual and service levels from public involvement. • Found that the added value was accompanied by unintended negative consequences – related to the involvement process, recruitment of participants, and the facilitation of the process. • Call for more attention to unintended negative aspects of public involvement. • Call for involving vulnerable groups of service users and training professionals to facilitate involvement in development processes.
13	2022	Usher & Denis	Meta-narrative review	Exploring expectations and assumptions in the public and patient engagement literature: A meta-narrative review	• Explored reviews published between 2000 and 2020 applying the terms public/ community/ citizen engagement/participation". • Identified 38 reviews; 15 were published within or after 2018. • Call for conceptual work to understand barriers to patient engagement. • Call for research on the context of patient engagement. • Call for research approaches to capture developments and initiatives across micro, meso, and macro levels to see how they support one another to drive, enable, and sustain change among users and providers. • Call for research to understand the actions of multiple actors to adapt to and integrate a different distribution of responsibilities.
14	2023	Sagen et al.	Scoping review	Patient engagement in the development and delivery of healthcare services: a systematic scoping review	• Identified lack of clearly defined outcomes concerning patient engagement related to healthcare professionals, patient representatives, managers, and patients. • Found that facilitating equity and meaningful co-creation requires representative stakeholders and patient engagement knowledge. • Underline the importance of earmarked finances to ensure sufficient patient engagement, representativeness, and knowledge among all stakeholders across healthcare settings.

15	2023	Ezaydi et al.	Systematic review	Service user involvement in mental health service commissioning, development and delivery: A systematic review of service level outcomes	• Found that co-production and -design were associated with more positive and substantial service- and patient-level outputs than more limited forms of involvement (i.e., service user consultation). • Identified that service perceptions may be valued more highly by service users than professionals who value clinical outputs highly. • Argue that service perception outputs should be considered equally important.

*This review is Article 1, which is embedded in this thesis.

Appendix 4. Focus group interview guide for healthcare professionals (in Norwegian)

FOKUSGRUPPEINTERVJU MED FAGPERSONER – 2 x 45 minutter

Velkommen på gangen	Fylle ut: • Samtykkeskjema • Sosiodemografisk-informasjon-skjema På forhånd er deltakerne bedt om følgende: Tenk gjennom et eksempel hvor du har samarbeidet med en eller flere med brukererfaring og andre fagpersoner for å lage eller forbedre helsetjenester. Noter deg gjerne noen stikkord. Bokgave legges på bordet sammen med papir til å notere på – og penner settes på bordet. Husk å la spørsmål få henge litt før de omformuleres. **Skriv opp på flip-over-ark og heng opp målet med fokusgruppeintervjuet.**
Introduksjon *Ikke båndopptak*	Hjertelig velkommen! Vi setter stor pris på at akkurat dere kunne komme – fordi dere representerer personer med erfaring om brukermedvirkning – og har ulik faglig bakgrunn og stillinger.

	Som del av forskningsprosjektet «Samarbeid om å fremme helse» gjennomfører vi nå intervjuer med fagpersoner og brukerrepresentanter som samarbeider for å utvikle kurs, temakvelder, lærings- og mestringstilbud eller helsetjenester. Regjeringen vil ha mer brukermedvirkning – men vi vet lite om hvordan dette skal gjøres – og hvilken betydning det kan få. Dette er det lite forskning på både her hjemme og i resten av verden. Det viser vårt omfattende litteratursøk. **Det er målet vårt å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til.** I dag ønsker vi derfor å lære av deres erfaringer; det er **dine erfaringer** som er viktige! (Mitt navn er Ann Britt Sandvin Olsson og dette er Mette Haaland-Øverby. Jeg er doktorgradsstudent og Mette er medforsker med brukererfaring. Jeg er utdannet fysioterapeut – og har mange års erfaring med å arbeide i tilknytning til lærings- og mestringsvirksomhet.)
Moderatorrollen	**Som moderator** skal jeg lede diskusjonen og forsøke å få dere til å komme med **konkrete erfaringer** knyttet til samarbeid for å utvikle helsetjenester. Både positive og negative erfaringer – gode og dårlige eksempler; de er like viktige! Jeg vil komme med noen oppfølgingsspørsmål underveis, men ønsker å størst mulig grad at dere har en samtale sammen som en gruppe.

Medforsker	**Mette noterer stikkord.** Hun følger litt med på lydbåndopptakeren og passer tiden for oss. Kanskje kommer hun også med noen spørsmål underveis.
Informert samtykke	Gjennomgå **informert samtykke.**
Taushetsplikt	Gjennomgå at alle har **taushetsplikt** om det som blir sagt og hvem som var med i diskusjonen. Dette er viktig – slik at dere kan ta fram både positive og negative erfaringer. Like fullt, er det helt OK å ikke si mer enn du er komfortabel med.
Lydbånd	Vi trenger å bruke båndopptaker for å få med oss alt dere sier. Selv om en av oss noterer, ønsker vi å passe på at vi får med oss alle nyansene i det dere sier. I artiklene og tekstene vi skal forfatte vil det ikke være mulig å spore bestemte personer tilbake til individuelle utsagn fra dere – det gjelder også når dere bruker eksempler.
Regler for samtalen	Det vi ønsker oss er konkrete fortellinger som beskriver deres erfaringer – både «gode og vonde». Det er det som vil gi oss robuste data! For å få det til, finnes det noen generelle regler for denne type diskusjonsgruppe. • Det er viktig at **alle slipper til** – og at alle bidrar til det. • Det er flott om bare **en person snakker om gangen**, da blir lydopptaket bra. • Det er også flott å unngå å avbryte hverandre. • Det er supert om dere får assosiasjoner til egne erfaringer fra samarbeid når de andre snakker, og deler dem med oss.

- Det er **ingen riktige eller gale** svar!
- Dere behøver ikke framstå som «flinke» eller kunnskapsrike: Vi trenger alle de erfaringene dere kan bidra med.
- Kom gjerne med «motsatte erfaringer» eller som bryter med det som har blitt sagt før.
- Små nyanser er også viktige – og de kan komme fram fra deg selv om noen andre har nevnt noe liknende før.
- Vi håper dere kan være **ærlige**. Dårlige eksempler er like viktige som gode eksempler!
- Vi er ikke ute etter om dere er enige eller uenige med hverandre.
- Vi trenger å få vite om deres forskjellige erfaringer knyttet til samarbeid.

Det er et poeng å få samlet så mange **forskjellige** erfaringer omkring samarbeidet som mulig. Her er det viktig at **alle** erfaringer med samarbeid kommer frem – både på godt og vondt, praktiske sider så vel som relasjonelle eller situasjonsbetingede. Kom gjerne med erfaringer om situasjoner hvor det oppstod noe som du ville likt å forstå mer av.

Dette fokusgruppeintervjuet blir best om vi sitter igjen med en rekke ulike konkrete fortellinger eller historier.

Intervjuet skal vare ca. 2 x 45 minutter – vi tar pausen litt etter som det passer. Vi avslutter til avtalt tid. Det er OK å reise seg og skjenke kaffe/te/vann eller bevege seg rundt.

Kort presentasjonsrunde *Med båndopptaker*	Flott om alle kan si sitt navn, hvor de jobber og sitt absolutte favorittsnop – bare sånn for å få oss litt i gang. (Skrur på lydopptaker).
Begynner fokusgruppeintervju	Nå vil jeg gjerne høre hvilket eksempel dere har tenkt på om BRUKERMEDVIRKNING I TJENESTEUTVIKLING (VIS TIL SPØRSMÅLET PÅ TAVLA – SPØR OM NOEN LURER PÅ HVA DET HANDLER OM). Her er det fint om dere andre kommer med kommentarer eller innspill dersom dere får assosiasjoner til erfaringer dere har gjort dere knyttet til samarbeid for å lage helsetjenester/kurs/tilbud. **Karakteristika av og kontekst for samarbeidet** • Kan du beskrive hva dette eksempelet besto i? ○ Hva var hensikten med samarbeidet? ○ Hvordan samarbeidet dere, konkret? ○ Når ble samarbeidet iverksatt? ○ Hvem var involvert? ○ Hva var din motivasjon for å delta? ○ Hvordan hadde du forberedt deg til dette samarbeidet? ○ Hva var rammene rundt møtet/samarbeidet?

- Kan du fortelle om den beste erfaringen med et samarbeid?
    - Hva bidro til dette?

- Kan du fortelle om et samarbeid som gikk «rett i do»?
    - Hva bidro til dette?

- Hva var det mest overraskende med samarbeidet?
    - Hva gjorde dette så overraskende?
    - Hva tenker dere andre om dette?
    - Er det noen som har motsatte erfaringer?

- Kan dere fortelle litt om samarbeidssituasjoner hvor det har vært uenighet?
    - Hva bestod uenigheten i?
    - Hvordan ble den løst, hvis den ble det?
    - Hvordan påvirket dette det å samarbeide for deg?

- Hva kan bidra til godt samarbeid når det gjelder praktiske sider som invitasjonen til å delta, stedet og omgivelsene hvor samarbeidet skal foregå?

Betydning av samarbeidet – når det fungerer godt og når det fungerer dårlig

- Nå har jeg lyst til å høre litt om hva som er viktig for dere når det gjelder å samarbeide med fagpersoner og brukerrepresentanter for å utvikle helsetjenester.
    - Hvilke egenskaper ved samarbeidet verdsetter dere?

	○ Hvilke sider ved samarbeidet er utfordrende? ○ Hva betyr det å ha fagkunnskapen tilgjengelig i samarbeidet? ○ Hva betyr det å ha erfarings-/brukerkunnskapen tilgjengelig i samarbeidet? ○ Hva kunne vært nyttig for deg om ble gjort i forbindelse med samarbeidsprosessen? ○ Har dere eksempler på resultater eller konsekvenser som samarbeidet bidro til – på «godt og/eller vondt»? ○ Hva kan ev. gjøres for å få til bedre samarbeid? • Nå vil jeg gjerne høre litt fra dere om hvordan dere har erfart det å møte brukerrepresentanter i samarbeidsprosesser. ○ Kan du beskrive en situasjon hvor det har vært spesielt positivt? ○ Hva bidro til dette? ○ Kan du beskrive en situasjon hvor det har vært vanskelig? ○ Hva bidro til dette?
Avrunding med medforsker	Gjentar målet med intervjuet: Målet vårt er å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til. ○ Har vi fått med alt, eller mangler noe? ○ Er det noe vi ikke har vært inne på som er viktig å få frem?

	Til slutt lurer vi på hvordan dere har opplevd å delta i denne diskusjonsgruppen? ○ Hva var bra eller dårlig? Hvis dere kommer på noe, både tanker eller refleksjoner eller innspill, nå i etterkant om det vi har snakket om i dag, så vær så snill å ring meg eller Mette eller send en mail. Det er god informasjon som vi kan bruke! • Kunne noen tenke dere å delta videre i studien? Da i form av å stille opp til et dybdeintervju? • Husk at alle må skrive under på samtykkeerklæringen og fylle ut bakgrunnsopplysningene. **Tusen takk for at dere tok dere tid og for alle tilbakemeldinger underveis i dag!**
Debriefing *Lydopptaker på*	• Temperaturen i samtalen? • Spenningsmomenter i gruppa? • God/dårlig gruppedynamikk •

Appendix 5. Focus group interview guide for patient representatives (in Norwegian)

FOKUSGRUPPEINTERVJU MED BRUKERREPRESENTANTER – 2 x 45 minutter

Velkommen på gangen	Fylle ut: • Samtykkeskjema • Bakgrunnsskjema På forhånd har deltakerne blitt bedt om følgende: Tenk gjennom et eksempel hvor du har samarbeidet med en eller flere med brukererfaring og andre fagpersoner for å lage eller forbedre helsetjenester. Noter deg gjerne noen stikkord. Få bokgaven etterpå. Husk å la spørsmål få henge litt før de omformuleres. Følg gjerne opp med oppfølgingsspørsmål og grav litt dypere. Skriv opp på flip-overark/whiteboard og heng opp målet med fokusgruppeintervjuet. Understrek: Målet i dag er å få deres konkrete fortellinger om samarbeid mellom brukerrepresentanter og fagpersoner – for å lage temakvelder/kurs/lærings- og mestringstilbud eller andre helsetjenester. Dette handler om samarbeidet med fagpersoner i møter eller faglige sammenhenger – men IKKE likemannsarbeid.

Introduksjon *Ikke båndopptak*	Hjertelig velkommen! Vi setter stor pris på at akkurat dere kunne komme – dere representerer personer med ulik erfaringskunnskap. Som del av forskningsprosjektet «Samarbeid om å fremme helse» gjennomfører vi nå intervjuer med fagpersoner og brukerrepresentanter som samarbeider for å utvikle kurs, temakvelder, lærings- og mestringstilbud eller helsetjenester. Regjeringen vil ha mer brukermedvirkning – men vi vet lite om hvordan dette skal gjøres – og hvilken betydning det kan få. Dette er det lite forskning på både her hjemme og i resten av verden. **Det er målet vårt å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til.** I dag ønsker vi derfor å lære av deres erfaringer; dine erfaringer er viktige! (Mitt navn er Ann Britt Sandvin Olsson og dette er Mette Haaland-Øverby. Jeg er doktorgradsstudent og Mette er medforsker med brukererfaring. Jeg er utdannet fysioterapeut – og har mange års erfaring med å arbeide i tilknytning til lærings- og mestringsvirksomhet.)
Moderatorrollen	**Som moderator** skal jeg lede diskusjonen og forsøke å få dere til å komme med konkrete erfaringer knyttet til samarbeid for å utvikle helsetjenester. Både positive og negative erfaringer – gode og «dårlige» eksempler er like viktige!

	Jeg vil komme med noen oppfølgingsspørsmål underveis, men ønsker å størst mulig grad at dere har en samtale sammen som en gruppe.
Medforsker	Mette skal notere stikkord. Hun skal følge med på lydbåndopptakeren og passe på tiden for oss. Hun vil også ha noen oppfølgingsspørsmål til oss til slutt.
Informert samtykke	Gjennomgå **informert samtykke.**
Taushetsplikt	Gjennomgå at alle har taushetsplikt om det som blir sagt og hvem som var med i diskusjonen. Dette er viktig – slik at dere kan ta fram både positive og negative erfaringer. Like fullt er det viktig at dere ikke sier mer enn hva dere er komfortable med.
Lydopptaker	Vi trenger å bruke lydopptaker for å få med oss alt dere sier. Selv om en av oss noterer, ønsker vi å passe på at vi får med oss alle nyansene i det dere sier. I artiklene og tekstene vi skal forfatte vil det ikke være mulig å spore bestemte personer tilbake til individuelle utsagn fra dere – det gjelder også når dere bruker eksempler.
Regler for samtalen	Det vi ønsker oss er konkrete fortellinger som beskriver deres erfaringer – både «gode og vonde». Det er det som vil gi oss robuste data! For å få det til, finnes det noen generelle regler for denne type diskusjonsgruppe. • Det er viktig at alle slipper til – og at alle bidrar til det. • En person snakker om gangen, da blir lydopptaket bra. • Det er også flott å unngå å avbryte hverandre.

- Det er supert om dere får assosiasjoner til egne erfaringer fra samarbeid når de andre snakker, og deler dem med oss.
- Det er ingen riktige eller gale svar!
- Dere behøver ikke framstå som «flinke» eller kunnskapsrike: Vi trenger alle de erfaringene dere kan bidra med.
- Kom gjerne med motsatte erfaringer» eller som bryter med det som har blitt sagt før.
- Små nyanser er også viktige – og de kan komme fram fra deg selv om noen andre har nevnt «noe liknende» før.
- Vi håper dere kan være ærlige. Dårlige eksempler er like viktige som gode eksempler!
- Vi er ikke ute etter om dere er enige eller uenige med hverandre.

Det er et poeng å få samlet så mange **forskjellige** erfaringer omkring samarbeidet som mulig. Her er det viktig at **alle** erfaringer med samarbeid kommer frem – både på godt og vondt, praktiske sider så vel som relasjonelle eller situasjonsbetingede.

Dette fokusgruppeintervjuet blir best om vi sitter igjen med en rekke forskjellige konkrete fortellinger eller historier.

Intervjuet skal vare ca. 1 ½ time – og vi tar en pause cirka halvveis. Hvis dere trenger mer pause, si i fra. Det er OK å reise seg, gå på do, eller skjenke kaffe etc. underveis i intervjuet. Vi avslutter til avtalt tid.

Kort presentasjonsrunde *Med båndopptaker*	Flott om alle kan si sitt navn, ev. hvilken organisasjon du er tilknyttet og ditt absolutte favorittsnop. (Skrur på lydopptaker).
Begynner fokusgruppeintervju	Nå vil jeg gjerne høre hvilket eksempel dere har tenkt på. Her er det fint om dere andre kommer med kommentarer eller innspill dersom dere får assosiasjoner til erfaringer dere har gjort dere knyttet til samarbeid med fagpersoner for å lage helsetjenester/kurs/tilbud. **Karakteristika av og kontekst for samarbeidet** • Kan du fortelle om et samarbeid du syntes var bra? ▪ Hva bidro til dette? • Kan du fortelle om et samarbeid som gikk «rett i do»? ▪ Hva bidro til dette? • Hva var det mest overraskende med samarbeidet? ○ Hva gjorde dette så overraskende? ▪ Hva tenker dere andre om dette? ▪ Er det noen som har motsatte erfaringer? • Kan dere fortelle litt om samarbeidssituasjoner hvor det har vært uenighet? ○ Hva bestod uenigheten i?

  - Hvordan ble den løst, hvis den ble det?
  - Hvordan påvirket dette det å samarbeide for deg?

  - Kan dere fortelle litt om samarbeidssituasjoner når folk ikke holder seg til saken eller «sporer av»?

Roller og forventninger
Nå vil jeg gjerne ha en runde rundt bordet – om roller og ulike hatter dere har på i samarbeid med fagpersoner.

- Har dere eksempler på forskjellige forventinger som fagpersoner har til dere?
- Hvilke forventninger har dere til fagpersonene?
- Ev. hvordan endrer forventningene seg underveis i et samarbeid?
  - Hva tør dere eventuelt å si i fra om – på forhånd og underveis?

Inkludering
- Hvordan kan det å bli inkludert/ekskludert arte seg i samarbeidet?
  - På hvilke måter har du opplevd å bli inkludert/ekskludert i samarbeidet?
    - Hva bidro til dette? (Hva gjør fagpersonene da?)
  - Hvilken betydning kan språket/begrepene som brukes ha for deg?
  - Hvilken betydning har antallet medvirkere i gruppa for deg?
  - Hva må til for at dine innspill eller forslag skal bli tatt med?
  - Gjør du noe spesielt for at dine meninger eller forslag skal bli hørt?

	○ Hva skal til for at du erfarer «å bli tatt på alvor»? ○ Hva er viktig for deg når du deltar i samarbeidsprosesser? ○ Eksempler på samarbeid dere dere har erfart å være del av gruppa – eller ikke tilhøre gruppa? (Å være i mindretall – hvordan er det?) **Betydning av samarbeidet – når det fungerer godt og når det fungerer dårlig** ● Nå har jeg lyst til å høre litt om hva som er viktig for dere når det gjelder å samarbeid mellom fagpersoner og brukerrepresentanter for å utvikle helsetjenester. ○ Hva ved samarbeidet verdsetter dere? ○ Hvilke sider ved samarbeidet er utfordrende? ○ Hva betyr det å ha fagkunnskapen tilgjengelig i samarbeidet? ○ Hva betyr det å ha erfarings-/brukerkunnskapen tilgjengelig i samarbeidet? ● Hva får du igjen fra å delta i samarbeidet? ● Hvilken betydning får det for brukere, pasienter og pårørende at dere samarbeider med fagpersoner? ● Har dere eksempler på at deres bidrag kom tydelig fram/ikke førte fram?
Avslutning og oppsummering 10 min	**Medforsker:** ● Gjentar målet med intervjuet**:** Målet vårt er å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til. ● Forsøker å oppsummere tema vi har vært innom. ● Spør om deltakerne synes oppsummeringen er dekkende for hva dere mener og hva vi har diskutert.

	○ **Har vi fått med alt, eller mangler noe?** ○ **Er det noe vi ikke har vært inne på som er viktig å få frem?** **Til slutt lurer vi på hvordan dere har opplevd å delta i denne diskusjonsgruppen?** ○ Hva var bra eller dårlig? Hvis dere kommer på noe, både tanker eller refleksjoner eller innspill, nå i etterkant om det vi har snakket om i dag, så ring gjerne meg eller Mette eller send en mail. Det er god informasjon som vi kan bruke! • **Kunne noen tenke dere å delta videre i studien? Da i form av å stille opp til et dybdeintervju?** • **Husk at alle må skrive under på samtykkeerklæringen og fylle ut bakgrunnsopplysningene.** **Tusen takk for at dere tok dere tid og for alle tilbakemeldinger underveis i dag!**
Debriefing *Lydopptaker på*	• Temperaturen i samtalen? • Spenningsmomenter i gruppa? • God/dårlig gruppedynamikk

Appendix 6. Individual interview guide for healthcare professionals (in Norwegian)

Semistrukturert intervjuguide for individuelle intervju med fagpersoner – 2 x 45 minutter

Velkommen før oppstart	Fylle ut: • Samtykkeskjema • Bakgrunnsskjema Skriv opp på flip-over-ark/whiteboard og heng opp målet med intervjuet. Ha en liten gave tilgjengelig til etterpå. Husk å la spørsmål få henge litt før de omformuleres.
Introduksjon *Ikke båndopptak*	Hjertelig velkommen! Vi setter stor pris på at akkurat du vil delta – du har erfaring fra å etablere kommunale tilbud i samarbeid med brukerrepresentanter eller brukere og andre fagpersoner. Hvorfor, hvordan, med hvilket grunnlag – det er vi interesserte i å høre mer om i dag! Som del av forskningsprosjektet «Samarbeid om å fremme helse» gjennomfører vi nå intervjuer med fagpersoner og brukerrepresentanter som samarbeider for å utvikle kurs, temakvelder, lærings- og mestringstilbud eller helsetjenester.

	MERK: Vi utforsker IKKE samvalg eller medvirkning i egne behandlingsvalg – men medvirkning på tjenestenivå – for å skape helsetjenester for andre pasienter, brukere, pårørende. Regjeringen vil ha mer brukermedvirkning – men vi vet lite om hvordan dette skal gjøres – og hvilken betydning det kan få. Dette er det lite forskning på både her hjemme og i resten av verden.Det er målet vårt å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til.
Intervjuer	Jeg er utdannet fysioterapeut – og har mange års erfaring med å arbeide i tilknytning til lærings- og mestringsvirksomhet. Jeg noterer litt underveis, og holdet øye med lydopptakeren og tida.
Informert samtykke	Gjennomgå informert samtykke.
Taushetsplikt	Gjennomgå taushetsplikt om det som blir sagt – mulig å ta fram både positive og negative erfaringer. Si bare det du er komfortabel med.
Lydopptaker	Vi trenger å bruke lydopptaker for å få med oss alt som sies og få med oss alle nyansene i det som sies. I artiklene og tekstene vi skal forfatte vil det ikke være mulig å spore bestemte personer tilbake til individuelle utsagn – det gjelder også om du kommer med eksempler.
Regler for samtalen	Det vi ønsker oss er konkrete fortellinger som beskriver dine erfaringer – både «gode og vonde». Det er det som vil gi oss robuste data! Noen «regler» er: • Det er ingen riktige eller gale svar!

	- Du behøver ikke framstå som «flink» eller kunnskapsrik: Vi trenger alle de erfaringene du kan bidra med. - Små nyanser er også viktige – inklusiv «bagateller» eller «saker som ikke synes viktig». - Vi håper du kan være ærlig. Dårlige eksempler er like viktige som gode eksempler! Det er et poeng å få samlet så mange forskjellige forhold omkring brukermedvirkning i utvikling eller forbedring av helsetjenester som mulig – både det som kan knyttes til relasjoner mellom folk og det som kan ses som betinget ut fra kommunale administrative strukturer eller politikk. Intervjuet varer fra èn time til maks 90 minutter – hvis du trenger en pause, si bare i fra. Vi avslutter til avtalt tid.
Kort presentasjon *Med båndopptaker*	Flott om du kan si ditt navn og yrke. (Skrur på lydopptaker).
Begynner intervju	**Tilnærminger til og kontekst for samarbeidet** Kan du fortelle litt om hvordan dere tilrettelegger for brukermedvirkning når helsetjenester skal utvikles eller forbedres; hvordan brukermedvirkning «skjer» hos dere? - Kan du fortelle om en gang dere hadde med brukere i utvikling/forbedring av tjenester – og hvor dette hadde betydning for deres tjenester/organisasjon? ○ Hva var din motivasjon for å gjøre dette? ○ Hvordan forstår dine kolleger det å involvere brukere i slike prosesser?

	○ Hvordan «fant» dere brukere? ○ Hva var hensikten med samarbeidet? ▪ Når ble samarbeidet iverksatt? ▪ Hvem ble inkludert og hvorfor? ▪ I hvilken fase av utviklingen ble gruppas ulike medlemmer involvert – og hvorfor? ▪ Hvem fikk du med deg og hvorfor akkurat dem? ▪ Hvordan formidlet du-dere hensikten med arbeidet for det andre ○ Hvordan forløp arbeidet? ▪ Hva manglet ev.? ▪ Hvor lå ev. motstanden/ hvordan utartet motstanden seg ev.? **Om brukermedvirkning** ● Hva betyr (begrepet) brukermedvirkning for *deg*? ○ Kan du reflektere over forskjellen mellom å være likeperson og brukerrepresentant ● Hvis du kunne bestemme «alt» - hvordan ønsker du at brukermedvirkning i helsetjenesteutvikling/-forbedring skal foregå i framtida? ○ Fra du blir bedt om å medvirke, til prosessen er ferdig ● På hvilken måte bidrar du til at brukermedvirkning kan «skje» slik det er i dag? ● Hvordan må en gruppe være sammensatt for at brukeres innspill skal få en betydning?

	- Kan du fortelle konkret hva som ligger til rette og ev. hva som mangler hos dere for å få til «god brukermedvirkning»?
	  - Lokalt (menneskelige ressurser)
	  - Administrativt (ledelse, verdier, visjoner)
	  - Organisatorisk (planer, ledelse, verdier, visjoner)
	  - Politisk (planer, ledelse, verdier, visjoner)
	  - Samfunnsmessig (offentlige dokumenter)
	  - Økonomisk (hvordan honorerer dere ev. brukere, har dere budsjett for brukermedvirkning)
	Helsebegrepet
	- Hva inngår i begrepet «helse» i en kommunal setting
	  - Hva må en kommune gjøre for å ivareta innbyggernes helse
	Roller, forventninger og mål
	- Kan du fortelle litt om de *roller* du tok eller fikk i et konkret samarbeid?
	  - Hvorfor tok eller fikk du denne/disse rollene?
	  - Endret din(e) rolle(r) seg underveis? Ev. hvordan?
	  - Hvilke roller hadde de andre fagpersonene og brukerne i dette samarbeidet?
	- Kan du fortelle litt om hva ditt/dine mål med og i samarbeidet var?
	  - Da du startet

  - Underveis
  - Etterpå

- Hvilke forventninger hadde du til brukerrepresentanten(e)/brukerne?
  - Hvordan representerte brukeren/brukerne ev. flere enn seg selv i samarbeidet?
  - Hva konkret bidro de med?

- Hvilke forventninger hadde du til de andre fagpersonene?
  - Hva bidro de med?

- Hvilke målsettinger opplevde du at andre hadde i samarbeidet?

- Hvordan gikk du fram for å nå ditt/dine mål?

- Hvilken fag-/kompetanse, strategier, teknikker og/eller egenskaper måtte du ta i bruk underveis i samarbeidet?

- Hvilke hjelpemidler brukte dere ev. underveis i samarbeidet?

- Kan du fortelle om saker som brukere tok opp eller kom med i prosessen – og som du valgte ikke å følge opp?
  - Hvorfor?

    - Hva kjennetegner saker eller innspill som er vanskelige eller som ikke oppleves riktige å følge opp?
    - Hva må ligge til rette for at brukernes innspill kan tas til følge?

- Kan du tenke litt høyt om det er lettere å følge opp saker som kommer fra en brukerrepresentant som du kjenner godt, har samarbeidet bra med før og som du stoler på, enn en som er ny?

Betydning av samarbeidet

- Hvordan vet du at/når brukermedvirkning «finner sted/skjer» i et samarbeid?

- Kan du fortelle om konkrete erfaringer med at medvirkning hadde en effekt og hvordan dette artet seg (både på «godt og vondt»)?
    - For involverte i samarbeidet
    - For tjenestene og ansatte
    - For organisasjonen
    - For samfunnet

- Kan du reflektere litt over i hvilke faser du mener brukermedvirkning er «viktigst» å ha med når tjenester skal utvikles/forbedres?

- Kan du også reflektere over hvilke former for brukerinvolvering kan være nyttig i hvilken fase?

	○ Innspill ○ Samarbeid ○ Tilbakemelding på tekst eller liknende ○ Workshop ○ Annet? • Når fagpersoner og brukere samarbeider, i hvilke situasjoner kan fagkunnskapen trumfe brukererfaringen – og/eller omvendt? • Kan du nevne konkrete eksempler på hva samarbeidet bidro til – på «godt og/eller vondt»?
Avslutning og oppsummering (10 min.)	Målet vårt er å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til. • Hva tenker du er det viktigste du har trukket fram i dette intervjuet? • Er det noe vi ikke har vært inne på som er viktig å få frem? • Hvordan du har opplevd å delta i dette intervjuet? Hvis du kommer på noe, både tanker eller refleksjoner eller innspill, nå i etterkant om det vi har snakket om i dag, ring meg gjerne eller send en mail. Det er god informasjon som vi kan bruke! **Tusen takk for at du tok deg tid og for ditt bidrag!**

Appendix 7. Individual interview guide for patient representatives (in Norwegian)

Semistrukturerte intervjuguide for individuelle intervju med brukerrepresentanter – 2 x 45 minutter

Velkommen før oppstart	Fylle ut: - Samtykkeskjema - Bakgrunnsskjema Skriv opp på flip-over-ark/whiteboard og heng opp målet med intervjuet – å få Ha en liten gave tilgjengelig til etterpå. Husk å la spørsmål få henge litt før de omformuleres.
Introduksjon *Ikke båndopptak*	Hjertelig velkommen! Vi setter stor pris på at akkurat du vil delta – du har erfaring med å bidra inn i utvikling/forbedring av kommunale tilbud i samarbeid med andre brukerrepresentanter og fagpersoner. Hvorfor, hvordan, med hvilket grunnlag – det er vi interesserte i å høre mer om i dag! Som del av forskningsprosjektet «Samarbeid om å fremme helse» gjennomfører vi nå intervjuer med fagpersoner og brukerrepresentanter som samarbeider for å utvikle kurs, temakvelder, lærings- og mestringstilbud eller helsetjenester.

	MERK: Vi utforsker IKKE samvalg eller medvirkning i egne behandlingsvalg – men medvirkning på tjenestenivå – for å skape helsetjenester for andre pasienter, brukere, pårørende. Regjeringen vil ha mer brukermedvirkning – men vi vet lite om hvordan dette skal gjøres – og hvilken betydning det kan få. Dette er det lite forskning på både her hjemme og i resten av verden. Det er målet vårt å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til.
Intervjuer	Jeg er utdannet fysioterapeut – og har mange års erfaring med å arbeide i tilknytning til lærings- og mestringsvirksomhet. Jeg noterer litt underveis, og holdet øye med lydopptakeren og tida.
Informert samtykke	Gjennomgå informert samtykke.
Taushetsplikt	Gjennomgå taushetsplikt om det som blir sagt – mulig å ta fram både positive og negative erfaringer. Si bare det du er komfortabel med.
Lydopptaker	Vi trenger å bruke lydopptaker for å få med oss alt som sies og få med oss alle nyansene i det som sies. I artiklene og tekstene vi skal forfatte vil det ikke være mulig å spore bestemte personer tilbake til individuelle utsagn – det gjelder også om du kommer med eksempler.
Regler for samtalen	Det vi ønsker oss er konkrete fortellinger som beskriver dine erfaringer – både «gode og vonde». Det er det som vil gi oss robuste data! Noen «regler» er: • Det er ingen riktige eller gale svar!

	- Du behøver ikke framstå som «flink» eller kunnskapsrik: Vi trenger alle de erfaringene du kan bidra med. - Små nyanser er også viktige – inklusiv «bagateller» eller «saker som ikke synes viktig». - Vi håper du kan være ærlig. Dårlige eksempler er like viktige som gode eksempler! Det er et poeng å få samlet så mange forskjellige forhold omkring brukermedvirkning i utvikling eller forbedring av helsetjenester som mulig – både det som kan knyttes til relasjoner mellom folk og det som kan ses som betinget ut fra kommunale administrative strukturer eller politikk. Intervjuet varer fra èn time til maks 90 minutter – hvis du trenger en pause, si bare i fra. Vi avslutter til avtalt tid.
Kort presentasjon *Med båndopptaker*	Flott om du kan si ditt navn og eventuelle tilknytning til en organisasjon. (Skrur på lydopptaker).
Begynner intervju	**Tilnærminger til og kontekst for samarbeidet** Kan du fortelle litt om hvordan du opplever at kommuner tilrettelegger for brukermedvirkning når helsetjenester skal utvikles eller forbedres; hvordan brukermedvirkning «skjer» der du har vært involvert? - Kan du fortelle om en gang du deltok i et prosjekt eller en gruppe for å utvikle/forbedre tjenester i din kommune? ○ Hva var din motivasjon for å gjøre dette?

  - Hvordan «fant» fagpersonen i kommunen akkurat deg?
  - Hva var hensikten med samarbeidet?
    - Når ble samarbeidet iverksatt?
    - Vet du hvorfor akkurat du ble invitert med?
    - I hvilken fase av utviklingen ble du inkludert i samarbeidet – og hvorfor?
  - Opplevde du at savnet kunnskap eller kompetanse om noe?
    - Hva hadde du ønsket å ha kunnskap eller kompetanse om innen du møtte opp, ev. underveis, etterpå?
    - Hvem burde sørget for å formidle den kunnskapen til deg eller lære deg opp?
      - Kommunen
      - Organisasjonen din

  - Hvordan forløp arbeidet?
    - Hva manglet ev.?
    - Hvor lå ev. motstanden/ hvordan utartet motstanden seg ev.?

- Kan du fortelle litt om ulike «lover» eller «regler» eller «rutiner» du har erfart å gjelde for deg i samarbeid du har vært involvert i for å utvikle/forbedre helsetjenester?

Om brukermedvirkning

- Hva betyr (begrepet) brukermedvirkning for *deg*?
  - Kan du reflektere over forskjellen mellom å være likeperson og brukerrepresentant

- Hvis du kunne bestemme «alt» - hvordan ønsker du at brukermedvirkning i helsetjenesteutvikling/-forbedring skal foregå i framtida?
    - Fra du blir bedt om å medvirke, til prosessen er ferdig

- På hvilken måte bidrar du til at brukermedvirkning kan «skje»?

- Hvordan bør en gruppe være sammensatt for at brukeres innspill skal få en betydning?

- Kan du fortelle konkret hva som må ligger til rette i en organisasjon for å få til «god brukermedvirkning»?
    - Lokalt (menneskelige ressurser)
    - Administrativt (ledelse, verdier, visjoner)
    - Organisatorisk (planer, ledelse, verdier, visjoner)
    - Politisk (planer, ledelse, verdier, visjoner)
    - Samfunnsmessig (offentlige dokumenter)
    - Økonomisk (hvordan honorerer dere ev. brukere, har dere budsjett for brukermedvirkning)

Helsebegrepet

- Hva inngår i begrepet «helse» i en kommunal setting
    - Hva må en kommune gjøre for å ivareta innbyggernes helse

Roller, forventninger og mål

- Når du blir invitert til å samarbeide for å utvikle eller forbedre tjenester, hvilke «hatter» har du ev. på deg?
    - (Spesifiser for informanten om det trengs)

- Kan du fortelle litt om *roller* du tok eller fikk i et konkret samarbeid?
    - Hvorfor tok eller fikk du denne/disse rollene?
    - Endret din(e) rolle(r) seg underveis? Ev. hvordan?
    - Hvilke roller hadde de ev. andre brukerne og fagpersonene i samarbeidet?

- Kan du fortelle litt om hva ditt/dine mål med og i samarbeidet var?
    - Da du startet
    - Underveis
    - Etterpå

- Hvilke forventninger hadde du til de andre ev. brukerrepresentanten(e)/brukerne?
    - Hvordan representerte du-dere brukere/pasienter/pårørende i dette samarbeidet?
    - Hva konkret bidro du (og ev. de andre) med?

- Hvilke forventninger hadde du til de fagpersonene?
    - Hva bidro de med?

- Hvilke målsettinger opplevde du at andre hadde i samarbeidet?

- Kan du fortelle litt om hvordan du generelt går fram for å nå ditt/dine mål i slike samarbeidsprosesser?
    - Hvilken strategier, teknikker og/eller egenskaper tar du i bruk?
    - Kan du reflektere over om du noen ganger lar noen saker «gå» for i stedet å få fram andre saker?
    - Hva passer du ev. på ikke å gjøre når du skal samarbeide med fagpersoner?

- Hvilke hjelpemidler brukte dere ev. underveis i samarbeidet?

- Kan du fortelle om saker som du eller andre brukere tok opp eller kom med i prosessen – og som ikke ble fulgt opp?
    - Hva tror du var grunnen til at det ikke ble fulgt opp?
    - Hva kjennetegner saker eller innspill som er vanskelig «å få gjennom»?
    - Hva må ligge til rette for at innspill kan tas til følge i slike samarbeid?

- Kan du tenke litt høyt om det er lettere å få gjennom saker når du samarbeidet med fagpersoner som du kjenner godt, og som du har samarbeidet bra med før, enn i nye samarbeidsrelasjoner?

Betydning av samarbeidet

- Hvordan vet/merker du at brukermedvirkning «finner sted/skjer» i et samarbeid?
    - Hvilke konsekvenser kan medvirkningen få?

- Kan du fortelle om konkrete erfaringer med at medvirkning hadde en effekt og hvordan dette artet seg (både på «godt og vondt»)?
    - For deg
    - For andre involverte i samarbeidet
    - For tjenesten
    - For organisasjonen og dens ansatte
    - For samfunnet

- Kan du reflektere litt over om det er noen faser i utvikling av tjenester du mener brukermedvirkning er «mest viktig» å ha med?

- Kan du også reflektere over hvilke former for brukerinvolvering kan være nyttig i hvilken fase?
    - Innspill
    - Samarbeid
    - Tilbakemelding på tekst eller liknende
    - Workshop
    - Annet?

- Når fagpersoner og brukere samarbeider, er det noen situasjoner hvor fagkunnskapen trumfer brukererfaringen – og/eller omvendt?

Avslutning og oppsummering (10 min.)	• Målet vårt er å finne ut mer om hvordan fagpersoner og brukerrepresentanter kan samarbeide godt – og hva samarbeidet kan lede til. ○ Hva tenker du er det viktigste du har trukket fram i dette intervjuet? ○ Er det noe vi ikke har vært inne på som er viktig å få frem? ○ Hvordan du har opplevd å delta i dette intervjuet? Hvis du kommer på noe, både tanker eller refleksjoner eller innspill, nå i etterkant om det vi har snakket om i dag, så ring meg gjerne, eller send en mail. Det er god informasjon som vi kan bruke! **Tusen takk for at du tok deg tid og for ditt bidrag!**

VID

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Nasjonal kompetansetjeneste for
læring og mestring innen helse

Appendix 8. Healthcare professionals´ demographics form

Bakgrunnsopplysninger – informanter som er fagpersoner

Kjønn: ____________

Alder: __________ år

Utdanning: ____

____

____

Har arbeidet i helsevesenet i ca. _________ år

Har arbeidet ved sykehus i ca. ___________ år

Har arbeidet ved kommunal helse-og omsorgstjeneste i ca. _________ år

Har vært med i ca. antall _____________ arbeids- eller prosjektgrupper for å utvikle eller forbedre helsetjenester (tilbud/kurs/temakvelder etc.) **sammen med** andre fagpersoner **og** personer med brukererfaring.

Eventuelle kommentarer:

VID

mestring.no
Nasjonal kompetansetjeneste for
læring og mestring innen helse

Appendix 9. Patient representatives´ demographics form

Bakgrunnsopplysninger – informanter med brukererfaring

Vennligst fyll inn eller sett kryss ved det som passer.

1. Kjønn: ☐ Mann ☐ Kvinne	2. Hvilket år er du født? ....
3. Hva er din diagnose, dersom du har en?	4. Hva er din sivilstatus? ☐ Ugift ☐ Gift/samboer ☐ Skilt ☐ Enke/enkemann
6. Hvor mange barn har du eventuelt?	5. Hvordan bor du? ☐ Bor alene ☐ Bor sammen sammen med noen
7. Hvilken utdanning er den høyeste du har fullført? ☐ Grunnskole 7-10 år, framhaldsskole ☐ Ett- eller toårig videregående skole, yrkesskole, real- eller middelskole ☐ Artium, økonomisk gymnas, 3-årig videregående skole ☐ Universitet og/eller høgskole opptil 4 år ☐ Universitet og/eller høyskole mer enn 4 år ☐ Hvis annet, vennligst spesifiser	8. Er du i arbeid utenfor hjemmet for tiden? (Sett bare ett kryss) ☐ Ja, heltidsarbeid ☐ Ja, deltidsarbeid ☐ Sykemeldt (helt eller delvis) ☐ Uføretrygdet ☐ Alderspensjonert ☐ Arbeidsledig ☐ Hvis annet, vennligst spesifiser

9. Hvilken brukerorganisasjon tilhører du, hvis du er tilknyttet en organisasjon?	10. Jeg har vært med i ca. antall ………………… arbeids- eller prosjektgrupper for å utvikle eller forbedre helsetjenester (tilbud/kurs/ tema-kvelder eller liknende).
Eventuelle kommentarer:	

Appendix 10. Written Concent Form

Invitasjon til å delta i forskningsprosjektet «Samarbeid om å fremme helse» – og samtykkeerklæring

Dette er en invitasjon til deg om å delta i forskningsprosjektet «Samarbeid om å fremme helse». Prosjektets overordnede mål er å bidra til at pasienter, brukere og pårørende får gode kommunale helsetjenester. Vi spør om din deltakelse fordi du har erfaring med samarbeid knyttet til å utvikle eller forbedre helsetjenester, kurs eller lærings- og mestringstilbud i din kommune.

Myndighetene oppfordrer kommuner til å samarbeide med brukere, pasienter og pårørende når det skal lages nye helsetilbud eller kurs, men bare noen få kommuner gjør dette. Ansatte i kommunene sier at de er usikre på hvordan få til et slikt samarbeid. Dette prosjektet vil utvikle ny kunnskap om hvordan brukere, pasienter og pårørende kan samarbeide godt med fagpersoner om å lage nyttige helsetjenester.

Forankring av forskningsprosjektet

Dette er et doktorgradsprosjekt i regi av Nasjonal kompetansetjeneste for læring og mestring innen helse (NK LMH), finansiert av ExtraStiftelsen. Funksjonshemmedes Fellesorganisasjon er samarbeidspartner. Prosjektet startet 01.03.2018 og ledes av stipendiat Ann Britt Sandvin Olsson. Mette Haaland-Øverby er medforsker med erfaringskompetanse. Prosjektet avsluttes 31.12.2021. For mer informasjon om forskningsprosjektet, se https://www.vid.no/forskning/phd-prosjekter-ved-senter-for-diakoni-og-profesjonell-praksis/samarbeid-om-a-fremme-helse/. For mer informasjon om NK LMH, se www.mestring.no.

Hva innebærer det å delta

Dersom du ønsker å delta i forskningsprosjektet, ber vi om din tillatelse til å delta som observatører i samarbeidsmøter du er med i og/eller ha deg med i et fokusgruppeintervju og/eller et dybdeintervju. Vi vil da være observatører i samarbeidsmøter som du til vanlig vil delta i. Fokusgruppa vil bestå av seks til åtte personer og vil vare i 2x45 minutter, med pause i midten. Spørsmålene vil handle om hvordan det er å samarbeide og hva som skal til for å samarbeide godt om å lage nyttige helsetjenester. I dybdeintervjuet vil vi spørre om hvordan du har opplevd samarbeidet, hva som har fungert, og hva som eventuelt kunne vært gjort annerledes. Intervjuet vil vare i 1,5 time. Vi vil gjøre lydopptak av både fokusgruppe- og dybdeintervju. Kun ansatte i prosjektet får tilgang til materialet. Vi vil tilpasse oss ønsker om når fokusgruppe- eller dybdeintervjuet skal finne sted.

Hva skjer med informasjonen om deg

Alle opplysninger om deg vil bli behandlet konfidensielt. Ditt navn blir tildelt en kode som brukes i stedet for navnet ditt når datamaterialet behandles. Kodelisten som kobler ditt navn til datamaterialet blir kun oppbevart på papir, i et låst arkivskap på et låst rom. Rutinen sikrer at ditt navn ikke knyttes til datamaterialets innhold. Verken deltakende kommuners eller informanters navn vil oppgis i prosjektgjennomføringen eller i forskingsprosjektets publikasjoner. Når forskningsprosjektet avsluttes, blir papir med ditt navn makulert.

Frivillig deltakelse

Vi håper du har lyst til å delta. Det er frivillig å være deltaker. Du kan trekke deg når som helst og uten å oppgi grunn. Din behandling i eller tilknytning til helsesystemet vil ikke bli påvirket av at du trekker ditt samtykke tilbake. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert.

Forskningsprosjektet er tilrådd Personvernombudet ved Oslo universitetssykehus. Prosjektet er tilknyttet VID vitenskapelige høgskole, med førsteamanuensis Anita Strøm som hovedveileder. Hun kan kontaktes ved spørsmål per telefon: 950 21 491 eller e-post: Anita.Strom@vid.no.

Du er også velkommen til å ta kontakt med oss om du har spørsmål.

Med vennlig hilsen

Ann Britt Sandvin Olsson	Mette Haaland-Øverby
prosjektleder/stipendiat	medforsker med brukererfaring
sandvin.olsson@mestring.no	mette.haaland.overby@mestring.no
Tlf. 47755002	Tlf. 92098399

Nasjonal kompetansetjeneste for læring og mestring innen helse (NK LMH)
www.mestring.no

Samtykke til å delta i forskningsprosjektet «Samarbeid om å fremme helse»

Jeg har mottatt informasjon om studien, og er villig til å tillate eller delta i (kryss av det som er aktuelt):

☐ observasjon ☐ fokusgruppeintervju ☐ dybdeintervju

Min kontaktinformasjon

- telefon:
- e-post:

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Sted/dato	Signatur av prosjektdeltaker/informant

Appendix 11. The right to withdraw from the research project form

Skjema for tilbaketrekking av samtykke om å delta i forskningsprosjektet «Samarbeid om å fremme helse»

Prosjektets overordnede mål er å bidra til at pasienter, brukere og pårørende får gode kommunale helsetjenester. Myndighetene oppfordrer kommuner til å samarbeide med brukere, pasienter og pårørende når det skal lages nye helsetilbud eller kurs, men bare noen få kommuner gjør dette. Ansatte i kommunene sier at de er usikre på hvordan få til et slikt samarbeid. Dette prosjektet vil utvikle ny kunnskap om hvordan brukere, pasienter og pårørende kan samarbeide godt med fagpersoner om å lage nyttige helsetjenester.

Forankring av forskningsprosjektet

Dette er et doktorgradsprosjekt i regi av Nasjonal kompetansetjeneste for læring og mestring innen helse (NK LMH), finansiert av ExtraStiftelsen. Funksjonshemmedes Fellesorganisasjon er samarbeidspartner. Prosjektet startet 01.03.2018 og ledes av stipendiat Ann Britt Sandvin Olsson. Mette Haaland-Øverby er medforsker med erfaringskompetanse. Prosjektet avsluttes 31.12.2021. For mer informasjon om forskningsprosjektet, se https://www.vid.no/forskning/phd-prosjekter-ved-senter-for-diakoni-og-profesjonell-praksis/samarbeid-om-a-fremme-helse/. For mer informasjon om NK LMH, se www.mestring.no.

Hva innebærer det å delta

Dersom du ønsker å delta i forskningsprosjektet, ber vi om din tillatelse til å delta som observatører i samarbeidsmøter du er med i og/eller ha deg med i et fokusgruppeintervju og/eller et dybdeintervju. Vi vil da være observatører i samarbeidsmøter som du til vanlig vil delta i. Fokusgruppa vil bestå av seks til åtte personer og vil vare i 2x45 minutter, med pause i midten. Spørsmålene vil handle om hvordan det er å samarbeide og hva som skal til for å samarbeide godt om å lage nyttige helsetjenester. I dybdeintervjuet vil vi spørre om hvordan du har opplevd samarbeidet, hva som har fungert, og hva som eventuelt kunne vært gjort annerledes. Intervjuet vil vare i 1,5 time. Vi vil gjøre lydopptak av både fokusgruppe- og dybdeintervju. Kun ansatte i prosjektet får tilgang til materialet. Vi vil tilpasse oss ønsker om når fokusgruppe- eller dybdeintervjuet skal finne sted.

Hva skjer med informasjonen om deg

Alle opplysninger om deg vil bli behandlet konfidensielt. Ditt navn blir tildelt en kode som brukes i stedet for navnet ditt når datamaterialet behandles. Kodelisten som kobler ditt navn til datamaterialet blir kun oppbevart på papir, i et låst arkivskap på et låst rom. Rutinen sikrer at ditt navn ikke knyttes til datamaterialets innhold. Verken deltakende kommuners eller informanters navn vil oppgis i prosjektgjennomføringen eller i forskingsprosjektets publikasjoner. Når forskningsprosjektet avsluttes, blir papir med ditt navn makulert.

Frivillig deltakelse – mulig å trekke seg uten at det får følger

Merk at det er frivillig å være deltaker. Du kan trekke deg når som helst og uten å oppgi grunn. *Din behandling eller tilknytning i helsesystemet vil ikke bli påvirket av at du trekker ditt samtykke tilbake.* Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert.

Forskningsprosjektet er tilrådd Personvernombudet ved Oslo universitetssykehus. Prosjektet er tilknyttet VID vitenskapelige høgskole, med førsteamanuensis Anita Strøm som hovedveileder. Hun kan kontaktes ved spørsmål per telefon: 950 21 491 eller e-post: Anita.Strom@vid.no.

Du er også velkommen til å ta kontakt med oss om du har spørsmål.

Med vennlig hilsen

Ann Britt Sandvin Olsson	Mette Haaland-Øverby
prosjektleder/stipendiat	medforsker med brukererfaring
sandvin.olsson@mestring.no	mette.haaland.overby@mestring.no
Tlf. 47755002	Tlf. 92098399

Nasjonal kompetansetjeneste for læring og mestring innen helse (NK LMH)
www.mestring.no

Tilbaketrekking av samtykke om å delta i forskningsprosjektet «Samarbeid om å fremme helse»

Jeg har tidligere gitt samtykke til å delta i forskningsprosjektet. Jeg ønsker nå å trekke tilbake samtykket.

Min kontaktinformasjon

- telefon:
- e-post:

--	--
Sted/dato	Signatur av prosjektdeltaker/informant

Oslo universitetssykehus

Oslo universitetssykehus HF

Postadresse:
Postboks 4950 Nydalen
0424 Oslo

Sentralbord:
02770

Org.nr:
NO 993 467 049 MVA

www.oslo-universitetssykehus.no

PERSONVERNOMBUDETS TILRÅDING

Til: Ann Britt Sandvin Olsson

Kopi: Siw Bratli

Fra: Personvernombudet ved Oslo universitetssykehus

Saksbehandler: Annika Mortensen

Dato: 20.03.2018

Offentlighet: Ikke unntatt offentlighet

Sak: Personvernombudets tilråding til innsamling og databehandling av personopplysninger

Saksnummer: 18/05851

Personvernombudets tilråding til innsamling og behandling av personopplysninger for prosjektet:

«Samarbeid om å fremme helse»

Formål: Dette forskningsprosjektet har som hovedmål å styrke kunnskapsgrunnlaget for hvordan brukerrepresentanter og fagpersoner kan samarbeide godt i utvikling eller forbedring av helsetjenester.

Vi viser til innsendt melding om behandling av personopplysninger / helseopplysninger. Det følgende er personvernombudets tilråding av prosjektet.

Med hjemmel i personopplysningsforskriften § 7-12, jf. helseregisterloven § 5, har Datatilsynet ved oppnevning av personvernombud ved Oslo Universitetssykehus (OUS), fritatt sykehuset fra meldeplikten til Datatilsynet. Behandling og utlevering av person-/helseopplysninger meldes derfor til sykehusets personvernombud.

Databehandlingen tilfredsstiller forutsetningene for melding gitt i personopplysningsforskriften § 7-27 og er derfor unntatt konsesjon.

Personvernombudet tilrår at prosjektet gjennomføres under forutsetning av følgende:

1. Databehandlingsansvarlig er Oslo universitetssykehus HF ved adm. dir.
2. Avdelingsleder eller klinikkleder ved OUS har godkjent studien, og prosjektet godkjennes av personvernombud i deltakende kommuner og brukerorganisasjoner. Utlevering av opplysninger til Oslo universitetssykehus må også godkjennes.
3. Behandling av personopplysningene / helseopplysninger i prosjektet skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
4. Data lagres som oppgitt i meldingen. Annen lagringsform forutsetter gjennomføring av en risikovurdering som må godkjennes av Personvernombudet.
5. Det gjøres ikke oppslag i journal i prosjektet.

6. Opptaksutstyr som benyttes eies av OUS.
7. Studien er frivillig og samtykkebasert. Innmeldte samtykke benyttes.
8. Eventuelle fremtidige endringer som berører formålet, utvalget inkluderte eller databehandlingen må forevises personvernombudet før de tas i bruk.
9. Kryssliste som kobler avidentifiserte data med personopplysninger lagres som angitt i meldingen og oppbevares separat på prosjektleders avlåste kontor.
10. Publisering i tidsskrift forutsettes å skje uten at deltagerne kan gjenkjennes direkte eller indirekte, så sant ikke annet fremgår eksplisitt av samtykket.
11. Eventuelle krav fra tidsskrift om at grunnlagsdataene utleveres, skal behandles som en utlevering av helse- og personopplysninger, jf. sykehusets eHåndbok og dokumentet «Utlevering av personopplysninger», dokumentID 15408. Se http://ehandboken.ous-hf.no/. Denne tilråding dekker ikke slik utlevering. I den grad det er mulig å utlevere data anonymt og samtidig oppfylle tidsskriftets krav til etterprøvbarhet og kontroll av artikkel som søkes publisert, kan alternativt opplysningene anonymiseres, dvs. at det ikke på noen måte er mulig å identifisere deltagerne direkte eller indirekte. Anonymt skal i denne sammenhengen tolkes strengt. Det er prosjektleder personlig som bærer ansvaret for at utleverte data er å betrakte som anonyme. Definisjon av anonymt må følge personvernombudets definisjon slik denne fremgår av regionens styringssystem for informasjonssikkerhet.
12. Kontaktperson for prosjektet skal hvert tredje år sende personvernombudet ny melding som bekrefter at databehandlingen skjer i overensstemmelse med opprinnelig formål og helseregisterlovens regler.
13. Data slettes eller anonymiseres ved prosjektslutt desember 2021 ved at krysslisten slettes og eventuelle andre identifikasjonsmuligheter i databasen fjernes. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.

Prosjektet er registrert i sykehusets offentlig tilgjengelig database over forsknings- og kvalitetsstudier.

Med hilsen

Annika Mortensen
Personvernrådgiver

Oslo universitetssykehus HF
Stab fag, pasientsikkerhet og samhandling
Avdeling for personvern og informasjonssikkerhet

Epost: personvern@oslo-universitetssykehus.no
Web: www.oslo-universitetssykehus.no/personvern

Appendix 13. Data Treatment Agreement (anonymized example)

Databehandleravtale

mellom

Nasjonal kompetansetjeneste for læring og mestring innen helse (NK LMH)
Oslo universitetssykehus HF
Org.nr. 993 467 049
Behandlingsansvarlig

og

Avdeling
Kommune
Org.nr.
Databehandler

Avtalen gjelder i henhold til Lov om behandling av personopplysninger 20.07.2018.

1. Avtalens hensikt

Avtalen skal sikre at behandlingsansvarlig verner om fysiske personers grunnleggende rettigheter og friheter, særlig deres rett til vern av personopplysninger, ved bruk av databehandler.

Avtalen regulerer partenes rettigheter og plikter etter Lov om behandling av personopplysninger 20.07.2018 og EUs personvernforordning.

Denne databehandleravtalen relateres til (Forretningsavtalen) (Dato), inngått mellom databehandler som leverandør og behandlingsansvarlig som kunde, og regulerer behandlingen av personopplysninger databehandler skal foreta for behandlingsansvarlig.

Begreper som benyttes i denne avtalen skal forstås på samme måte som i norsk lovgivning om behandling av personopplysninger.

2. Formål med behandlingen

Formålet med behandlingen er å gi behandlingsansvarlig tilgang til og informasjon fra informanter tilknyttet kommunens Frisklivs-, lærings- og mestringssenter eller for å gjennomføre forskningsprosjektet «Samarbeid om å fremme helse».

Prosjektets hovedmål er å styrke kunnskapsgrunnlaget for hvordan brukerrepresentanter og fagpersoner kan samarbeide godt i utvikling eller forbedring av helsetjenester.
Prosjektet defineres som helsetjenesteforskning, har et kvalitativt design og vil anvende observasjon, fokusgruppe- og dybdeintervjuer for å samle inn data.

3. Behandlingsgrunnlag

Databehandler må sende ut informasjon om prosjektet til potensielle informanter som inkluderer informasjon om at det er frivillig å delta og at det er mulig å trekke seg når som helst uten begrunnelse, forespørre om villighet til å delta og formidle kontakt med behandlingsansvarlig for de som er villige til å delta. Navn, tilknytning til arbeidssted eller frivillig organisasjon, samt kontaktinformasjon i form av e-postadresse og telefonnummer formidles fra databehandler til behandlingsansvarlig. Jamfør artikkel 6 og 89 i forordningen.

4. Databehandlers behandling av personopplysningene

Databehandler samler inn følgende opplysninger fra den registrerte; navn, tilknytning til arbeidssted eller frivillig organisasjon, samt kontaktinformasjon i form av e-postadresse og telefonnummer. Dette sendes behandlingsansvarlig i e-post.

Databehandler har ansvar for å slette kommunikasjon med behandlingsansvarlig om registrerte i forskningsprosjektet etter avsluttet datainnsamling (se punkt 10).

Det er kun behandlingsansvarlig som samler inn ytterligere opplysninger fra de registrerte/informantene og som legger inn opplysningene om dem.
Personopplysninger i form av navn, adresse, alder, utdannings- og yrkesbakgrunn, antall år som yrkesaktiv eller som brukerrepresentant, samt kontaktinformasjon vil da etterspørres. Hver registrerte/informant vil bli tildelt en kode for å avidentifisere vedkommende sitt navn i relasjon til datamaterialet.
Papir med kodeliste vil bli oppbevart innelåst i et brannsikkert skap i låst rom hos behandlingsansvarlig. Kodeliste vil ikke lagres digitalt. Prosjektets datamateriale vil lagres på K:/Sensitivt/Forskning i Oslo universitetssykehus´ datasystem. Papirnotater produsert under datainnsamling vil bli låst inn i brannsikkert skap på låst rom hos behandlingsansvarlig. Lydopptak låses også inn der.

Databehandler kan ikke benytte opplysningene til egne formål og kan heller ikke utlevere opplysninger til eksterne parter uten at det går eksplisitt frem av denne avtalen.

Personer som hos databehandler skal behandle opplysningene skal være autorisert for dette. De skal også forplikte seg til å behandle opplysningene fortrolig eller være underlagt en egnet lovfestet taushetsplikt. Taushetsplikten gjelder også etter avtalens opphør.

Databehandler skal sørge for å behandle personopplysningene på en sikker måte i henhold til forordningen artikkel 32. Databehandler gir ved denne avtaleinngåelse tilstrekkelig garanti for at de vil gjennomføre egnede tekniske og organisatoriske tiltak som sikrer at behandlingen oppfyller kravene i denne forordning og vern av de registrertes rettigheter.

5. Bruk av underleverandør

Databehandler skal ikke benytte underleverandør.

6. Overføring til utlandet

Personopplysninger vil ikke bli overført til land utenfor EU/EØS (tredjeland).

7. Ivareta den registrertes rettigheter

Databehandler vil håndtere henvendelser fra informanter som har samtykket til å delta i forskningsprosjektet med hensikten å avtale tid for fokusgruppe- og/eller dybdeintervju – per telefonisk kontakt og/eller per e-post. Databehandler vil også videreformidle denne informasjonen til behandlingsansvarlig.

Henvendelsene vil rettes til databehandler ved (navn), da vedkommende oppgis som kontaktperson. Henvendelsene vil omhandle opplysninger om navn og kontaktinformasjon i form av e-postadresse og telefonnummer, og avtale om hvor intervju skal foregå.

(Se pkt. 8 hva gjelder sletting av opplysningene etter endt prosjektperiode).

Henvendelser utover det databehandler skal håndtere, henvises til personvernombudet i kommunen: (navn, e-postadresse)

Databehandler skal bidra til at behandlingsansvarlig kan imøtekomme den registrertes rettigheter innenfor de frister regelverket setter.

Databehandler skal behandle personopplysninger på en slik måte at behandlingsansvarlig når som helst skal kunne be om at personopplysningen overføres til en annen behandlingsansvarlig i henhold til forordningens artikkel 20 (Rett til dataportabilitet).

8. Informasjonssikkerhet og avvik

Databehandler skal, når behandlingsansvarlig ber om det, redegjøre for sikringstiltak som er iverksatt for å sikre konfidensialitet, integritet og tilgjengelighet i behandlingen av personopplysningene. Databehandler skal føre protokoll over behandlingsaktivitetene og gi behandlingsansvarlig innsyn og bidra til å gjennomføre revisjoner. Databehandler skal også på forespørsel fra behandlingsansvarlig redegjøre for tilganger og fremlegge logg.

Databehandler skal bistå behandlingsansvarlig ved vurdering av personvernkonsekvenser, gjennomføre forhåndsdrøftelser og øvrige forpliktelser i personvernforordningen artikkel 32 til 36.

Foreligger det godkjente adferdsnormer etter artikkel 40 eller godkjente sertifiseringsordninger etter artikkel 42 som databehandler har påtatt seg å overholde eller være sertifisert etter, plikter databehandleren å etterkomme disse.

Databehandler skal uten ugrunnet opphold melde avvik og sikkerhetsbrudd til behandlingsansvarlig. Meldingen til behandlingsansvarlig skal minimum inneholde:

1. Beskrivelse av arten av bruddet (kategorien av og antall registrerte som er berørt og om mulig antall registreringer/behandlinger/journalposter som er berørt).
2. Kontaktopplysninger til den hos databehandler som kan gi mer opplysninger om bruddet.
3. Beskrivelse av sannsynlige konsekvenser av bruddet.
4. Beskrivelse av de tiltak som allerede er iverksatt eller som er planlagt iverksatt for å redusere konsekvensene av bruddet.

Dersom ikke alle opplysningene kan gis i første melding, gis de suksessivt så snart de foreligger.

Uavhengig om databehandler melder sikkerhetsbrudd til Datatilsynet, er det behandlingsansvarliges plikt å vurdere behov for varsling av de registrerte og melding til Datatilsynet.

Er databehandler av den oppfatning at en instruks fra behandlingsansvarlig er i strid med personvernforordningen, norsk lov eller annen regulering av behandling av personopplysninger, skal databehandler umiddelbart varsle behandlingsansvarlig om dette.

Databehandler skal dokumentere rutiner og andre tiltak for å oppfylle kravene i denne avtalen.

Det skal gjennomføres sikkerhetsrevisjoner jevnlig.

Ved slutten av samarbeidet vil behandlingsansvarlig etterse at databehandler har slettet all kommunikasjon som omhandler personopplysninger knyttet til registrerte i forskningsprosjektet.

Behandlingsansvarlig vil ivareta regler for personvern, forskningsetiske retningslinjer, samt lagring og sletting av data vil bli ivaretatt som foreskrevet. Innhenting av samtykke fra informanter vil skje både muntlig og skriftlig. Samtykkeerklæring godkjent av Personvernombudet ved Oslo universitetssykehus vil benyttes. Deltakere i forskningsprosjektet vil ha mulighet til å avslutte involveringen i forskningsprosjektet når de måtte ønske det og uten å oppgi årsak. Ingen kommuner eller informanter vil tilkjennegis ved navn i prosjektets gjennomføring eller publikasjoner.

9. Avtalens varighet og ansvar ved opphør

Avtalen gjelder fra den er undertegnet og så lenge databehandler behandler personopplysninger på vegne av behandlingsansvarlig, eller til den erstattes av en ny avtale.

Ved brudd på denne avtalen eller personopplysningsloven kan behandlingsansvarlig pålegge databehandler å stoppe den videre behandlingen av opplysningene med øyeblikkelig virkning.

Avtalen kan sies opp av begge parter med en gjensidig frist på 1 år.

Dette skjer ved opphør av denne avtalen:

Databehandler har ansvar for å slette kommunikasjon med behandlingsansvarlig om registrerte i forskningsprosjektet etter avsluttet datainnsamling (se punkt 10). Databehandler må påse at dette vil bli slettet på en hensiktsmessig, fullstendig og sikker måte.

Behandlingsansvarlig ved prosjektleder vil sørge for at papiret med kodelisten og ev. andre papirnotater fra datainnsamlingen som har vært oppbevart innelåst i et brannsikkert skap i låst rom hos kompetansetjenesten vil bli makulert ved prosjektslutt – som regnes å være når disputas er godkjent. Prosjektets datamateriale som har blitt lagret på K:/Sensitivt/Forskning i Oslo universitetssykehus´ datasystem vil bli slettet på en hensiktsmessig, fullstendig og sikker måte.

Databehandler skal skriftlig dokumentere at sletting og eller destruksjon er foretatt i henhold til avtalen innen rimelig tid etter avtalens opphør.

10. Henvendelser og meldinger

Alle henvendelser og meldinger relatert til denne avtalen skal gjøres til:

Behandlingsansvarlig: Siw Bratli, leder av Nasjonal kompetansetjeneste for læring og mestring innen helse (NK LMH), Oslo universitetssykehus HF

Databehandler: (navn, tittel, avdeling, kommune)

11. Lovvalg og verneting

Avtalen er underlagt norsk rett og partene vedtar Oslo tingrett som verneting. Dette gjelder også etter opphør av avtalen.

Denne avtale er i 2 – to eksemplarer, hvorav partene har hvert sitt.

(Sted og dato)

Behandlingsansvarlig	Databehandler
Siw Bratli	(Navn)
NK LMH	kommune

Articles

1. Sandvin Olsson, A. B., Strom, A., Haaland-Overby, M., Fredriksen, K., & Stenberg, U. (2020). How can we describe impact of adult patient participation in health-service development? A scoping review. *Patient Education and Counseling*, *103*(8), 1453-1466. https://doi.org/10.1016/j.pec.2020.02.028

2. Sandvin Olsson, A. B., Haaland-Øverby, M., Stenberg, U., Slettebø, T., & Strøm, A. (2022). Primary healthcare professionals' experience with patient participation in healthcare service development: A qualitative study. *PEC Innovation*, 1, 100068. https://doi.org/10.1016/j.pecinn.2022.100068

3. Sandvin Olsson, A. B., Stenberg, U., Haaland-Øverby, M., Slettebø, T., & Strøm, A. (2023). Enabling Primary Healthcare Service Development with Patient Participation: A Qualitative Study of the Internal Facilitator Role in Norway. *Primary Health Care Research and Delivery*, 24, e57. https://doi.org//10.1017/S1463423623000488

4. Sandvin Olsson, A. B., Haaland-Øverby, M., Stenberg, U., Slettebø, T., & Strøm, A. Contextual Factors that Matter for Participation in Developing Primary Healthcare Services. *Submitted for publication*.

Articles

Article 1.

Sandvin Olsson, A. B., Strom, A., Haaland-Overby, M., Fredriksen, K., & Stenberg, U. (2020). How can we describe impact of adult patient participation in health-service development? A scoping review. *Patient Education and Counseling*, *103*(8), 1453-1466. https://doi.org/10.1016/j.pec.2020.02.028

Abstract

Objective

Patient participation represents a worldwide policy, but its impact lacks research. This study investigates impact of patient participation in health-service development by providing a comprehensive overview of how the literature describes it.

Method

A scoping review with a broad search strategy was conducted. The literature was examined for study characteristics, purpose for, approaches to and impact of patient participation. The data were analyzed using a thematic analysis.

Results

The 34 included primary studies reported impacts of patient participation that were interpreted to constitute two categories: 1. The participatory process´ impact on involved patient representatives and health professionals, and the organization´s patient participation practice itself. 2. The participatory service development´s impact on the design and delivery of services regarding patients and health professionals, and the organization.

Conclusion

The literature describes a broad variation of impacts from health-service development, relevant for health professionals and patient representatives when initiating or participating in such processes. Our review provides an overview and discussion of these types of impact.

Practice implications

The findings can be of practical relevance to those aiming to develop services, quality indicators regarding effects of patient participation, or to further investigate aspects of participatory service development.

Article 2.

Sandvin Olsson, A. B., Haaland-Øverby, M., Stenberg, U., Slettebø, T., & Strøm, A. (2022). Primary healthcare professionals' experience with patient participation in healthcare service development: A qualitative study. *PEC Innovation*, 1, 100068. https://doi.org/10.1016/j.pecinn.2022.100068

Abstract

Objective

How healthcare professionals experience patient participation in health service development impacts its use. This participatory study explores primary healthcare professionals' perceptions of developing health services with patient representatives.

Methods

Four focus group interviews with primary healthcare professionals (*n* = 26) were conducted. We analyzed data by applying Braun and Clarke's reflexive thematic analysis.

Results

The healthcare professionals perceived having a complementary interprofessional relationship with the patient representatives and regarded them as colleagues. However, the professionals navigated between a position of authority and collaboration, reconciling the need for participation with its challenges, e.g., to identify the representatives' collective representation among their personal experience, to ensure a more evidence-informed result that they and their colleagues would endorse.

Conclusions

Regarding patient representatives as colleagues can blur the line between professionals and representatives' positions and functions and further complicate health service development. Our results indicate a need for skilled facilitators to lead the process.

Innovation

This study identifies issues that professionals are uncertain about when collaborating with representatives to develop primary healthcare services; difficulties that professionals must overcome to collaborate constructively with representatives. Our findings can inform healthcare professionals' education about patient participation on all levels. We have suggested topics to address.

Article 3.

Sandvin Olsson, A. B., Stenberg, U., Haaland-Øverby, M., Slettebø, T., & Strøm, A. (2023). Enabling Primary Healthcare Service Development with Patient Participation: A Qualitative Study of the Internal Facilitator Role in Norway. *Primary Health Care Research and Delivery*, 24, e57. https://doi.org//10.1017/S1463423623000488

Abstract

Aim:

To explore how primary healthcare professionals (HCPs) tasked with facilitating primary healthcare service development with patient participation perceived their role.

Introduction:

Patient participation in health service development is a recognized means of ensuring that health services fit the public’s needs. However, HCPs are often uncertain about how to involve patient representatives (PRs), and patient participation is poorly implemented. Inspired by the Promoting Action on Research Implementation in Health Services framework, we address the innovation (patient participation), its recipients (PRs, HCPs, supervisors, and senior managers), and its context (primary healthcare at a local and organizational level).

Methods:

We conducted semi-structured individual interviews with six HCPs working as internal facilitators in primary healthcare in four Norwegian municipalities. The data were analyzed by applying Braun and Clarke’s reflexive thematic analysis.

Findings:

The themes show that to develop primary healthcare services with patient participation, facilitators must establish a network of PRs with relevant skills, promote involvement within their organization, engage HCPs favorable toward patient participation, and demonstrate to supervisors and senior managers its usefulness to win their support. Implementing patient participation must be a shared, collective responsibility of facilitators, supervisors, and senior management. However, supervisors and senior management appear not to fully understand the potential of involvement or how to support the facilitators. The facilitator role requires continuous and systematic work on multiple organizational levels to enable the development of health services with patient participation. It entails maintaining a network of persons with experiential knowledge, engaging HCPs, and having senior management’s understanding and support.

Article 4.

Sandvin Olsson, A. B., Haaland-Øverby, M., Stenberg, U., Slettebø, T., & Strøm, A. Contextual Factors that Matter for Participation in Developing Primary Healthcare Services. *Submitted for publication*.

Abstract
Background
Patient participation can contribute to establishing high-quality, sustainable health services. This study explored patient representatives´ perceptions of developing primary healthcare services to identify contextual factors that matter to their participation.
Methods
Applying a bottom-up research approach, we conducted four focus groups and six individual interviews with patient representatives from four Norwegian municipalities. The participants had prior experience collaborating with healthcare professionals to develop healthcare services. Braun and Clarke's thematic analysis was used for data analysis, guided by involvement in research throughout the research process.
Findings
Two themes were identified as key contextual factors with implications for patient participation.
Firstly, the lack of an overall plan for patient participation in primary healthcare was perceived to limit the degree of involvement. Secondly, the lack of an organizational culture supporting patient participation was understood as making involvement complicated and laborious.
Conclusion
This article indicates that the intention of patient participation is not realized and that primary healthcare is unprepared for involvement. Our findings warrant discussion on policy and local levels about the prioritization of patient participation in primary healthcare service development.